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THE ECOLOGY OF SUFFERING
(An Ecological-Anthropological Analysis of the Experiences of Victims of
Transfusion-Related HIV and Viral Hepatitis Infections in Canada)

by

OLAF KRASSNITZKY, DR. MED. UNIV. (VIENNA), B.A. (CARLETON)

A thesis submitted to
the Faculty of Graduate Studies and Research
in partial fulfillment of
the requirements for the degree of

Master of Arts

Department of Sociology and Anthropology

Carleton University

Ottawa, Ontario

December 1, 1994

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**The Ecology of Suffering: An Ecological-Anthropological
Analysis of the Experiences of Victims of Transfusion-Related
HIV and Viral Hepatitis Infections in Canada**

submitted by

Olaf Krassnitzky, B.A.Hons.

in partial fulfilment of the requirements for
the degree of Master of Arts

Thesis Supervisor

Chair, Department of Sociology and Anthropology

Carleton University

January 6, 1995

"Footnote to the title":

"AIDS will never be an important disease, because, in the end, it will always be a disease of the marginalized of society". This quote is based on a recollection by Dr. Michele Brill-Edwards. The comment was made by a senior official of the Health Protection Branch of Health and Welfare Canada, around the time when a parliamentary subcommittee looked into transfusion-related AIDS.

While such a comment may give cause for outrage, it should really give cause for alarm. For AIDS is not a disease of those labelled 'marginalized', because it was transmitted to the 'non-marginalized' via blood and blood products. Ecology would predict that, if no attention is paid to the sufferings of the 'marginalized', it will sooner or later become the suffering of the 'non-marginalized', who think of others as 'marginalized'.

The ways in which the AIDS epidemic unfolded suggest that the idea of 'diseases of the marginalized' may not be just the product of some distorted senior bureaucratic minds. The handling of the epidemic involved a large number of bureaucrats, doctors, politicians, insurers, lawyers, judges, pharmaceutical industry executives, administrators, scientists, economists and other 'experts'. Many of them did not start their career from a privileged socio-economic position, but as members of 'society at large'. 'Society at large' acquiesced. Therefore, I suggest that the events surrounding transfusion-related AIDS may not be a reflection of a small elite, but that this 'distortion of mind' may be ubiquitous, 'normal' and generalized, throughout society. Those who are categorized as 'marginal' may not be visibly oppressed or persecuted. But they can be - with wide-spread tacit approval - neglected.

"The problem of modern man isn't to escape from one ideology to another, nor to escape from one formulation to find another;The [whole] picture can only be the outcome of all the empathy given to many things observed in common. When many things are observed in common by the many who constitute a society, we will have reached a condition worth celebrating". (Federick Sommer, "The Poetic Logic of Art and Aesthetics," quoted in Berman 1990, "Coming to Our Senses," page 341).

Abstract

'Pain-related phenomena' (suffering, compassion, empathy, and the infliction of pain and suffering) are evaluated in the context of a model of 'human ecology'. The model consists of fields of neurocognitive and emotional processes as 'inner ecology', and 'objectively' accounted-for processes of human behaviour as 'outer ecology'. 'Human ecology' is equated with 'culture'. The model is derived from a variety of perspectives, notably from the work of ecological anthropologists (I. Prattis, R. M. Netting, John M. Bennett, G. Bateson); from C.D. Forde's 'middle-term' in his interpretation of 'cultural ecology'; of bioculturally oriented anthropologists (C. Laughlin Jr., A. McElroy and P.K. Townsend, C. Shear Wood), and symbolic anthropologists (C. Laughlin Jr., I. Prattis, J. Campbell, A. Baring, J. Cashford). The suffering of victims of the contamination of the Canadian blood supply with HIV and hepatitis viruses is examined from this perspective. Particular attention is paid to the influence of conditions of civilization (and its conditions of inner and outer ecologies) on the infliction and experience of suffering. The model of 'human ecology', in conjunction with specific paradigms, such as the 'cycle of meaning', 'double-hermeneutic', 'monophasic rational culture' and 'obedience', appears to be useful for the explanation of pain-related phenomena, including those associated with the contamination of the blood supply. It is shown that manifestations of pain-related phenomena are shaped by epoch-specific 'human ecological processes' of civilization. The model is suggested to be a feasible integration of a variety of ecological-anthropological perspectives, cross-culturally and historically.

Dedication

I wish to dedicate this thesis to all individuals who were infected by blood transfusions, blood component therapy or plasma fraction therapy; to those who were infected by their transfused spouses or partners; and to the children who were infected by their transfused mothers; to those who are alive and to those who have died. Their suffering and the testimonies of their suffering have been my teachers. I also wish to dedicate this thesis to a Canadian, the late Mr. Christmas, whose name has been firmly associated with Hemophilia B ('Christmas disease'), ever since I studied hemophilia at the Medical School in Vienna, Austria during the early and mid-sixties. He died from transfusion-related AIDS and was one of the activists who tried to make the lives of infected hemophiliacs more tolerable.

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I wish to thank Joan Kent, Kenneth Arenson, Gail Rock, M.D., for opening my eyes early in 1993; Andrew Kaegi, M.D., for encouraging me to take a position on the issues; Michele Brill-Edwards, M.D., for patiently explaining to me the 'larger picture', and for assisting me in my understanding of the role of the Federal Government of Canada and the regulation of drugs and in the contamination of the Canadian blood supply; Derhane Wong-Rieger, Ph.D., President of the Canadian Hemophilia Society, and Lindie David, Executive Director of the Canadian Hemophilia Society, for providing me with important pointers in the direction of the early origins of the disaster; Joleen Ottoson (Colorado) for giving me help, information and encouragement; John Roberts, M.D. (pseudonym; California) for his offers of help during 1983; Astrid Starrach-Caspar, Dr. Med. Vet. (California), for explaining to me the significance of animal viruses in the production of biological pharmaceuticals; Dr. Med. Braun, President of the German Hemophilia Society, Dr. Med. Oldenburg of the Hemophilia Treatment Centre in Bonn, Germany, and Mr. Heisig, President of the Austrian Hemophilia Society, for giving me valuable insights into the contamination of the blood supply in Germany and Austria; the Decarie family (Bill, Johanne and their daughter Billy-Jo) for discussing their story of infection with me, and for their willingness to appear in a medical anthropology class at Carleton University; Mr. Jerald Freise and Alan Powell, PhD., for providing me with a wealth of information and documents and for keeping my spirits up; Prof. Steven Richer, Prof. Florence Edwards, Prof. Terry Nosanchuk,

Prof. Charles Laughlin, Prof. Carryl Steffens of Carleton University for providing some stress relief by listening to me during trying times; the reporters Johanne McDuff and Michael Hornbrook of CBC Radio, David Todd and Brad Evenson of Southam News, for believing my story; my colleague Judy Barber, for letting me use the manuscript and reference collection for her honours essay on the subject of healing and cosmology; my colleague Linda Bertrand for references on Humanitarian Law; my seminar colleagues who were patient enough to listen, when I broached the subject from time to time from various angles, and who provided helpful comments and encouragements; Prof. Gertrude Neuwirth for introducing me to Zygmunt Bauman's writings and their relevance to the issues at hand; Prof. Ian Prattis and Derek Blair, whose ideas set me on the track of trying to operationalize consciousness and related phenomena ecologically; Prof. John Cove, for his advice on the overall structure of the thesis. I need to acknowledge my city of birth, Brno, where Gregor Mendel presented his theory - he turned my interest irrevocably towards biology; my high school in Vienna, which tried to give us a balanced education by purposefully integrating the humanities and the sciences. I wish to acknowledge my wife Rosina and my children Sonja and Claudio. They gave me the strength and support to carry on, although they were damaged by circumstances beyond their choice.

I would like to extend special acknowledgements to the late Randy Shilts, who mapped the most important 'tracks'; without his contribution, the AIDS crisis would have remained incomprehensible for me; to Dr. Donald Francis: Randy Shilts's account of his story lead me to the 'critical cross-

roads' of the North-American health-care system; and to the late Randy Connors and his wife Janet Connors, who took it upon themselves to suffer under the gaze of a televiewing public, and thus disclosed the true face of transfusion-related AIDS.

I would like to extend my thanks to all the victims whose testimony I watched, or whom I had the opportunity to meet, but whose contributions are not included in this thesis. Special thanks go to Vic Parsons, the father of an infected hemophiliac, and to Yves and Bernadette Roy of Nepean, Ontario. Yves was infected with HIV by a blood transfusion, and Bernadette was subsequently infected by her husband. Very recently, the indestructable Bernadette was elected trustee of the Carleton Separate School Board.

Finally I need to acknowledge all those who are sources of my understanding and awareness, who have contributed to the writing of this thesis. While I can no longer identify them, their knowledge and understanding have become integral parts of what I know and understand.

Olaf Krassnitzky

Orleans, Ontario

December 1, 1994.

Contents

	Page
Footnote to the title	ii
Abstract	iii
Dedication	iv
Acknowledgements	v
Table of Contents	viii
List of Figures	ix
Preface	x
1 Introduction, Part 1: Approaches to Human Ecology	1
1) Hypotheses: origins and motivations	1
2) The use of an ecological framework for the exploration of pain-related phenomena	28
3) Aspects of 'outer ecology'	56
4) Aspects of 'inner ecology'	68
2 Introduction, Part 2: The Ecological Role of Pain-Related Phenomena	69
1) What class of phenomena are pain-related phenomena?	69
2) An ecological interpretation of pain-related phenomena	81
3 Examples of Human-Ecological Analysis of Pain-Related Phenomena	150
4 Methodology	175
5 Summary of Transfusion-Related HIV and Hepatitis Infections in Canada	187
6 Letter from Dr. Hershfield	228
7 'The Medical Semiotic Jungle', etc.	235
8 Accounts of Victims	253
1) Jerry and Marlene Freise	254
2) The Ottosen-Swain family	270
3) The Decarie family	285
4) Alan Powell	303
5) Randy and Janet Connors	315
9 Discussion	338
Appendix 1 Summary of Events Related to the Contamination of the Canadian Blood Supply	403
Appendix 2 Pain-Related Phenomena Interpreted from the Fleur-de-Lys	430
Appendix 3 Autobiographical Notes	454
References	475
Documents (abbreviation in text: 'DOC')	489
Glossary	495
Addenda (abbreviation in text: 'ADD')	499

List of Figures

Figure	Description	Page
1	Contexts for the Legitimation of Inflicted Suffering	23
2	The Shamanic Cycle of Meaning (From Laughlin et al., 1990)	24
3	The Fragmentation of the Cycle of Meaning in Late Modernity	26
4	Internal and External Cultural Patterns	34
5	The Relationship Between Cognized Patterns of 'Organization' and the Cognition of Time	45
6	A Model of Internal and External Human Ecology	53
7	'Human Ecology' and Its Diachronic and Synchronic Elaborations	54
8	The Relationship Between Material and Symbolic Cultural Processes (1): The Symbolic Process as Locus of Control	112
9	The Relationship Between Material and Symbolic Cultural Processes (2): The Material Process as Locus of Control	113
10	The Authoritative Rational Attenuation and Block of Symbolically Dissonant Experiences	141
11	The Authoritative Symbolic Amplification of Legitimizing Meanings and Block of Rationally Dissonant Experiences	142
12	The Shamanic Resolution of Dissonant Experiences	143
13	Evocation and Resolution of Dissonance in the Autonomous Individual	144
14	The Productive - Reflective Cycle of Human Consciousness	436
15	The Fleur-de-Lys as Mandalic Symbol for the Productive - Reflective Cycle of Human Consciousness	438
16	Duality and Symmetry in Symbols of Human Consciousness	439
17	Feminine and Masculine Restrained Consciousness	443
18	Introverted and Extraverted Restrained Consciousness	443
19	Ego-Centred and Other-Centred Grieving of 'Loss of Other'	448

Preface

Late modernity witnesses a progressive commodification of the human organism, of health and illness, and corporate and market control over every aspect of our lives from conception to death. 'Transfusion medicine' is an example of possible damaging consequences from such commodifications, and of the networks of scientific, legal, economic, political and, lately, ethical constructions arising from them.

The commodification of the natural environment has already taught a lesson about what these damaging consequences may be. The human organism, as part of the natural environment, has not evolved separately from it. It is not any less vulnerable than the natural environment. Remedies consist of some protective codes and awards of compensation for damages, and some fines in the cases of environmental damage. However, such measures are relatively rare occurrences and have become little more than a 'cost of doing business' which can be recovered with appropriate financial strategies. They are not effective as deterrents, in particular when a commodity is in 'short supply' and in 'high demand'.

Problem-solving discourses arising in a commodified life-world do not achieve a net-reduction of problems, but are part and parcel of the problem-generating enterprise: problem definitions are kept as narrow as possible, while the boundary conditions to the problems are 'controlled', ignored or remain unknown. Once a solution is implemented, all boundary conditions, known or unknown, adapt irreversibly and cannot be reconstituted to the state of conditions before the action was taken. There are no repeatable 'real-life experiments' and no experiment can predict all of the

outcomes of its 'real-life implementation'.

The unpredictability of consequences from human 'problem-solving' imposed on nature far outpaces the intrinsic unpredictability of nature' which it has done so since the beginning of civilization. To stop experimenting is no longer an option. We can only try to predict as many side-effects as possible from all forms of human engineering and to make the best use of early warning systems available to us. Once the warning signals are received, however, we must act on them - immediately.

There are two sets of such warning signals: one is constituted from 'objective' observations. The other, in particular when human engineering directly affects the well-being of humans, consists individual subjective experience, perception and emotion, including suffering and empathetic responses to the suffering of others. The institutions of civilizations need to be forced to improve the early warning systems as well as the responses to them. Most importantly, they must be prohibited from ignoring, suppressing or manipulating the warning signals which arise from human subjective experience. Subjective experiences are not sufficient signals by themselves, but they are as necessary as 'objective data'.

The people responsible for the contamination of the blood supply ignored the objective early warning signals, when Hepatitis B was spread through the newly developed Factor VIII concentrate for the treatment of hemophilia. Not to heed such signals might have been negligent. However, the additional, active suppression and manipulation of subjective and objective warning signals in the interest of commercial goals should be viewed as 'crimes against humanity', in a context of international principles of law and humanitarian law. The suppression included scientific signals;

the expression and communication of suffering directed at those who might have been able to help; and the empathetic action of those who understood the suffering and its origins and might have been willing to help. Clever manipulation of meanings of existing legal texts, codes and of 'scientific controversy', or riding roughshod over them, does not change the nature of what has happened. It invites even worse long-term consequences. Precedents can be found in environmental ecology:

"The evidence is everywhere. Populations of fish and shellfish, of corals and mollusks, of lowly ocean worms are plummeting. Toxic tides, coastal development and pollutant run-off are increasing in frequency and dimensions as the human population expands. The oceans - near shore and in the abyssal deep - may be reaching a state of ecological crisis, but, for the public, what is out of sight is out of mind. "The oceans are in a lot more trouble than is commonly appreciated" rues Jane Lubchenko of Oregon State University.As Butman and Carlton describe, hunting whales may already have altered the oceans irrevocably. Because deep-sea organisms rely on food falling from the surface, large carcasses of whales may have been one of the major sources of nutrients for the bottom of the food-chain. ... (Holloway, Marguerite, 'Diversity blues: Oceanic biodiversity wanes as scientists ponder solutions'. Scientific American, August 1994: 16-17.) [Saving the whales for the sake of saving whales is, therefore, a wrong definition of the problem and a sign of lack of understanding.]

We are 'cultivating' our categorical/rational faculties and purposively restricted warning systems obsessively (such as economic evaluations and valuations). We are 'controlling' our emotions and 'atomizing' symbolic interpretations of our life-world just as obsessively. By 'masking' or 'repressing' our emotions we are 'controlling' and effectively shutting down our naturally endowed warning systems. This is absurd. We need to control our intellectual endeavours and to cultivate our emotional and symbolic faculties. Eventually we may find an ecologically optimal state of mutual

confoundedness of both warning systems. We cannot make science, law, economics or politics empathetic and compassionate. But we can cultivate scientists, legal experts, business-persons and politician to be empathetic and compassionate: they are the locus where the warning systems are confounded.

"Since music is without practical use and so it is to be eliminated" states Dr. Fung Yu-lan in exposition of the views of Mo Tzu, "all the other arts are naturally to be eliminated as well. Being products of emotions, they are capable only of appealing to these emotions....According to his positive utilitarianism, man's numerous emotions are not only of no practical value, but moreover of no significance. Hence they should be eliminated, so as not to be impediments to human conduct." (Mo Tzu lived ca. 480-400 B.C.; see Campbell 1991b:419. Confucius, who lived shortly before him, believed in the cultivation of emotions not their 'elimination'. Fortunately for China, Confucius prevailed for most of China's history, and Mo Tzu gained stature only with the arrival of Chairman Mao, more than two millennia later; see Campbell, 1991b:505-516. Historically, ecological illiteracy in the service of civilization and power may have been a common phenomenon).

This thesis is 'ecological'. I am suggesting that 'culture' and 'human ecology' are interchangeable terms. '*Aikos*' is the 'home and household', '*colere*' means 'looking after'. The notion that 'culture is human ecology' may help us to reach an awareness necessary to truly 'look after our household'. 'Ecological anthropology' is an extension of the anthropological tradition of looking after those human faculties, potentials and vulnerabilities, which are no longer looked after by anybody else.

Throughout the thesis I will use the term 'empathy', and not very often the term 'compassion'. I am guided and influenced by the meanings of the German terms, '*Einfuehlung*' ('feeling into') and '*Mitleid*' (suffering with), respectively. I perceive 'compassion' as a 'suffering experience'

which arises in the immediate experiencing of another suffering being. 'Empathy' signifies much more (but includes the meanings of 'compassion'). It signifies a process of feelings and emotional responses which lead to 'Verstehen' of the experiential processes, past, present and anticipated; of other beings ('good' or 'bad', suffering or not); and of the circumstances (the 'environment') in which they take place.

'Compassion' can serve and help the Other only as much as 'empathy' has grown or atrophied. 'Compassion without empathy' may misread the other being and its circumstances, and fail to understand both (*'es miss-versteht beide'*). Thus it may appear to be 'without practical use', or worse: it may become entirely misdirected, Self-directed and perverted into ego-centred, rationalized passion ('greed' is but one such perverted passion). This may have been Chairman Mao's destiny: did he not start out as a 'compassionate individual', who wanted to deliver his people from suffering, and did he not lack empathy? Western medicine (and I suspect Western culture, of which it is part) is embarked on such a course, even believing that it is 'natural', 'normal', or even 'desirable'. It is suggested that a 'human ecological approach' may help to bring about some kind of course correction. Yet 'empathy' itself is vulnerable. The human propensity of transforming compassion into Self-serving passion may be accompanied by a transforming of empathetic understanding into utilitarian rational analysis. Combined as 'rational choice', Self-serving passion and rational analysis may be the *"systematic distortions of view, contained in human consciousness, which, when implemented by modern technology, become destructive of the balances between man, his society and his ecosystem"* (Bateson 1972:440). The capacity for such distortions and the capacity for

inventing technology may, however, just be deeply confounded expressions of the same 'hubris', which knows something but understands little, which invests all human passion in inventing the future, but does not invest in the empathetic understanding necessary to make such an invented future liveable when it has become the present. Human Self-awareness (an 'empathy for the Self'), under the conditions of the present, may be the only antidote for the vexing confoundedness of human existence and the distorting effects of the trajectories of an invented future. Simply put: before we 'become', we ought to find out what we 'have become' and what we 'are'; therefore, from time to time, we ought to get back 'down to earth' of which our Selves are part. The contamination of the blood supply teaches what can happen if we don't.

1 Introduction, Part 1: Approaches to Human Ecology

1) **Hypotheses; origins and motivations.**

Hypotheses:

a) Pain-related experiences, thought processes and behaviours are phenomena of human consciousness and, as such, participate in 'human ecological processes'; they play a significant role in the ecological regulation of homeostasis and transformation in individual humans, social organizations and in the interactions of humans with the natural and human-made environments;

b) This ecological effect of pain-related phenomena (such as suffering, compassion, empathy and the infliction of suffering) is shaped by specific forms of social organization and processes of civilization.

Late-modern civilization is characterized by processes:

i) which seek to 'eliminate' suffering, while it cannot be eliminated;

ii) which, therefore, seek to prevent or suppress pain-related phenomena from being experienced and/or publicly displayed, or failing that, to deny them; and

iii) which use mediated displays of actual suffering (through mass-media, courts or inquiries) to mitigate against suppressive strategies or denial;

c) Such modifications to the ecological role of pain-related phenomena, in turn, are predicted to influence homeostasis (adaptedness, situational and cyclical adaptation) and development (transformational adaptation) of individuals, social groupings, the natural and artificial human made environments and their mutual relations and interactions.

The validity of these hypotheses will be examined in three stages:

a) a discussion of anthropological models of human ecology;

b) a discussion of pain-related phenomena in the context of a model of human ecology derived from existing models; and

c) an examination of the experiences of victims of the contamination of the Canadian blood-supply with HIV and hepatitis viruses; how the hypotheses may help explain victims' experiences and encounters; and to see if the victims experiences may support the hypotheses.

Introductory notes regarding the contamination of the Canadian blood-supply

A brief introduction to hemotherapy and blood-borne viral diseases

In Canada, blood and plasma is collected from voluntary blood donors. Single blood units are then divided into 'blood components', by methods of centrifugation and physical separation. The products most commonly derived from a unit of blood are 'packed red cells', 'platelets' (needed for bleeding disorders), 'cryoprecipitate' (by fast freezing and slow thawing of plasma, a process which yields a small amount of a white precipitate rich in Factor VIII, the clotting factor needed by type 'A' hemophiliacs), and plasma. Plasma thus collected, as well as plasma collected from 'plasma donors' (who have their red cells returned to them) is industrially separated into plasma protein fractions (also referred to as 'blood or plasma derivatives'), by physico-chemical precipitation methods and subsequent purification. This process is referred to as 'plasma fractionation'. The main products are Factor VIII concentrate for hemophiliacs; albumin, a blood volume expander, often given to burn victims; and gamma globulin, the pool of circulating antibodies to microbial and other antigens. Blood components and plasma fractions may also be referred to as 'blood products'.

Many viruses enter the blood-stream through broken skin and blood vessels, either via insect vectors (eg. yellow fever), but also via human vectors. A number of viruses (hepatitis B, C, HIV, cytomegaly virus, Epstein Barr virus) share similar blood-related routes of human to human transmission: intravenous drug abuse, sexual contact, blood transfusion and intrauterine transmission from mother to child. Without special measures,

the odds of acquiring such infections through plasma fractions is higher than from products derived from single units, because plasma for fractionation is pooled from as many as 20,000 donors. Thus a single infected unit may contaminate an entire pool and all the products manufactured from it. The odds of viral transmission are substantially reduced by screening and selecting blood donors by criteria of high risk behaviours; by using blood tests which detect viruses (specific tests), or which are indicative of a high likelihood of presence of a virus ('surrogate tests'); and by 'sterilizing' (pasteurizing) plasma proteins. Cellular products (like red cells and platelets) cannot be heat-treated, as the cells would lose their viability and clinical efficacy. It should be noted that whatever risks of infection apply to blood products apply to organ and tissue transplants or extracts prepared from organ tissues. Organs contain blood vessels and thus, inevitably, blood. Cornea is an exception, as it normally does not have blood vessels.

A brief sketch of the contamination of the Canadian blood supply

In Canada, between 1978 and 1985, more than 2000 individuals were infected with HIV through blood and blood products. Possibly tens of thousands were infected with hepatitis viruses between 1975 and 1990. Several hundreds of the patients infected with HIV have died. An unknown number of people infected with hepatitis viruses (possibly several thousands) have developed chronic, eventually debilitating, liver disease. A substantial number of these infections, at least in 'hindsight', would have been avoidable, as acknowledged repeatedly by various medical directors of Red Cross

blood centres before the Commission of Inquiry on the Blood System in Canada. The Commission is presided by Justice Krever and has been in session since November 1993; it is still in session during the writing of this thesis.

Today it appears (and this will be shown) that, at various stages in the contamination of the blood supply and during the aftermath, economic 'rational choices' influenced action and inaction in the protection of the public from viruses contaminating blood products. While the possibility of liability will be discussed, no conclusion will be drawn in this paper whether this action or inaction was civilly or criminally negligent. It should be noted however, that the 'Pitman case' in Toronto (Mrs. Pitman was infected sexually by her HIV-transfused-infected husband) did establish a civil liability with respect to non-disclosure of HIV-positivity to transfused-infected people (DOC 12). Criminal charges were laid in France, Germany (Karcher 1993; Gedye 1993) and Switzerland. In France, two medical/scientific officers working for the government-operated French blood transfusion service received prison sentences for their participation in issuing infected products (Ottosen 1993:280; based on reports in the "Los Angeles Times", "San Francisco Chronicle" and "New York Times" during July of 1992).

The outburst of anger in France and the laying of criminal charges were very likely motivating factors causing the Federal Government to establish a judicial inquiry and to grant some compensation. Such measures were likely intended to control and diffuse the anger which had been building up amongst infected hemophiliacs and other transfused-infected Canadians. According to public statements of the former Federal Minister of Health, Benoit Bouchard, neither the Federal Government, nor the Canadian

Red Cross Society, nor the Canadian Hemophilia Society had an interest in a public inquiry. Once the parliamentary inquiry started, the Red Cross suddenly began to '*welcome an independent inquiry*'. Justice Krever, as sole Commissioner, is neither 'independent' (he reports to Cabinet) nor 'uninvolved' (he is partially responsible for transfused infected people and their spouses not having been notified from 1988 until today).

The likelihood and nature of the suffering inflicted on recipients of infected blood products had been anticipated as early as 1982 (DOC 22; Appendix 1). Once the damage had been inflicted, no comprehensive action was taken or even attempted to find infected individuals, to alleviate their hardship, and to prevent further spread. This latter 'omission' occurred despite the availability of rough estimates of the number infected (Appendix 1, *passim*; DOC 5), and were implicit in the report on AIDS in Canada, prepared under the auspices of the Royal Society, upon request by Health and Welfare Canada in 1988 (DOC 1; with respect to Justice Krever see page 146).

The approach taken in this thesis assumes as given that either a certain degree of scientific uncertainty (as claimed by decision-makers and advisors of the 'Canadian Blood System'), or an economic rationale (as suggested in this thesis), or both were governing the thinking of the decision-makers; that these rationales and considerations came to bear at a time when there was little reasonable doubt that the AIDS contagion had entered into the blood supply and that the consequences of infection with the AIDS-related agent would be socially, psychologically and physically devastating. A retrovirus was suspected as per reverse-transcriptase clues discovered by Dr. Gallo of the National Cancer Institute in Bethesda by

November 1982 (see Shilts 1988:201-202; for later 'official dates see Panem 1988:153-161). The early patterns of the AIDS epidemic in the gay community pointed to a pattern of exponential spread and a high likelihood of lethal outcome. The victims' experiences can be characterized generally as a profound sense that medical professionals and institutions did not care about the patients' exposure to serious risks to health and life from medical treatment, nor about the actual damages which actually had been inflicted by exposing them to these risks. They are convinced that many of the infections could have been prevented, if the decision-makers had acted according to what any 'reasonable, socially conscious person' would have done under the circumstances, with 'the information available at the time', and in accordance with requirements by the Food and Drug Act (DOC 24). Mr. Michael Worsoff, officer and volunteer counsel on the Board of Directors of The Canadian Red Cross Society in 1983, is on record for having advised the board of the Red Cross in early 1983 that the Red Cross had foremost the moral and legal obligation to protect the public before any other consideration; this was read into the record of the Krever Commission on September 20, 1994; see also Arenson's investigation, DOC 18).

The full consequences of the contamination of the Canadian blood-supply were concealed from the public between 1975 and 1992. They were exposed by media-supported public displays of the experiences of the victims and the exposure of wrong-doings in France. These initiatives eventually led to some financial compensation, to the (judicial) 'Inquiry on the Blood System in Canada' (from hereon referred to as the 'Krever Inquiry'), and some, still underfunded, ineffective and unverifiable efforts to locate infected individuals. Dr. Susan King's effort to find infected patients of the Sick Children's Hospital in Toronto was an exception. She has testified

before the Commission.

Note: I am paying little attention to organizational or professional entities, governmental or otherwise, except four: the Cabinet, the Health Protection Branch (HPB) of Health and Welfare Canada, The Canadian Red Cross Society (CRCS) and commercial fractionators, in particular Cutter/Miles-Canada, an arm of the German pharmaceutical giant Bayer. They were responsible and accountable for what was given to Canadian physicians for hemotherapy and to hemophiliacs for home-treatment: the CRCS as the primary manufacturer (by its own choice); the plasma companies under sub-contract with the CRCS; the HPB as the statutory body to both regulate and to enforce the law; and the Cabinet as ultimate executive with special legislative powers (through Orders in Council). Thus the Commission's undertaking to endlessly parade provincial and local public health agencies, community groups and treating physicians can only serve to confuse the public, to bury the truth under a mountain of paper, and to obfuscate the accountabilities of the primarily responsible entities. I am determined not to surrender to the legal and public relations spin-doctoring which has been in progress for more than a decade.

Background and motivations for this thesis

There are three areas of interest which led to the particular formulation of the hypotheses:

a) The connection between cultural practice and pain-related phenomena:

This is a brief list of a variety of sources: a general interest in possible limitations of rational decision systems of modernity ('rational choice'; see the discussion of 'rational choice' and 'inner authenticity' in Appendix 2); observations on the conflicts between 'inner authenticity' and 'public accountability' (Norris on Kant, 1993); in how the strategic use of semiological deconstruction and reconstruction of concepts, values, meanings undermines 'inner authenticity' as well as 'public accountability', in particular as this may affect health and illness; differences between modern and pre-modern conceptions of health and illness, between objective observation and subjective experience, between analytical and holistic conceptions of the human life-world; shamanic conceptions of illness and healing (in particular, the utility of and the intervention in the 'suffering experience') in preliterate societies (Barber, 1993); in Giddens' hypothesis (Giddens, 1991), regarding the sequestration of certain experiences from every-day life in late modernity (disease, death, madness, suffering etc.); Bauman's analysis (1989) of the Holocaust as a phenomenon of modernity and rationality (the effect of 'problem-solving' and 'distancing' between decision-makers and

those who suffer the direct consequences and 'side-effects' of their decisions); Tyrer's (1993) suggested goal of 'pain eradication' in late modern medicine (1993) through pain clinics (to avoid the medical 'embarrassment' of continuing wide-spread pain and suffering experiences); personal experiences with the 'distancing' properties' of scientific discourse and text, as contrasted with empathetic 'anthropological poetics' (e.g. Prattis 1987); 'victimism', as a trend of late modernity which uses, amplifies and manipulates 'mediated' strategic public displays of suffering and responses to it (Sykes, 1992); the powerful role of authority and obedience in the infliction of suffering (e.g. Milgram 1963;1974); discussions by Berman (1986, 1989) of modern societies being characterized by a fragmentation of knowledge, community and cultural practice; a discussion of 'horrendous death' and 'thanatology', the study of the human propensity to collectively commit atrocities on other collectives (*"Horrendous Death, Health and Well-Being"*, edited by Daniel Leviton (1991)).

b) The significance of pain-related phenomena, as it pertains to phenomena of the contamination of the Canadian blood supply:

This interest arose from having been a participant in the Canadian (and formerly the European) health-care system between 1960 and 1990, as student, clinical practitioner, clinical researcher, administrator, project manager, policy, organizational and strategic planner. My background includes personal experience in hemophilia treatment, the prevention of transfusion related Hepatitis B (e.g. Krassnitzky et al. 1970, (a) and (b)),

quality control/assurance in medical production facilities, and corporate operational and strategic control systems. I also infected myself in the course of laboratory research into clinical and transfusion related hepatitis B. I was hospitalized four times for surgical procedures. While I was not involved in the decision-making processes which contributed to the contamination of the blood supply, I was engaged in many of the contingent decision-making processes of the Canadian Blood System, while working for the Canadian Red Cross Society (DOC 23). Since January 1993, I have been working closely with some victims and self-help groups. My strongest motivation remains a decoration which I had received from the Austrian Red Cross Society for my efforts in implementing a rapid blood donor screening program for the exclusion of Hepatitis B antigen positive donors, beginning in 1969. Austria was the first country to have such a rapid screening program in place. During my thirty years of study and work in the health-care system, I gathered many impressions of the development of diagnostic and therapeutic medical technology in Europe, and then in North-America. During that period, medical technology virtually exploded; medical judgement and art gave way to scientific proof and measured probabilities; fairly humble personal and institutional services became large and small corporate enterprises; the patient-doctor relationship gradually took the nature of a legal contract; informed consent began to replace trust; human error and failure was differentiated from calculated risk; benefit to the individual was transformed into economic benefit to society; individual judgement was replaced by 'consensus'; and service to the human being became increasingly transformed into commercial exploitation of the human organism (Lindorff, 1993; see also Arnold S. Relman, M.D. 1992, former Editor-in-Chief of the New England Journal of Medicine, expressing his fears that his profession

has lost its ethical ways through commercialization).

The following references were used with respect to the AIDS epidemic in general and to its impact on the practice of blood transfusion Fee and Fox (1992); Kirp & Bayer, eds. (1992); Madhok et al., eds. (1987); Mann et al., eds. (1992), perhaps the most comprehensive overview on AIDS, prepared by members of Harvard University; Ottosen (1993), an investigation of a person who had lost both parents through transfusion-related AIDS; Panem (1988); Shilts (1988); (Altman, 1987).

c) The connection between human cognition, production and ecology:

The third area of interest covers the relationships between the natural 'operational environment' (see Laughlin on Rappaport, 1989), human experiencing and modelling of the operating environment, and the interactions between the two: again as this may pertain to modern health-care practices. Approaches to 'cultural ecology' (eg. Netting 1986; Bennett 1993), to ecological medical anthropology (McElroy and Townsend, 1989) and ideas regarding the ecological participation in ecological process developed by Bateson (1972) led me to look at pain-related phenomena, such as suffering, empathy and the infliction of suffering in an ecological context. In a sense, I am looking for an 'ecological pathology' ('pathology' in the root-sense of the term, the 'science of suffering'), and a 'cultural epidemiology', of which such an ecological pathology would be part (suggested by C. Laughlin). The interest was triggered by the simple assumption that the human organism, including its 'cognizing nature', the brain, are part of and have evolved with the natural environment.

Therefore, the nature of all the consequences from human engineering interventions in the natural 'external' environment would be, in principle, of the same kind for the human organism, as part of the total natural environment. The assumption is axiomatic, yet much of what humans do onto themselves and to each other ignores this axiom. While we may be concerned over what the damages resulting from human intervention to the 'external environment', in turn, could do to the human organism, we are much less concerned over the effects of direct human engineering on the human organism. It seems that we have become accustomed to a dualism which is similar in kind to the mind-body dualism: we tend to define 'ecology' as the study of the processes in an environment external to humans, without recognizing that we are part of the environment.

"In just 300 years a huge chunk of the geological capital of the ages was consumed as if it were an ever growing annuity guaranteed until the end of time....The fundamental philosophical choice - can human beings dominate nature or are they limited by nature - now divides both capitalism and socialism. It may well be the issue on which a true "convergence" of the market economies and the centrally planned economies takes place" (Barnet, 1980:301; quoted by Leviton in Leviton (ed.) 1991:326).

This brief passage points to the ecological pervasiveness of this error in Western thinking which reaches all the way into 'philosophical choices' and across major political orientations: human relationships to nature, 'market economies', 'central planning' are considered without recognition of that which is producing these phenomena: the human organism itself. It impressed on me the need and urgency to participate in the work towards a correction of this error.

Pain-related experience as (one of) the most fundamental imprints of human experience.

Human suffering has a special place in symbolic anthropology, as well as in transpersonal anthropology, particularly in the context of the shamanic experience. Many of the interpretations of human suffering are 'symbolic', religious, philosophical, 'poetic', mythological, rather than scientific. While such conceptualizations are not at all difficult to comprehend, they are difficult to operationalize for purposes of scientific analysis. Joseph Campbell (1991a:50), for instance, summarizes the 'imprinting' of the suffering experience on human consciousness:

"The 'grave and constant' in human suffering, then, leads - or may lead - to an experience that is regarded by those who have known it as the apogee ["away from the earth"] of their lives, and which is yet ineffable. And this experience, or at least an approach to it, is the ultimate aim of all religion, the ultimate reference of all myth and rite."

Morris Berman (1986:302), a science historian, points to the antiquity of the 'pathogenicity' ('pathos' meaning here 'suffering') of civilization and the 'compromise in the quality of the life experience' any form of civilization represents:

"There is a famous papyrus in the Berlin Museum, no. 3024, titled 'Rebel in the Soul', and dating somewhere from 2500 to 1900 B.C. This was the so-called Intermediate Period of Egyptian history, between the Old and Middle Kingdoms, a time of total social breakdown, widespread chaos and disruption. It reflects an age similar to our own, in which old values had collapsed and new ones not yet taken their place. The document records something unheard of in bicameral culture - an identity crisis. Its author is preoccupied with the meaning of life, his self (ego), the conflict between reason and emotion, and possible suicide. "Brother", says his soul to him, "as long as you burn you belong to life". This is effectively what Teiresias tells Odysseus when the latter visits him in Hades and asks

the prophet to show him the way home and put an end to his restless search. But Teiresias is disapproving of this twenty-year search for the Self; he hints to Odysseus that a life that is equivalent to "burning" might be well worth giving up. Contemporary existentialist philosophers, such as Rollo May, by contrast, have made a career out of the notion that such anxiety, and pre-occupation with identity, is a sign of health. They never seem to grasp that we, like the author of the 'Rebel', live in times so crazy that Angst and vitality get mistaken for one another."

Teiresias, the Rebel's soul, Rollo May, Joseph Campbell and Morris Berman seem to be in agreement that the suffering experience per se is not entirely perilous, but that it carries the seeds for the improvement of the human condition. Suffering (*dukkha*) is the main motive for awakening in Buddhist psychology (C. Laughlin, personal communication).

The human infliction of suffering (by 'commission') may be an even stronger imprint than the experience of suffering from 'natural causes' (which may involve human 'omission' of preventive action). The Ten Commandments, for instance, consist of nine rules concerning 'commissions', only one concerning 'omissions'. Even the latter, respect of one's parents, can be construed as a rule which forbids the commission of disobedience towards one's parents. Human suffering from 'commission' and 'omission' by others is a legal-ethical-moral quagmire which has deeply concerned humankind from time to time, but which is not anywhere near unambiguous comprehension. Because the operational environment is transcendental, the number of possible omissions with possible consequences is infinite and unpredictable. Intentionality of omission is difficult to prove. Commissions and their prohibitions are fairly finite, they can be feasibly enforced, and their intentionality is more readily proven. The Christian myth directs its sanctions mostly against 'omission' of the love for god and one's neighbours. The Apostle Paul would have preferred to do away with the 'Law'

and its prohibitions, and replaced it with some form of 'universal empathy'.

When early Christian communities were small and dispersed (comparable to small preliterate social organizations, comparable also to 'nascent volunteer organizations' in our society - see page 62), this might have been feasible for a while. In the context of the Roman Empire, or any other empire thereafter, it was not. The 'Law' remained part of the Christian code. The 'empathetic failure' of Christianity (and Buddhism, Confucianism etc.; see Fox, 1989:240-241) is not inherent in Christian faith. The origins of its failure needs to be looked for in the problems of 'civilization' (see Fox 1989:203-241, regarding his 'palaeoterrific' solution to social problems).

In modernity (e.g. in the context of American notions of 'pursuit of happiness') and in late modernity (in response to the carnage of two world wars but those imprinted by the events of the wars), we are finding it increasingly difficult to legitimize any form of inflicted suffering, with the exception of the penal system. (Note: retaliatory infliction of suffering, in the sense of 'an-eye-for-an-eye', as human ecological adaptation, and its Christian transmutations are not discussed in this thesis). We would have little use for the ends which may come from suffering such as the formation and transformation of myth and rite, the transformation of the individual. If we follow Campbell's train of thought,

"And of such imprints, suffering itself - the raw material of tragedy - is surely the most general, since it is, in preliminary sense at least, the sum and effect of all"; [and regarding the 'ends':] "Whereupon, with a cry of joy, leaving both humanity and intelligence behind, the soul may leap to what it then suddenly recognizes beyond the mask. Finis tragoediae: incipit comoedia. The mode of the tragedy dissolves and the myth begins." (Campbell 1976a:50-51),

we find that suffering has become the 'crux of late modernity' and

an intractable paradox. We have deligitimized the infliction of suffering, while it remains inevitable. We '*the soul can no longer leap beyond the mask*'. Instead we observe strategic concealment and forced exposure, at the same time. (See the discussion of Ernest Becker by Morgan, John D., in Leviton (ed.) 1991:49-75). We can no longer dissolve our tragedies: we look for the 'mask of justice' which locks us into the perpetual 'tragoedia' of legitimated infliction of suffering: 'penalty'.

"Suffering itself is a deception (upadhi); for its core is rapture, which is the attribute (upadhi) of illumination. The imprint of the rapture enclosed in suffering, then, is the foremost "grave and constant" of our science. Compassed in the life wisdom of perhaps but a minority of the human race, it has nevertheless been the matrix and final term of all mythologies of the world, yielding its radiance to the whole festival of those lesser upadhis -or imprints - to which we now must turn." (Campbell, 1991a:56-57).

The late-modern ideas of deligitimation (protective codes) of the infliction of suffering, or the elimination of suffering as experience (Sykes 1992), taken to its fullest consequence, would thus eliminate not only religion, myth and rite, but a whole range of experiences would lose an important context and reference. The objective rational codes seem to arise from conditions of human social control, which are expressed in the teachings of Mo Tzu (between 480 and 400 B.C. in China) and point to an attitude towards suffering and emotions which is diametrically opposed to Campbell's vision. Campbell reports Mo Tzu's tenets (Campbell 1991b:418-422):

- o Arts are useless;
- o Emotions are of no practical value;
- o Only what profits the country and the people has value;
- o In the beginning people were selfish, and life was short and brutish (!);

- o Therefore there had to be a ruler and the only truth is his;
- o He who fails to report a malefactor is a malefactor;
- o Discrimination is at the root of all evil and must be eradicated;
- o Instead of discrimination there shall be 'all-embracingness';
- o Enemy armies must be totally annihilated.

This agenda is an array of Hobbesian elements, 'human rights', but also has capitalist, socialist and totalitarian nationalist facets. Socialism, capitalism, the idea of the modern sovereign and the idea of human rights, however, are all hewn with the same rational axe from the same material block. None of them has a formal use for emotions. Mo Tsu had no lasting impact in his time. His ideas were transformed into concrete action more than 2000 years later in the form of Chairman Mao's brand of Communism. They produced the bizarre, psychopathic-psychotic character of the massacre of Tibetan Buddhists (Campbell 1991b:505-516). Similar ideas of other 'rationalists', in different combinations, also made possible the Holocaust, the October Revolution, the massacres of peasants and city-folk by the Mongol hordes, mass burnings of witches, slaughters of Christian gnostics. Such atrocities were not committed in the 'heat of passion', but under the rule of reason, social control and material calculation. Mo Tsu's ideas and the 'rebel's dialogue with his soul' indicate that the problems of 'social organization of emotions' in late modernity are not modern at all. They remain rooted in the ancient rational 'compromist-seeking' processes of 'civilization'. The schism between 'natural' existence and civilization, as the source and condition of 'human suffering', as the result of rational cognition, is described in Genesis.

While the most vulgar and crass forms of infliction and experiences of suffering may have declined in Western societies - there is no objective indication that the 'net'-suffering' has been diminished:

"A recent survey done at the University of Michigan found that half of all Americans suffer during their life-time from one or another of the illnesses in the DSM (Diagnostic and Statistical Manual of mental Disorders IV (DSM-IV), published by the American Psychiatric Association). This does not include 'minor depression' (or 'normal' grieving of all sorts, or suffering associated with acute losses, physical ailments, physical disabilities and so forth). More importantly, one third of all Americans are so afflicted in any given year." (Kristin Leutwyler in Scientific American, September 1994:17-18)

The argument that one has to be aware of 'undue psychiatric labeling' does not eliminate the reality that people are suffering. Suffering, severe enough to be psychiatrically classifiable and gradable, is a way of life for more than a hundred million Americans. Suffering from environmental processes has been reduced through measures of hygiene and the provision of basic subsistence resources. Thus the remaining suffering in Western societies must be assumed to be the product of social processes (e.g. homelessness in the U.S. is the product of distributing resources badly, not a lack thereof; domestic violence can occur without material deprivation).

In late-modern every-day life, in casual social interaction, little suffering is noticeable. It is hidden, concealed, individually and by institutions (Giddens, 1991). On the other hand, selected categories of suffering are displayed and amplified through mass-media (Sykes, 1993). Our late-modern Western culture, like other cultures, may have developed specific patterns of inflicting, experiencing and displaying suffering, which, as suggested, appear to be related to the delegitimation of inflicting pain and suffering while it remains inevitable. Operational responses of corporations and allied institutions (in particular government) will be discussed as, perhaps, the most important 'locus of control' of how pain-related phenomena are shaped in late modernity.

Sources for an ecological framework to ameliorate the diversity in interpretations of pain-related phenomena

The conflicting interpretations of the same pain-related phenomena within such a paradigmatic diversity suggests that a paradigm transcending this diversity (not merely a metatheory) may ameliorate what appears to be discrepancy, contradiction and paradox (additional diversity will be discussed in Chapter 2). Ecological modelling has helped to solve many biological puzzles. It is suggested that it may be used similarly in the interpretation and explanation of pain-related phenomena (see also the note on page 33, on the ecological epistemic process).

Such an approach was derived from the ecological perspectives employed by McElroy and Townsend in medical anthropology (1989); approaches to human ecology discussed by Netting (1986) and Bennett (1993); ecological considerations (in particular with respect to the notion of an 'inner ecology', which are implicit in neuro-phenomenological structuralism; see Laughlin et. al 1991); Bateson's approach to a phenomenology of the mind (1972); transformational orientations (Varela 1991); and discussions of the impact of scientific inquiry on Western consciousness (Berman 1986, 1991).

The 'epistemic project' of this thesis was then to see if three levels of classifications of pain-related phenomena, each belonging to different sets of paradigms, would intersect sufficiently, so that they may inform each other. This thesis is thus situated at an assumed intersection of three theorized fields:

1) Ecological conceptions of our life-world;

2) Conceptions of pain-related phenomena;

**3) Interpretations and conceptions of events and experiences
associated with the contamination of the Canadian blood supply.**

There are two anthropological approaches which I considered to be helpful in tying the three fields into a meaningful relationship. One was the historical progression of human social adaptation, changing the experience and interpretation of pain-related phenomena.

The following table attempts to characterize the progression of this change across an array of phases of civilization. The columns are not intended to represent absolute changes, but rather a progressive layering and interpenetration. Older elements and vestiges, in some partial transformation, are possibly still with us in our pain-related experiences. I am distinguishing between late modernity (present) from postmodernity (some possible future conditions) as historical epochs.

'Postmodernism' represents critical tendencies, movements and interpretations of a 'subset' of phenomena of modernity which are the by-product of conditions of late modernity, in particular of what has been described as the 'information age'. Meanwhile the 'juggernauts' of modernity, science and technology, are still operating, but they are less visible. Also, what they are doing is far less comprehensible: they are, in part, operating in the nano- and pico-dimensions of our life-world, amongst molecules, conducting and semiconducting matter. While the products and

by-products of high modernity are being challenged in the visible world, modern processes continue at a level which is not directly accessible to ordinary human experience: it is too small, too complicated, too complex, the data are too numerous and can no longer be abstracted with our natural cognitive faculties. 'Postmodernity' is thus tabulated as a hypothetical future set of conditions for human life, when modernity may have reached an awareness of engineering from beyond engineering. (See also Grant on 'technique', 1969, quoted in Laughlin 1989, discussing our *'inability to comprehend technique from beyond technique'*). I suggested that 'post-modernity' will be 'ecological', 'adapted', yet 'adaptive', in some sense. But it will not be what is comprehended as 'post-modernism' today.

The contribution of post-modernism will most likely be the propagation of paradoxes and contradiction to the point of such 'insufferable' absurdity, and such a high degree of incompatibility of modernist, post-modernist, professionally produced, semiological deceptions, that some adaptive reaction will set in. This may in part be 'reactionary' or even regressive. In part it will be, hopefully, a transcendence of regressive, reactionary reconstruction.

	Preliterate	Civilization	Modernity	Late Modernity	Post- Modernity
Life-world	Symbolic	Split order Symbol dominated	Sign-order Verbal- rational	Sign-order (Scientific) Mathema- tics	Verbal-rational /scientific- Rational Conflict
	Cosmology	Religion	Enlighten- ment Enginee- ring	Science Engineering Economistic Ecology Post- Modernism	Ecology??
	Steady- state	Expansion, Transfor- mation	Expansion, Transfor- mation	Transfor- mation, State- Turbulence	Towards Global Steady- State?
	Weak territorial	Territorial	Extreme territorial	'Trans- territorial' 'Markets'	'Neo- territorial?'
	Tribe	Empire	Nationstate	Corporation	??
Ecological Paradigm	Holistic Ecologi- cal	Functional /Relational	Functional /Relational Cybernetic	Functional /Relational Cybernetic Transfor- mational	Holistic Ecological
Pain Related Experience	Part of Symbolic Order	Social Control	'Price of progress'	Suppress Denial 'Victimism'	Part of Holistic Ecological Order?
<p>Experiences of the victims of the contaminated blood supply</p> <p style="text-align: center;">?</p>					

Fig.1 Contexts for the Legitimation of Inflicted Suffering

The second concept, the 'cycle of meaning', is taken from Laughlin et al. (1990). It is specifically articulated for shamanic interventions. 'Every-day life' has been added in the centre of this diagram to indicate that the cycle of meaning weaves itself into every-day practice and informs the cycle at various points and is informed by the cycle ('double-hermeneutic').

Fig. 2 *The Shamanic Cycle of Meaning (From Laughlin et al., 1990)*

The second, derivative diagram applies 'the cycle of meaning' to late-modern adaptional processes. This version does not indicate a consolidation

and gradual transformation of the overarching understanding (a relative steady-state), but the opposite occurs. More and more problems pile up, more and more 'rights issue' accumulate, life is 'problematized'. Instead of life of routines, ritual, 'knowing', and gradual transformation and adaptedness, we are in a permanent state of adaptation, learning, orientation. Knowledge remains 'explicit', 'unfinished', 'unintegrated'. It never has enough time to become 'implicit', to become 'taken for granted', or at least temporarily settled within a steady-state.

This application of the cycle of meaning, and the substitutions of its elements with elements of late modernity is based on phenomena of late modernity described by Giddens (1991), Fox's discussion of Leviathan (modernity) (1989:233), and personal observations of contemporary phenomena which are likely to play a role in our present-day state of the cycle of meaning. The suggestion of the universe of problematics and 'rights' codes replacing cosmology is mostly intuitive. Admittedly, this kind of application of the cycle of meaning will need empirical research. The phenomena surrounding the contamination of the blood supply will serve as such an empirical test of late modern content of the cycle of meaning.

This cycle is no longer a 'complete cycle', encircling every-day life. Every-day life no longer organizes and is being organized by the cycle, but it has become a mere element in a 'subcycle', in which technology is central. Technology organizes and is being organized by the three 'fields' contingent on it. The rest is 'sequestered' from this cycle, it attempts to 'penetrate' and is blocked from doing so, it may erupt in anger, anxiety and violence, or sink into depression from exhaustion. On occasion, an individual may transform spontaneously. The questions of such 'distortions' have been raised by Gregory Bateson:

"A question of great scientific interest and perhaps grave importance is whether the information processed through consciousness is adequate and appropriate for the task of human adaptation. It may well be that consciousness contains systematic distortions of view which, when implemented by modern technology, become destructive of the balances between man, his society and his ecosystem." (Bateson 1972:440).

Fig.3 The Fragmentation of the Cycle of Meaning in Late Modernity

The model, as applied to conditions of late modernity, would suggest that distortions of consciousness which are destructive of balances are possible without technology. The lack or break-down of a coherent cosmology is sufficient to permit an infinite number of possible 'deviation amplifying' processes to emerge. Some specific examples of 'consciousness becoming destructive of balances' will be shown on pages 141-142). Bateson's contribution points, with some urgency, to the necessity of human consciousness to be included in human ecological modelling. Only then can 'human ecology' serve as an explanatory paradigm. At present it is merely an advanced environmental-economic or social-economic engineering project, amplifying the sequestration rather than attenuating it.

2) The use of an ecological framework for the exploration of pain-related phenomena

Ecology: 'perspective' or 'theoretical framework'?

This discussion intends to show that there are currently two main orientations for research in human ecology, which may be used individually or simultaneously. The first looks strictly at specific relations and exchanges between an organism, or between a group or class of organisms with its 'external environment'. The other orientation recognizes that all constituents of the life-world form a 'whole' above and beyond the sum of all individual ecological relations: this may be referred to as a 'general outlook' or 'perspective' - it may be theorized, but it is difficult to operationalize for empirical scientific inquiry.

The more restrictive view-point of ecology can be readily reconciled with the design of empirical inquiries in other fields of ecological interest (eg. in agriculture). The hope for some potential 'unification' of various disciplines by taking an 'ecological approach' has been expressed (Vayda and Rappaport 1986:492).

This kind of ambiguity in ecological thinking makes the term 'human ecology' a source of theoretical problems for the kind of exploration which is attempted here. At this point there are no good working definitions of the term 'ecology'. McElroy and Townsend (1989:39), for instance, try to define ecology as the "*field of study concerned with the interrelationships between populations and their environment which constitute ecosystems*". Such a definition is tautological as it states that 'ecology is the study of ecosystems which are defined by a 'population'.

Further down in the text, 'population' is defined as "*groups of individuals living in a given habitat with the same pattern of environmental adaptation*". Here the population is defined, in a circular fashion, by the very processes it is supposed to define. Thus the difficulty of definition arises already from the field of specific 'relations and exchanges', without even trying to give consideration to the 'deeper' aspects of ecology. (See note on 'deep ecology', ADD 1)

'Netting's excuse' gives some insight into the difficulties of definition:

"If cultural ecology were a little older, rather less diverse, and not so lively, it might be possible to develop a connected theoretical and methodological summary in the following pages. I believe that such an overview is premature - we are too busy dealing with the details of specific subsistence systems, instances of microevolution, and limited regional comparisons to begin the process of definition and synthesis characteristic of a more mature discipline. There is only one way to explain what cultural ecology is: to show what it is doing." (Netting, 1986:6)

Netting is expressing that 'ecology' is constituted as 'traditional ecological knowledge', that it can be 'intuitively understood', but not theorized (or at least not yet); that ecology is a form of 'holistic knowing' that cannot be broken down into a sequence of causal relations; that this intuitive knowing is sufficient to guide empirical research at least in some specific areas of interest which will be recognizably 'ecological'; and that empirical research thus guided can make the 'ecological' intuitively knowable. Similar views of ecology have been expressed by Sheppard (1969): "*ecology is not a discipline: there is no body of thought and technique which frames an ecology of man;*" and Bates (1953): "*it is a pervasive point*

of view rather than a special subject matter" (Sheppard and Bates quoted in Netting, 1986:1).

Vague formulations of this sort, however, make it difficult to frame an ecological question unambiguously, to select, collect and to interpret data which would inform such a perspective. Consequently, much of human ecological writing, as an anthropological discipline, continues to see the human being as adapting to the natural environment (also to the 'engineered' environment which humans produce in the process of adaptation); by modelling it, exploiting it and modifying it; by producing and reproducing systems of interpretation of the environment which result in a tendency towards 'optimal' extraction of food and other resources from the environment; and by inventing ways of protecting themselves from 'adverse conditions' in the environment (predators, poisons, disease, weather, and most importantly, other humans). Consideration may be given to the division of labor and to population control.

In this conception, the human species in general, the individual and the social group under observation are seen as external to the environment, not part of the environment. This orientation is derived from the definition provided by Haeckel (see page 32; see comment, page 13). It is obvious in the early observations by Boas (e.g. Boas discussed by Netting 1986:8), who explored the relations between seasonal variations in Eskimo social organization, ice conditions and seal hunting. This approach works well, as long as culturally patterned groups are viewed as a kind of human 'subspecies' with fixed behaviours of material existence in a fixed material environment, living in a steady-state.

Netting is aware of such limitations (1986:100):

"A continuing danger confronting cultural ecology is the tendency among some anthropologists to see as a reductionist calorie counting, mindless number crunching, or vulgar materialism. A symbolic or structuralist conception of culture as meaningful order is often contrasted to culture as a means of meeting biological needs or as a trivial epiphenomenon of economic action and 'practical reason'." (Netting 1986:101; quoting Sahlins, 1976)

Only a few pages further down he commits himself to a rather 'vulgar' steady-state economistic ecology:

"As our dependence on the physical environment and the effects of disturbing intricately functioning ecosystems become more critically apparent, we need to know more about the varieties of long-standing successful human adaptation. It is both possible and necessary to gather empirical data on operating social groups, describing their technology of production and protection, distinguishing the variables that are effective in their surroundings and assembling quantitative profiles of population, labor input, rights to resources and consumption." (Netting 1986:103)

Earlier, he comments on the rights to resources and consumption:

"Ecologically-directed analyses have shown that rights to resources are not simply correlates of particular stages in social evolution, manifestations of cultural values, or legal creations. Rather, such rights are bound up with the way a resource is used and the degree of competition for it." (Netting 1986:78)

Rights, values, competition remain 'external' phenomena. This plainly 'economistic' cultural ecology is quite devoid of any 'inner ecology', the kind which Bateson would have envisaged.

The inclusion of consciousness into ecological thinking

Since the initial biological framing of the term 'ecology' by the

German biologist Ernst Haeckel and his coining of the term in 1870 (Netting, 1986: 1), the meaning of ecology has undergone extensions and transformations, which exceed his original meaning of the term. Haeckel's definition is as follows:

"The study of the economy, the household, of animal organisms. This includes the relationship of animals with both the inorganic and organic environments, above all the beneficial and inimical relations that Darwin referred to as the conditions of the struggle for existence." (Haeckel quoted in Netting, 1986:1)

This view, with a focus on energy consumption, acquisition, distribution and exchanges, food chains, habitats and so forth is elaborated for instance in Odum's introductory text (1986). After the initial interest of detecting 'cultural patterns' in ecological processes, the interest shifted to 'inner patterns, those which produce the observable patterns:

"Between the physical environment and human activity there is always a middle term, a collection of specific objectives, and values, a body of knowledge and belief: in other words, a cultural pattern" (Forde, 1963, p.463; quoted in Netting 1986: 4).

Once one realizes that human cognition, rational or symbolic, conscious or unconscious, is not just a representational and productive device that learns, computes and produces action, but that it does so under changing patterns and tolerances of its own, then a human ecology without accounting for those processes seems unjustifiably restricted. While Forde's statement 'feels' correct on first sight, it is ostensibly wrong if one tries to operationalize it. The problem is in the sequencing of its elements and the absence of perception. The 'middle-term' is situated between human

activity and perception, which are two middle-terms between human cognition and the external world. The interesting part of Forde's statement is that he considers 'cultural pattern' to be the 'inner' reference to human activity, rather than to be the observable pattern of human activity as products ('markers') of inner references. Forde's concept is represented in the following diagram (with the suggested adjustments): this model will serve as basis for a more general human ecological model (see page 53).

Note: I have been asked why I am giving so much credit to Forde's model, when I believe it to be flawed and have replaced with a model which is quite removed from his conception. The reason is ecological: I appreciate what I consider his error as having been requisite information for my own awareness. This 'paradoxical recognition' is similar to other paradoxes, such as suffering being the source of 'awakening', or destruction and death being the source of higher levels of organization. Many paradoxes are the result of valuations, of cognitive artefacts, not contradictions in an ecological context. For instance, one could say that Parsons was wrong and stop with this valuation. Or one could say that he was essential for the processes leading to Garfinkel.

This has an important ecological implication for theory construction. Theory which is derived from political (or other) valuations will produce contradictions and paradoxes: firstly because political focus ignores contingent processes (or 'boundary conditions'); secondarily, because the implementation of such limited theory changes the boundary conditions under which the theory was conceived. In the implementation phase, however, paradoxes and contradictions may become manifest as observable damages. Such data should not merely be used to adjust the theory but also the valuation from which the theory was conceived. But if the old theory and its founding values have been thrown out, such an adjustment may no longer be possible. This may preclude true progress. (See also discussion of 'menopause' later on). Therefore, a 'scientific process' (and 'progress') (eg. as described in Singleton et al. 1988:28-29), which does not account for implementation and side-effects of implementation is ecologically seriously flawed and therefore unreliable - or even dangerous. Theory derived from any valuation (or value system), once implemented, must allow revaluation to take place relative to the changes in boundary conditions it has produced.

How did I move from a question regarding the relevance of Forde's model to a critique of the scientific process? The ecological epistemic process taken in this thesis requires me to recognize that 'Forde's middle term' may, in fact, be a widely used cognitive pattern in cultural theory construction and practice (e.g. concepts

of ideology); that the suggested shift in the location of the 'middle-term', if implemented, would affect these practices, producing side-effects which I am obliged to explore. I expect that at some point I will have to go back not only to the discussions and propositions advanced in this thesis, but also to the origins of these proposition. By giving Forde's middle-term prominence, I have at least flagged a point of bifurcation from which I can examine the side-effects which my propositions could bring about if implemented.

'Human activity' and 'perception' and reciprocal relations are the most difficult aspects of such a model, because they are part of the internal ecology as well as the external ecology. During action, they may also be closely linked, by perceptual monitoring of activity in a closed circuit. Besides, action can be 'imagined', in which case perception and precedent of action cannot be separated. In this circular, iterative, transformational arrangement, cognition (if it would include perception) could be seen as a middle-term between human activity and the external environment. However, the 'cognized' as well as 'activity' informs perception, in opposite directions, and may not result in further activity. Therefore Forde's notion of the 'middle-term' is of limited utility.

Fig. 4 *Internal and External Cultural Patterns*

'Cultural patterns' (in Forde's sense) are not only generated from interactions between humans and the physical environment, but also from interactions between the individual and the interactions with other humans; and from interactions of the individual with itself (also referred to as 'reflection on the Self'). Thus 'the cultural pattern' is confounded by processes which have nothing to do with what is commonly understood as the 'physical environment' - in its narrow biological-ecological sense, the world external to the species.

Forde's conception of human ecology is thus compatible with and structurally extends Haeckel's or Odum's (1979) conceptions of ecology and, as such, retains some of its limitations. In the 'interacting objects view' (as expressed by Haeckel or Odum) ecological patterns relate to transfers of materials, energy or information between living objects and changes or equilibria arising from such transfers.

This perspective does not impute any inner transfers of materials, energy or information. The participating (cognizing) objects are treated as 'black boxes'. The concept of 'cultural pattern' would add an assumption of a 'wiring pattern in the black box', from which the functions of the black box can be explained and predicted. It does not assume that the wiring pattern has processes of its own, multiple operational modes and is transformed/transforming over time. It is therefore not a 'wiring pattern', an 'interface', or giant 'transducer', but a subset of ecological processes in its own right.

Gregory Bateson addresses this kind of construction of human ecology and ascribes a central role to human consciousness in processes of human ecology.

"Three cybernetic or homeostatic systems will be considered: the individual human organism, the human society, and the larger ecosystem. Consciousness will be considered as an important component in the coupling of these systems." (Bateson 1974:440)

This is why the operational/cognized environment distinction was developed by Rappaport ('*Pigs for Ancestors*' (1968), and more extensively in an essay in '*Ecology, Meaning and Religion*' (1979) on "cognized models" ; see ADD 2).

Forde's conception of 'cultural pattern' could be seen as Bateson's 'consciousness'. The term 'component' does not elevate it over the 'systems concept' in Wiener's analogy between animal and machine (Wiener, 1961). Thus 'consciousness' in Bateson's view is still some kind of (black-box) 'interface'. Bateson (like Fox) preferred to remain at a 'cybernetic - homeostatic' level of ecological epistemology, and was not at ease with deviation transcending established tolerances and control limits (he may have remained a 'functionalist at heart').

The problem of integrating human consciousness into a general ecological concept cannot be solved without a radical revision of how we classify ecological phenomena. The habits of our rational/relational constructions force us into an 'object' ('sign', noun, 'iconic') view of the world. We are describing 'objects' (living or not) which are 'interacting' and 'exchanging' something. In doing so we may lead ourselves, erroneously, to believe that we have a 'process outlook'.

If one examines symbolic life-world constructions in other cultures, however, one cannot overlook that most of them (such as ritual or myth) are processes or accounts of processes, not static images or icons.

The symbolic image is a trigger of processes. The symbolism of the

'golden calf' is in the dance around it not in the statue. A mask without its acting bearer has limited meaning (see Laughlin et al. 1990:163, on the 'symbolic process'). The 'medicine wheel' is a process, and so is the Navajo sand painting ritual (without the ritual it is just a pleasing artefact). In Western medicine, the physical examination used to be the significant symbolic process, which broke the interpersonal barrier, and had some similarities with shamanic healing practice. Today it is quite insignificant, while chiropractors and massage therapists are taking full advantage of the 'terra deserta'. The modern-day physician is a rule-governed 'object' or 'information system' interacting with another 'object' or 'information system', the patient, not one life-process engaging with another.

Thus a radical ecological view would depart from older mechanistic views and consider patterned fields as more or less bounded and more or less linked processes, all of which involve transfers of energy and information. From this view-point, it is easy to include consciousness and cognitive processes. We can ascertain that human consciousness is an energy consuming process, as can be demonstrated with various brain scanning methodologies (e.g. PET scans; the brain actually consumes a fifth of the oxygen supply to the human tissues). On the basis of such reasoning, 'subjective experience' is a significant participant in 'caloric' ecological processes as well. The fact that we cannot objectively observe these experiences does not diminish their ecological importance: we just have to accept accounts (e.g. myth) and behaviours (such as enactment in ritual) as the available indirect markers of these externally (still) inaccessible processes. Not to account for them at all would not be 'bias' but essential omission. A case in point: the maintenance of belief in powerful deities led to massive symbolic architecture, the building of which consumed enormous

amounts of energy, but yielded none in caloric terms. However, it organized the caloric energy exchanges of an entire people.

The following terminology will be used: processes participating in consciousness (which includes the field of unconscious processes) will be referred to as 'internal or inner ecology' within the 'internal or inner environment'. All other processes will be referred to as the 'external or outer ecology' in the 'external or outer environment'. Sensory/perceptual ('experience') and motor processes ('activity') of the human organism will be given a special and ambiguous 'gate' status as processes 'mediating' between the inner and outer ecological processes. They are part of the 'inner ecology' and of the 'outer ecology'. Once we abandon (or at least temporarily suppress) the notion of the 'object', and replace it with 'process', we have to assign it some 'pattern' to make it operationally meaningful. While our sensorium may be surrounded by an undifferentiated energy field, the cognitive process by which we differentiate cannot be an undifferentiated field itself (otherwise it could not differentiate anything else). Neither is the 'referent reality' which produces the 'undifferentiated field', otherwise cognition could produce nothing relevant. Finally, the differentiatedness of the processes which make up our life-world and the differentiatedness of our cognitive processes must exist in a meaningful correlation, otherwise we would be in mortal danger at all times. How to turn this into a working methodology remains to be worked out (and cannot be attempted here).

Once we are committed to the notion of 'transformational process', we can no longer admit the notion of 'structure' in its strict sense (which would bring us back to 'object'). We need to replace the notion of 'structure' with constraints which processes are exerting on each other. The

brain is a good paradigm for this purpose, since patterns of cognition are generated not so much by 'neurons firing', but by neurons being constrained from firing by other neurons or by neurotransmitters. The breakdown of such constraints is known as 'epileptic seizure', a synchronization of disinhibited, discharging cells. In social terms, the breakdown of constraints is known as 'social unrest', 'upheaval' or 'uprising'.

This discussion was meant to show that:

1) a paradigm of human ecology can accommodate human consciousness and its related phenomena; that it can avoid 'mind-body' problems (mind and brain merely being different cognitions of the same processes);

2) therefore, pain-related phenomena, which are part of the processes of consciousness, such as the infliction and experience of pain and suffering, are (constraining) participating processes in the totality of human ecological processes;

3) therefore, constraints which come to bear on pain-related processes must necessarily, at least in principle, modify their constraining influence on other life-processes.

Accounting for 'adaptation'

Alexander Alland's notion of cultural adaptation does not account for the variability and ambiguity of human adaptation.

"In developing his classic medical anthropology text, *Adaptation in Cultural Evolution* (1970), Alexander Alland recalls (1987:427) he "felt that many adaptations, at least in the area of disease prevention, occurred alongside of, or inspite of naive theories" of disease. Alland's self critique of this position is that "when disease functions in native theory as a metaphor for social problems, behaviour concerning disease becomes a complex set of compromises involving social as well as ecological adaptation. It is necessary to include social factors as well as belief systems, in any attempt to unravel complex patterns of cultural adaptation." (McElroy and Townsend, 1987:427)

A sharper distinction between 'adaptation', 'adaptedness', and 'adaptability' would lift some of the difficulties with the concept discussed by Anthony Giddens (1984:227-280: he condemns the concept as "*vacuous, serving logically deficient functionalist explanation and falsely predicating dynamic tendencies in human societies*"). Here is the distinction:

Adaptation: the processes of re-establishing equilibrium between the operations of an organisations (or organism), when such an equilibrium is disturbed from the environment or from within the organization (or the organism). This may be observed as:

a) a (reversible) shift in central tendencies of operating parameters within fixed tolerance limits of an organization or organism (eg. physiological adaptation; the 'adaptability of the automaton');

b) an (irreversible) shift in tolerance limits (and thus the 'design') of an organization or organism (e.g. biological evolution; the 'adaptability of the autonomaton').

Adaptedness: a state of oscillatory equilibrium between the operations of an organization (or organism) and those of its boundary conditions.

Adaptability: the capacity of an organization (or organism) to achieve reversible and/or irreversible shifts without losing its viability (ability to survive). (See Stafford Beer, 1972, on 'viable systems').

Two kinds of ambiguities arise from these distinctions: at the state of highest adaptedness, when there is a 'perfect fit with the environment', we are most dependent on the environment and on the boundary conditions it represents, and therefore least adaptable and most vulnerable to changes in the boundary conditions (see Bateson). This includes the boundary conditions of our 'inner ecology'. We may then try to control (restrain) such changes in the boundary conditions which threaten the steady-state, so as to maintain 'perfect adaptedness', until the additional disturbance in the boundary conditions thus created begins to overwhelm our ability to maintain a steady-state (See Fox 1989, on 'Leviathan').

On the other hand, in a state of perpetual adaptation (as in human competition and modern day communication; see Baudrillard 1993:12), we may try to modify those boundary conditions whose persistent steady-state stands in the way of our competitive adaptation to a set of perpetually changing conditions - to 'soften the boundaries', including those of our inner ecologies. Again, this may create enough havoc in the boundary conditions that the 'adapting system' is eventually overwhelmed. Amongst those 'boundary conditions', the conditions of 'human inner ecology' are the most frequently and intensely targeted, either way or both ways.

Without such distinctions, their situational variations and their implications, the concept of 'adaptation' would be, of course, vacuous, logically deficient and falsely predicating. Alledort's proposition would be difficult to operationalize. The complicated set of 'compromises' (i.e. the control of boundary conditions to simultaneously maintain steady-state and sustain competitive-adaptive processes) which is unfolding in the Inquiry on the Blood System in Canada calls for the inclusion of 'belief systems' and their origins (as manifestations of 'inner ecologies') as boundary conditions for social processes of organization). This may help in the unraveling the 'ecological and social adaptational processes' which resulted in the contamination of the blood supply and its aftermath.

Ecology and the cognition of time

Modernist ecological thinking went through three (cumulative) stages (they have been included in the table on page 23). The three stages in scientific ecological thinking have not resulted in successive replacements (there have been no 'paradigm shifts'), but rather in mixture, interpenetration and cumulative layering. The gradual perceptual progression from 'instrument', to 'automaton', to 'autonomaton' is indicative of the human cognition of the life-world. It is, at the same time, indicative of cognition of its own cognitive evolution (what we see teaches us how we see). This section seeks to emphasize the need to clarify time-related modalities of cognition, not only at the level of the individual but also at levels and varieties of human organization:

1) The 'caloric, functional, economistic, Heackelian viewpoint' (multi-factorial analysis, competition for resources, 'survival of the fittest'; stage of the 'instrument');

2) The 'cybernetic, steady-state, equilibrium, cyclical, balancing, reversibility view-point' (so-called 'ecological' analyses, analysis of linked control loops, steady states, conservationist, 'operating control'; see Wiener, 1954; stage of the 'automaton');

3) The 'transformational, irreversibility view-point' (derived from 'theory of chaos', 'dynamic equilibria' - see Waldrop 1992; stage of the 'autonomaton').

While the 'truth' of our life-world may be transformational, many of the 'practical realities' are still functional/relational or cybernetic, especially with respect to short time-spans of observation or action in our engineered life-world.

Ecology is a field of knowledge where the cognitions of time, as scalar, vector or non-entity, make a crucial difference. Functionalism hardly considers time at all. Cybernetics can be satisfied with the scalar term of time (processes are reversible). For the transformational view (which sees all processes as irreversible) the time vector is fundamental.

The cognition of time is also a significant aspect of pain-related processes. In an alarm or emergency experience, or 'intensive orientation', time is cognitively suspended: the experience is 'functional', removing the individual from immediate danger. A recurring headache may lead us to reduce stressful activities or experiences, repeatedly and return us to full

restitution (in a cybernetic process time matters in its attribution of duration and frequency, but not direction). If we go through a major grieving process, we may be transformed. In the latter context, time has direction, as our state before and after the grieving may differ.

In the strictest sense, all three experiences are 'transformational', we have learned something in the alarm experience (therefore we are not quite the same after), repeated headaches may teach us after a while that we better not push it to the point that we get a headache. We may control our activities and experiences in such a way that we get no more headaches. We are not quite the same before and after a headache.

The non-transformational view-points remain eminently 'practical' however. These ecologically engaged paradigms of time are cognitive artefacts, not 'true' reflections of a total referent reality. Each of them is 'adaptive in its own right'. Ecological representations of our life-world can use each paradigm separately, for a limited context, but should be integrated into a common 'composite frame'. I consider this to be the most potent aspect of 'operationalizing the ecological perspective', and to move from 'structure' to 'process pattern'.

The following is a highly simplified model of life-processes and the different cognitive modalities which may be used to describe and exploit them. It should serve, at least, to show that, unless the transformational trajectory is cognized, trajectories from relational and cybernetic cognition can be 'off' and be predictively misleading. It also means to show that the trajectory of any one 'circumscribed process' is linked with trajectories of contingent boundary conditions (which are also 'processes'). It should be possible to see a 'boundary trajectory' as access to the 'controlling trajectory', which in turn gives access to other 'controlled boundary trajec-

tories'.

It will be suggested that the transformation of the commercial plasma industry was the 'controlling trajectory', surrounded by bundles of contingent trajectories. The patterns of such contingent trajectories, such as the case histories of victims, can help to access the controlling trajectory, and to reconstruct its process patterns, although direct evidence, such as industrial documentation, has not come to light. Once the pattern of the controlling trajectory is reconstructed, other contingent (perhaps very important) trajectories can be discovered (e.g. the process of deregulation of the pharmaceutical sector).

'Organization'

Fig. 5 *The Relationship Between Cognizing Patterns of 'Organization' and Cognizing Time.*

Transformations in ecological theorizing and concomitant ideologies.

Today, human ecology is not just a 'perspective' or a field of scientific theorizing. Through the 'cycle of meaning' it has become a set of ideologies and, to some degree, a set of modes of professional thinking such as in economics or medicine. This esoteric-exoteric mixture is a mixed blessing: it gives ecological research public and political support. Yet it is easily influenced by political and economic agenda, which siphon off the immediate utility value and discard the substance, or would not even consider it.

Human ecology may move towards a cosmological totality. But on the way, it is fragmented by these different ideologies, linked to different modes of cognitions and purposes and the kind of ecological models which they utilize. Thus this progression in the ecological conceptions (scientific or ideological) is a trajectory in its own right. (Note: Giddens (1991) uses the term trajectory, but in the sense of 'inventing the future', not in an ecological sense).

1) The functional view:

This view-point is closely associated with 'high modernity', industrialism, capitalism, colonialism, seeking maximal exploitation of resources, under false expectations of 'unlimited' natural resources. Such an ecology looks at the evolution of an individual species in relation to the boundary conditions of its existence ('classical Darwinism', adaptedness). This ideology is linked with a belief in a 'technological imperative', in successive problem-solving, the achievability of an ideal state of human existence (inclu-

ding 'technological utopia'), in a belief that all problems can eventually be solved technically and sequentially. All Western societies are still operating in this 'project oriented' manner: 'One problem solved is one problem eliminated'. Such extreme problem-solving view-points have been rationalized recently with threats of meteorite hits, ice ages, drifts of continental shelves, global overpopulation, mass starvation, and other megacatastrophic, apocalyptic threats to human natural existence.

Medically, this ideology anticipates an engineering solution to all medical problems, including inherited defects. It seeks to legitimize 'eugenics' through genetic mapping, sterilization or early abortion, in vitro fertilization, related rights and selection criteria (such as parenting licences). Hemophilia treatment with Factor VIII concentrate and its capacity to 'normalize' the life of a hemophiliac was the product of these ideologies. Because of the disasters it caused, it is now substituted with a solution of the same kind: Factor VIII produced with recombinant technology. Future solutions will probably be 'gene-therapy', that is insertion of Factor VIII producing DNA into the human organism with viral vectors. Ultimately, in response to 'rising health costs', a eugenic approach appears to be virtually inevitable.

2) The cybernetic view

The second view-point is a reaction to the ravages of high modernity, the realization that natural resources are limited and that the biosphere is an immensely complex system of networked smaller sub-systems. It resulted in a sometimes radical conservationism, such as the Green

Movement. It coincided with and was strongly influenced by the development of cybernetic thought, which was derived from technologies by which processes are controlled in a steady-state (the industrial quality control movement preceded the development of cybernetic engineering. Some crude cybernetic control thinking - the manager and the assembly line - is inherent in Fordism and Taylorism).

A change in the control settings of one system would lead to adjustments in all other contingent systems (e.g. the 'green-house effect'). 'Environmentalism' and extreme conservationism values steady-state human existence: this includes Bateson's views and Fox's 'palaeo-terrific' fantasy (Fox, 1989), which consider the modern technological life-world as a 'maladaptation' or aberration in cultural evolution; this ideology is rationalized with arguments of pollution, degradation of the environment, irreversible losses of non-renewable as well as renewable natural resources and threats of 'social upheaval'. Morris Berman, discussing Bateson, was strongly influenced by such systems of thought (Berman, 1986). They give preference to a symbolically, mythically constructed life-world, a 'return to the cave' (men), to 'mother earth' and the 'priestess' (women).

Paradoxically, this ideology supports 'heterodox medical practices' as well as orthodox interventions, but as 'opposites' or 'alternatives'. Orthodox medicine includes this concept with a number of discoveries of 'control' cycles such as hormonal regulation, the autonomous nervous system, even to an enlightened view which looks at pathology as 'adaptational processes' (*restitutio ad integrum*). The most prominent example of this thinking is the theory of stress (Selye, central to the ecological discussions of medical anthropological problematics by McElroy and Townsend 1989).

This view of medicine as 'control-engineering' is counterpointed with

other homeostatic views derived from other-cultural healing practices and 'holistic' approaches. This medical view is superior to the functionalist view because it accomodates 'stochastic' processes (with 'central tendencies' and 'tolerances'). It remains the most powerful paradigm in biochemical theorizing and clinical application. The notion of 'immortality' (the maintenance of 'steady-state' in perpetuity) is thus in opposition to 'mortality' and a transformational ecology.

3) The transformational view-point

The third view-point was influential in the 'sustainable development' movement, which attempts to optimize 'human-made transformation' as a compromise between steady-state and maximal exploitation. (See the Brundtland report (1989), the culmination of this 'sort of thinking'.) In evolutionary terms, the entire biosphere is seen to be in transformation, continuously (e.g. Margulis 1981). On closer inspection, however, the 'practical compromise' is not so much a blending of the three view-points, but rather an allocation of steady-state economies to developing nations, while developed nations still try to maintain (sustain) the growthrates they have become accustomed to (this is what the term 'sustainable development' means).

Medicine in this context displays the earlier mentioned dichotomies (orthodox/heterodox), but this time as 'complementary', in some confused 'holistic' sense. From the same kind of confusion comes instrumentalized neo-Cartesian thought ('mind over matter'), but also positivist science applied to 'mind' through bio-cognitive engineering ('designer-drugs', for

the use of mood and behaviour modification), and genetic design of life (gene-therapy, cloning, selecting of sperm samples by intellectual accomplishment of the donor). In a way, medicine has moved from production engineering (maintenance), to quality engineering (control), to design engineering (technological transformation). Thus medicine has embellished the design elements of the 'corporation', critical to corporate viability. (See discussion on page 64). Medicine seeks both transformation and 'cost-containment' (cybernetic control synchronized with transformation), and has invented hybrid terms like 'health rationing', 'partnerships' (with industry) and 'complementary medicine'. The latter concept initiates the utilization of 'heterodox medicine in cost-containment (e.g. as an inexpensive placebo), control of radically different healing methods (e.g. regulation of herbal remedies), and commercial exploitation (inclusion chemical compounds of herbal origin in the repertoire of orthodox pharmacology).

Ideologically, this 'transformational view-point' is rather a hodge-podge of all three view-points, which is being spread by ideological diffusion, without explication of how these view-points relate to each other. There is 'struggle' to come to terms with transformational phenomena, but we are only beginning to 'liberate' our thoughts from traditional, functional and steady-state views. Intuitively perhaps, proponents of 'sustainable development' realize that the transformational view is not so much important in terms of 'inventing the future', but to protect us from the 'unintended consequences' of such inventions, regardless of whether they are intended to exploit or to protect the environment and the human being ('we may have to protect ourselves from protection').

A model of human ecology

The following diagram has been assembled as an extension of the modification of Forde's model. The items should be seen as 'fields of ecological processes', not as physical object entities. The model is highly abstracted. It can provide little more than a highly reduced 'map' for the ecological exploration of the fluxes and changes in the human life-world. In this configuration we see human action and perception mediating between the 'external ecology' and the internal ecology' (they are, in effect, part of both). Culture does not have a distinct identity in this model. Rather, it appears identical to 'human ecology' for a group of people, however bounded for a period of time (for a segment of the 'arrow of time'). 'Human ecology' is thus depicted as a field of processes which are physically or communicatively linked with each other and 'constraining each other'.

The model accomodates an apparent dichotomy in anthropological inquiry and elsewhere in the social sciences: the 'materialistic' and the 'mentalistic' representation of culture. It proposes correlations between the two, which are the effect of their mutual interpenetration and information via perception and action.

Most of eco-anthropological work is currently performed in the 'upper portions of the model', on phenomena which can be 'observed' by the ecologist and be expressed in measurable variables and relations of such variables. The lower portion can be, at least partially, 'experienced' by a participant observer. Only partially, because the observer has to report his experiences and his observations against the background of his experiences consistent with the background understandings of his own culture and

discipline.

Just as the paradigm of the cycle of meaning, the paradigm which this model represents is epoch-independent, while the specific 'contents' or 'substitutions' differ. The design of the cycle of meaning is a good candidate for a 'neurocognitive universal'. The ecological model could be seen as a 'neurocognitive' universal as well. This would heighten the hope that the modalities of human cognition could eventually converge towards an ecological paradigm. (Of course I would prefer to replace 'neurocognitive' universal with 'universal pattern of neurocognitive constraint').

Fig. 6

A Model of Internal and External Human Ecology

I cannot 'prove' the validity of the model. Rather, this thesis is meant to be a step in the direction of such modelling. In looking at the entire field of human ecology then, adaptations can be expected to occur in the outer environment, in the inner environment, and between the inner and outer environment or within each individual field. Most importantly, the model induces a search for correlations between multiple fields, and side-effects, which may arise from spontaneous and engineered changes in any one field.

For practical purposes, the model is best used in conjunction with the first two models, the diachronic representation of social processes and, synchronically, the corresponding varieties of the 'cycle of meaning':

Fig. 1 *'Human Ecology' and Its Diachronic and Synchronic Elaborations*

It should be noted that, given the three cognitive (time-related) modalities in which ecological processes can be modelled (see page 45), the models in use here will remain ambiguous. Perhaps this circumstance of complicatedness and complexity of ecological inquiry has led the ecological anthropologists to either shy away from explicating 'ecological method' and, at the same time, to keep it as a 'guiding perspective'. However, the need for an encompassing ecological paradigm is urgent. If one tries to apply the cycle of meaning and the ecological model to different historical epochs, the contents of the two models can be expected to become 'mergeable'. The cycle of meaning, with inclusion of its double-hermeneutic properties, is the transformational process which brings the transformations in the ecological model about - in its inner, outer and 'gate' aspects. However, with much regret, this 'merge' could not be accomplished here.

3) Aspects of 'outer ecology'

The human organism

The ecology of the human organism, in its aspects of 'external environment' ('operational environment'), can be summarized as physiology and pathophysiology which, of course, cannot be accommodated here to any satisfactory degree. Three aspects, however, were significant for the ecology of the contamination of the blood supply: autonomous healing processes; the lack of cognition of the 'damaging agent or process'; and the 'timelaps between damage and overt suffering'.

A premodern healing system cannot explicate such ecological circumstances. The disconcerting aspect of the contamination of the blood supply is that our scientifically/technologically enhanced cognition did explicate them, but did not act on them. In other words, the 'biomedical model' failed in an area where it was expected to be most effective.

The nervous system produces models of the organism it controls (e.g. body image, ego etc.), as well as models of the environment in which the organism operates. It also produces models which can reconcile the operations of the environment with the processes of the organism. When there is a discrepancy between the sensed 'referent realities' and pre-existing models, a reorientation (or adaptation) may be attempted. The registration of sense of 'loss of integrity' occurs in terms of a non-specific response, which could also be referred to as 'cognitive dissonance' (Festinger 1957), or 'orientation response' (discussed by Laughlin et al. 1990, *passim*). If the discrepancy is severe and lasting, it may be experienced as 'suffering'. Just as pain may inhibit further motion and further damage, suffering

may inhibit exposure to further discrepancies, stresses and further damage, until the processes of adaptation to the 'conditions at hand' are complete (the 'healing' is complete). This 'orientation' may include specific actions and interventions which could aid in the adaptive process, by the affected individual or by empathetic, and/or compassionate others. This means that the human organism plays an 'instrumental' role in the adaptive process. (If someone 'suffers' from hunger, the human organism acts to find food.)

There are many organismic processes which intervene without conscious or even central neural control, such as immune defences, or metabolic processes and regenerative tissue processes. For instance, many cases of hepatitis are 'subclinical', which means that at no point may the patient have an awareness of his or her condition. These processes become 'ecologically engaged' through tests which are markers for such disease processes, sometimes long after the fact. The suffering may then become a consequence from cognitive processes which are not triggered by the organic process itself but by the 'knowledge of it'.

In the context of HIV and hepatitis viruses, time plays an important role. There may be an interval of many years of distance between the 'injurious event' (transmission of the infectious agent) and manifest damage and suffering. This was one of the difficulties in establishing the etiology of Kuru - see McElroy and Townsend, 1989:44-48. Similar problems may delay the explanation of multiple sclerosis, Alzheimer, Creutzfeld-Jacob disease. I would include those forms of schizophrenia which are characterized by frontal and temporal atrophy of brain structures. (See also the literature on Creutzfeld-Jakob's disease and 'prions': for instance Prusiner 1987; and transmission via extracts from human hypophyses: see dis-

cussion by Gerson 1993, also on the withdrawal of the product from the British market in 1985. It was kept in use in France until 1988 and resulted in possibly hundreds of infections. Because of long latency period, it will not become manifest for years. Possible links of late-modern disease complexes with attenuated viruses used for vaccination (Sabin, rabies, small-pox), which are grown in animal tissue or cells, have raised questions: DOC 3.) A virus (or any other micro-organism) is not cognizable like a violent individual, an attacking animal or even a parasitic worm.

Some important cognitive processes are lacking when this kind of damage occurs. Under such circumstances the human being cannot engage experience and response as it would under 'normal', macro-conditions of threatened integrity. The biomedical professions have bridged that gap technologically (with signs mostly meaningful to them). They can communicate the danger to the affected or threatened individual. It is not sufficient, however, to bridge the gap of understanding. The gap in empathetic understanding and compassionate response, with a resulting social response, must be bridged as well. This means that, in the patient, a dissonant, suffering response, and in the physician, an empathetic dissonant response must be induced to evoke signs accessible for the patient, for 'normal adaptational processes' to take place. The contamination of the blood supply shows that the 'inner ecological bridging' of the gap cannot be taken for granted, may be absent, or may be suppressed. (See DOC 51, 52 on the deliberate infection of individuals in order to obtain 'scientific evidence' on the 'efficacy of surrogate testing' for the exclusion of blood units suspected to transmit hepatitis C.)

Natural and engineered environments

Humans are in an ecological relationship not only with the natural environment but also with an 'engineered, artificial' environment. At the same time, these artefacts are interacting with the natural environments - the two environments are 'encroaching on each other' (all societies have at least some artificial environment which encroaches on the natural environment and vice-versa). By the same token, the 'engineered environment' cannot entirely exclude the natural environment. At a very minimum it exists in the form of the human organism itself (which is the worst infection control problem for hospitals). People are quite ingenious in reintroducing a natural environment into the engineered environment in which they are confined for one reason or other (eg. '*The Birdman of Alcatraz*').

Modernity has not only been trying to control the natural environment, but also to keep it out of engineered spaces and, if necessary, eliminate or destroy it (eg. pesticides, herbicides, etc). Encroachments of the natural environment on the engineered environment led to unending 'routine reorientations' ('problem-solving'). Modernity's capacity (and available energy resources) for problem-solving was not only used 'productively' and 'competitively', but also had to be invested in conflicts with the natural environment, including the human organism and its 'internal ecology'. Due to the transcendentalty of the operational environment, predictions were persistently of limited reliability. Most of the negative consequences of the encroachments of the technologized environment and the natural environment are not known initially. They become cognized only when the integrity of the natural environment is severely compromised, and

when humans happen to have their sensing technology and cognitive-experiential attention focused on those changes. This applies to environmentally significant technology, medical technology and social engineering alike.

Human adaptedness to human technology requires that processes which would interfere with this adaptedness are excluded, suppressed, eliminated, etc., including essential warning systems. Worse perhaps, it is thus conceivable, that the pervasive imprinting of the systems of technology at a very young age become so pervasive that the faculties of emotion and symbolic construction, and the cognition of discrepancies between the engineered-predicted (the 'ought-to-be') and the 'truths' of the operational environment become developmentally atrophied and can no longer serve as essential 'warning systems'. While this may avoid stresses and cognitive dissonance from 'natural' intrusions into the technologized life-world, it may lead to distortion and disturbances in the human life-world which are left unperceived - until major 'unintended consequences' erupt.

Social organization and human ecology.

After the acquisition and accumulation of material goods and surpluses and their reproduction, the symbolic and/or administrative-rational social control of '*inimical as well as beneficial relations*' has been the most significant energy investment of human societies. The benefit of such a cost is a matter of ongoing debate (in business this is generally referred to as administrative and strategic 'overhead' or 'cost of government').

While it cannot be conclusively proven, there is at least some indication that social conditions in large population aggregations without such controls and substantial energy investments become chaotic and unadaptive (e.g. Somalia, Kampuchea, 'inner cities'). An alternative view-point would suggest that advanced agricultural societies, in particular during the Bronze and Iron Ages, experienced incursions from plundering, invading populations. The emergence of large scale, organized and increasingly technologized war brought about a patriarchal order, the emergence of classes, 'horrendous suffering', and the oppression of women (Bahring and Cashford, 1991 *passim*).

True homeostatis thus seems to exist more likely under rather harsh and marginal, subsistence conditions, supporting a low-density population, where even small deviations from the total set of norms would be immediately devastating. Perhaps the original conditions of life of the !Kung might have been of this kind; or of subarctic and desert societies. Even the earliest history of modern humans was characterized by vast migrations and a colonization of the entire globe. Thus the notions of 'steady-state' societies may be somewhat fictional, or a (time-related) ecological fallacy, an elusive dream, nostalgic or even utopian, something modern humans never accomplished for any considerable length of time, for the majority of the species, except in the 'out-backs' of civilization. Steady-states in civilizations, on the other hand, were accomplished at a horrendous cost, including 'horrendous death'.

Phenomena of civil organization under conditions of population growth and wealth can be observed in the development of voluntary organizations (I have observed it in the Red Cross). They usually start out as small informal groups, with fairly strong individualism, symbolisms, little

hierarchy, relative egalitarianism, little written record, little 'problem-solving' activity (unless they prematurely hire a 'consultant', a 'hidden technocrat' - see Kellner and Heuberger 1992). Initially, activities are of the 'encounter' variety, reactive, spontaneous, situational (perhaps like Neandertal humans may have conducted their life and hunts). Eventually it settles into some kind of steady-state, and there may be more ritual and symbolism (such as award ceremonies). All transactions are face-to-face, conflict within the group is fairly easily settled (but can be stormy). Some groups may never go beyond this stage (Alcoholics Anonymous never did, on purpose).

Once these groups grow beyond a critical size and level of resources, for instance through the availability of government grants, all the paraphernalia of civilization come into play. Of course these are not 'invented', but enter by 'diffusion' and faithful copy from existing larger organizations with the help of consultants or board members from the business community and from governmental experts. The symbolic control is, however, maintained and enhanced (for instance with buildings), at the same time processes are formalized and administered. Again, they may reach a steady state, and again may not go beyond that stage. Universities remained in this stage for a long time.

Eventually, when the size of the organization increases further, features of governmental, military or corporate bureaucracy become evident. 'Encounter' is replaced by 'strategy' and 'survival' (this is what is happening to universities now). At that stage non-profit organizations can hardly be distinguished from profit-making corporations. They may actually become a profit-making enterprises or 'spin off' commercial enterprises.

Universal rights

In late modernity, the concept of 'a universal right to pursuit of individual happiness' has led to a deligitimation of the infliction of suffering, expressed in various protective codes, such as human rights codes, codes concerning 'crimes against humanity', and even some environmental codes. At the same time, the pursuit of happiness is interpreted as a 'personal responsibility', while the requisite for the pursuit of happiness, technology, has become largely incomprehensible.

A positivist science (as employed in industrial enterprise) implemented in a transcendental operational environment makes the infliction of suffering inevitable. This conjunction of contradictory tendencies may lead to some adaptation, possibly in the form of relegitimation of inflicting suffering, interpreted as 'self-inflicted', the consequence of 'omission' or as the consequence of the 'transcendental operational environment'. The emergence of such 'adaptations' can be observed amongst the circumstances surrounding the contamination of the blood supply. When all is said and done, there will be a class of people, who will be blamed for their misery, who have no 'productive value for society', or who simply are 'out-of-luck'. Their suffering will be of no concern to those who have been successful in pursuing their happiness. This has a familiar ring to it; people thus marginalized have not fallen from the 'Grace of God', but out of the 'Blessings of Science'.

The corporation in late modernity

In the context of the contamination of the blood supply, the corporation as a form of social and economic organism needs particular attention (e.g. Drucker 1989; Beer 1972; DOC 38). Ecologically, the corporation is an extension of the human individual as an operating and adapting entity. In late modernity, corporations have acquired an unprecedented ability of simultaneously being in a state of adaptedness and adapting to their competitive environment as well as natural and social boundary conditions. In essence, corporations 'operationalized' the earlier discussed modalities of cognition (relational, cybernetic and transformational). In addition, they learned how to transform without serious disruption of 'adaptedness'. A key-phenomenon is that the principles of operating systems (summarized in the term 'business-like fashion') have penetrated all other life spheres, including public institutions, families and individuals. Thus the 'business-like' mode of existence has become the 'natural order' of our times and will not be challenged in the near future. Besides, all minorities, which had been discriminated against in the past from participating in the 'economic arena' will embrace the benefits it offers to them. This kind of 'viability' (ability to survive) surpasses any other form of life organization.

In addition, corporations acquire and control vast amounts of resources, wealth and a degree of autonomy which is not shared by any other form of social organization. They induce economic dependency on corporate viability for a large number of people. This includes individuals and organizations which appear 'independent', but still depend on the wealth which is corporately created and on the services which cannot be obtained in any other way (these people depend on the so-called 'economic spin-offs')

and 'technological interconnectedness').

Anthropologically, there is little which can be compared with the phenomenon of the corporation. It is simply the ultimate expression of the human capacity to organize and create realities with sign-ordered classification systems for the optimal, competitive exploitation of resources under a wide range of boundary conditions, including emergencies. Because of their adaptability, corporations may be acquiring potentials of 'virtual immortality'. The essential design of corporations may be the expression of another 'neurostructural universal'. It may also be an expression of the supreme predatory nature of corporations - which people may vaguely recognize, but cannot explain. 'Capitalism is a necessary partial, but no longer a sufficient explanation of the late-modernist modes of production and consumption; free market is now a bogus concept, as almost all 'demands' today are 'invented' and 'pushed' and are thus not expressions of true 'needs'.

The only comparable form of organization, (and actually its predecessor in design) is the 'standing army' of late and 'pre-late modernity'. Such armies have 'transformational projects' (the military campaign); 'routine operations' (the steady-state of maintenance in garrisons at home or in occupied territory); military staff, which is permanently in a planning and scenario-building mode like a corporate development department; and, finally, the standing army has a high command, including the government executive, equivalent to corporate boards. However, military organizations do not enjoy the degree of autonomy which characterizes corporate operations (except in the form of military dictatorships after successful military coups). The Roman republic was the closest to the corporate/military model in antiquity, as it differentiated peace-time administration and the appoint-

ment of a time-limited dictator in an emergency.

Technology is the key to the survival of corporations, and there should be no doubt that technology serves primarily corporate survival, share holders second, and only thirdly, humankind in general, in terms of services or economic survival. Therefore, technological strategy must be seen in this light. Again, there are some similarities with military technology, which also has not served humankind well. Since technology is dependent on the evolution of science, science remains the servant of corporate and military development.

Spiritual and rational authority

The expansion of science and technology and their integration into corporate processes ensuring viability ('the corporate control of boundary conditions') have made spiritual authority virtually irrelevant for the vast majority of processes of late-modern civilization. However, corporations still have to deal with governmental legal authority, which is still legitimated, to some degree, by 'the people'. The more the corporate ideology penetrates these institutions and 'the people', the less will there be a challenge from regulatory-legal institutions or by 'the people'. While 'spirituality' undoubtedly exists as a boundary condition to corporate organization, it is largely irrelevant for corporate survival, unless it can be economically exploited.

Spiritual authority may make statements and proclamation without any means of enforcing them against corporatism, which is its (controlling) boundary conditions. Rather, business may be discussed after the gather-

ring in the church. Whenever spirituality tries to penetrate into rational materialism, it is rebuffed or just plainly ignored. Finally, 'business-like practices' have entered into spiritual organizations long time ago. Both organized spirituality (e.g. the churches) and humanist material ideology (e.g. socialism) have become anachronistic: they are dealing with technology and its impact on inner and outer ecology only in so far as it 'encroaches', but not with science and technology as transformational loci of control. The Church may take positions against reproductive technology, socialism may take issue with electronic supervisors and job security.

Alan Hunt's discussion of Marxism challenges its limited interpretation:

'The explanatory task of Marxism is to explain the social and historical conditions that make social relations take the form that they do. This project is deeply and profoundly empirical, (without being in the least empiricist)'....Frequently we will need to make use of relevant concepts developed in other political or theoretical traditions Marxism can most fruitfully be understood as a method of coming to grips with empirical reality in order to engage politically in its transformation. (Hunt 1991:29-30).

Alan Hunt may not agree with me, but I am seeing his brand of Marxism (in particular in its empirical character) taking on an ecological appearance, which can transcend the bankruptcy of our spiritual and rational authoritative institutions. If the understanding of ecological transformational processes could be recognized to be the requisite knowledge for political transformational processes, this kind of Marxism would be indistinguishable from the kind of ecological analysis proposed in this thesis.

4) Aspects of 'inner ecology' (A Note)

Attempts to textually represent 'ecological inclusiveness' is riddled with the problem of avoiding duplication. Analytical textual representation is relational, not processual, and tends to avoid the inclusion of contingent boundary processes. Without the availability of alternative representational tools such as animation, computerized transformational representation, as they are, for instance, in use for some palaeontological evolutionary studies, some compromise had to be found.

It would be appropriate to discuss 'inner ecology' and the 'inner-outer ecology connection in general ecological terms first, and then in the more specific context of pain-related phenomena. Instead, all of this will be provided in the following chapter. The (weak) rationale for this compromise is that external ecology fits better into a general discussion of ecology, and pain-related phenomena (as subjective experiences) may be better discussed as 'inner ecology'.

2 Introduction, Part 2: The Ecological Participation of Pain- Related Phenomena

1) What class of phenomena do pain-related phenomena belong to?

Note:In Chapter 1 some introductory historical and cross-cultural differences in the meaning of suffering were discussed. This section of Chapter 2 gives a fuller account of contemporary, multiple classification systems which come to bear on inquiries into pain-related phenomena.

Psycho-social classifications of 'suffering'

Pain (*algos*), as a sensation or 'somaesthetic stimulus', is now preferably explained with the 'gate-control theory'. (Melzack and Wall, 1965). 'Suffering' (*pathos*) is not in current scientific use as a distinct psychological class of phenomena. Instead, related experiences such as 'distress', 'anger', 'sadness', 'shame', 'fear', 'anxiety', 'depression', are categories which may arise in the course of a particular 'suffering' experience (Wade and Tavris, 1990: 312-342). Stress theory could be seen as a physiological/ pathophysiological interpretation of 'suffering' (for its application in medical anthropology see McElroy and Townsend 1989:241-289, and their references to Hans Selye 1976). 'Grief' as an interpretation of suffering is not used as an emotional category by psychologists. However, the grieving process, as a sequence of emotional phenomena, particularly in the field of thanatology, is well studied by psychologists and

psychiatrists (see Kaplan and Sadock 1988:51-55; Kuebler-Ross 1969). Some of these experiences could also be referred to as 'moods'. Emotion cannot be readily segregated from 'motivation'. Like emotions, motivations are explained as a cognitive set of phenomena confounded in 'feelings'. Pain and pain-related phenomena ('punishment') are amongst the most significant participants in 'learning' processes (as for instance in Skinner's 'operant conditioning'), and are closely linked to 'motivation'. (For summaries on motivation, including operant conditioning, see Wade and Tavris 1990:344-381.)

The two medical anthropological texts which were consulted for this thesis (McElroy and Townsend, 1989, Shear-Wood 1979) do not carry the terms 'pain' and 'suffering' in the index. But they are discussed, implicitly, from the limited perspectives of 'stress' and 'illness'.

While pain may be contrasted with pleasure (the pain-pleasure complex, see Sasz 1975), suffering is not normally contrasted with pleasure (but then the authors may mean 'suffering' when they say 'pain'). The experiences of pain and pleasure appear to be mutually confounded, in particular when trade-offs between pain and pleasurable rewards are accounted for. While pain and pleasure signify an experiential contrast, there is no single signifier which would correspond to the signification of 'suffering'. Terms like 'joy', 'elation', 'fun', could fill the void. Just like 'suffering', and perhaps for similar reasons, these terms are currently of little scientific interest.

Superficially, pain and pleasure look like a structural dichotomy. Yet, there are other experiential states which are neither painful nor pleasurable. Contentedness, balance, indifference are states which are with most

of us, most of the time. Such states are not recognized as 'emotional states' of interest by authors who deal with emotions - with one exception: the lack of empathy as a characteristic of psychopathy and sociopathy. Their restricted range of emotional experiences and expression has caught the attention of psychologists, psychiatrists and criminologists.

Religious interpretation of pain and suffering is abundant (see also Joseph Cambell's discussions quoted in Chapter 1). There is philosophical interest in emotion and pain-related phenomena, primarily as reference for ethical problematics. Emotion per se, as a philosophical problematic, is quite intractable. Examples of philosophical treatments are those by Brena (1972) and Sartre (1990). Suffering as a matter of sociological interest is presented by Ranjan Roy (1992), who focuses on child abuse as a possible origin of chronic pain. There is considerable interest in the influence of culture on the responses (e.g. Zborowski 1953; Lipton 1984; Sargent 1984; Zatzik and Dimsdale 1990; Pugh 1991; Barber 1993). Typically, such accounts concentrate on pain, as it is better circumscribed and 'testable' than 'suffering', and therefore more amenable to 'engineering interventions' (problem definition, plan of action, action and evaluation, based on measurement). Concepts of 'suffering' and 'illness', but also the corresponding experiences related to pleasure. They are more fuzzy and, scientifically, 'messy' phenomena to deal with.

Suffering experiences which constitute 'somatizations' of 'emotional states', such as lower backpain, headache, migraine, 'stiff neck', are also accessible to medical interventions, while the underlying neurocognitive condition may be missed. For instance, in older people and during menopause, depression and anxiety are frequently somatized and thus 'masked'.

(On 'somatoform disorders' see Kaplan and Sadock 1988:335-344; on an anthropological account of the 'menopausal syndrome' see Lock 1993.)

The most rapidly evolving field of scientific inquiry is related to brain physiology and neuropharmacology, not just from clinical perspectives, but also within the range of 'normal life experiences'. Two examples are 'mood-altering' drugs and 'endorphins'. The role of endorphins has been studied in an anthropological context, in particular with respect to shamanic experience and other heterodox medical practices (see for instance Prince 1982 (a and b), with respect to shamanism; and Pomeranz 1982, on acupuncture).

Empathy and lack thereof

In the preface, a distinction between 'empathy' and 'compassion' was attempted. This distinction is not common in psychology, where compassion has no separate meaning. Generally, the signification for empathy is very similar to that given in the preface. (See Wade and Tavis 1990:489-491. See also Hoffman's writings on empathy, 1977, 1987, 1989). Empathy may be confounded with the complex of 'altruistic behaviour' (narrowly defined as helping others without ostensible selfish 'motive'; see Hinde 1987:100-105), or 'caring', which is an objectively (and legally) verifiable behaviour and obligation, not necessarily a subjective experience. Empathy is also described as a 'moral emotion' (Wade and Tavis, 489-491), together with 'guilt' and 'shame'. It is not clear, however, how these emotions relate to other 'social emotions', such as anger, fear or pride. Interpretation of

empathy is highly fragmented and ambiguous, situated in a sort of 'ecological interpenetration' of emotion, cognition and social circumstance.

The phenomenon of psychopathy (or the 'antisocial personality') and the absence of empathy and other moral emotions, have been as scientifically intractable as empathy itself. They may be, in part, adaptations to a neurological disorder or the result of childhood neglect. Normal social emotions may arise in a peer environment. (Kaplan and Sadock, 1988; Hare, 1993). Far more troubling than psychopathy itself is the phenomenon of people who may display normal 'moral emotion' in the private domain, but may be inhuman, unfeeling, guiltless in the performance of their professional activities (the 'Eichman phenomenon'), in particular when such behaviour is authorized, legitimized and rewarded. The difference between the 'inner ecology' of 'tough decision makers' and psychopathy is an area which remains unexplored. (Note: this is not to say that 'tough decisions' are always psychopathic. Many of them may arise from true empathy.)

Finally, there is a state of mind which can best be described as 'indifference', which does not result in damaging action, but may also be 'without empathy'. Such states may be of interest as 'therapeutic goals' ('relaxation therapy'), whereas their signification of states of 'wholeness', 'normal range', 'adaptedness', 'equilibrium' and so forth finds little attention. Such indifference may be apparent when people have left the 'arena', or the 'kennel'.

Rational-legal interpretations

There is legal interest in pain-related phenomena, in particular when

suffering is inflicted by other human beings, and when it is associated with a state of dependency or helplessness of the sufferer. In social sciences other than psychology, the emphasis has been on the phenomena of 'infliction' of pain and suffering such as violence, child abuse, battery, sexual assault, oppression, exploitation and so forth; as the phenomenon of the 'victim' (loss of self-esteem, disempowerment and 'learned helplessness'); or as an instrument of behavioural conditioning ('penology'; 'pain' is derived from the Latin '*poena*', meaning penalty). Scientific and legal disciplines give little or no credence to emotional experience and will interpret the infliction of suffering as the result of 'rational choice', 'or at least of a 'rational choice not to make a rational choice'. The issue of infliction of pain and suffering as 'revenge', 'retaliation' belongs to this field. Its significance is evident in the wide-spread popular support for capital punishment. Although it may be rationalized as a 'deterrent', the retaliatory nature is also manifest in responses of victims and families of victims, when the accused goes free or receives what is or is perceived to be a 'light sentence'.

Common language meanings of suffering

Common language often uses the term 'pain' to signify suffering (*pathos*), even when there is no physical pain involved (e.g. 'suffering losses'). Sometimes common language use is more precise: the notion of 'pain being suffered' may be used (e.g. 'the chronic pain sufferer'). While our vocabularies are growing rapidly with technological and legal-rational

signifiers, the discourse on emotional matters remains the same or may be in atrophy. In past civilizations, poets, other artists and religious teachers may have been considered to be 'expert' communicators and interpreters of emotional experiences (see Cambell's notes on suffering in Chapter 1). Poetry or other art forms and mythical or religious representations may be necessary communication tools to represent emotional content. Today, 'arts' and religion' are on the retreat (except in their commodified, commercial form), without substitution.

Human suffering (and other emotions) in contemporary Western culture are experienced in an interpretive as well as expressive wasteland. While arts and religion have been deligitimized in favor of 'scientific-logical' entrainment, there is no coherent science of 'pain-related experiences' replacing them: there is no 'pathology' which could engage 'suffering' meaningfully in the cycle of meaning.

There are different cultural valuations of the expression of suffering and empathy. It may be considered as a sign of 'character strength', if people are managing to 'grit their teeth' and 'suffer quietly' or 'make tough decisions' in the face of the suffering their decisions inflict. In some cultures, for instance, the suppression of expressing suffering from labor pains is believed to be essential to avert suspicions that some scornful ancestors are taking issue with something socially unacceptable perpetrated by the women in labor. (Shear Wood 1979:141-157).

The human brain, the site of these experiential processes, has little meaning in the construction of the human life-world. According to C. Laughlin's ethnoneurology project (Laughlin et al., 1992), most cultures have made only limited connections between the nervous system and con-

scious experience, which would include emotions. For instance, ancient Egyptians did not consider the brain to be an essential organ (they thought that it produces the mucus which flows from the nose). During mummification they removed and discarded it. The heart was the presumed seat of some kind of conscious experience and left in the body; the other entrails were removed and preserved outside of the body. Apparently these parts were considered essential for the Egyptian notion of 'ka' (Bahring and Cashford on 'ka', 1992:242-243). The heart and the region of solar plexus are common sites of somatization of depression and anxiety (eg. mitral-valve prolaps is classical symptom of anxiety). Strangely, the Habsburgs of Austria stored the hearts of the emperors in special urns in the so-called "Crypt of Hearts".

Our own culture has not incorporated conceptions of the brain into every-day conscious experiences – beyond that of a 'black box': we use the knowledge of its functions, not the knowledge of how it operates. In much of social theory the brain is not even a black box, it does not even have a function relevant to social phenomena, even when 'personal view-points', 'individual experience' (such as 'experiencing' oppression or abuse) are entered as variables into theorizing.

The place of pain-related phenomena in whole and fragmented inner ecologies

This section is meant to bring into focus the significance of 'modes of thinking' for the interpretation of pain-related experiences and how

such modes may relate to social organization. Barber (1993), in her cross-cultural review of various healing practices, suggests that the meanings of illness, pain and suffering (and corresponding healing practices) are profoundly shaped by different cosmologies. Cosmology meaningfully connects a system of constituent symbols and thus represents the highest-level symbolic model of referent realities which are partially represented by interrelating individual symbols.

As discussed, Western models of our life-world (although striving for it in some field of knowledge, such as theoretical physics, are fragmented, incoherent, constructed from different, 'incommensurable' paradigms. The degree of epistemic fragmentation is apparent in the discussion of meanings of pain-related phenomena.

The Genesis myth, and later the Christian myth, indicate that humans had not succeeded in bringing the external processes of civilization into a dynamic balance with their inner ecology at the time of myth production; and that civilization had become a 'run-away' problem (this is manifest in repeated interventions of the 'prophets'). In contrast, in small steady-state societies, a good degree of the sacred, the absolute, of the 'ecological community' is achieved. The experienced shaman has 'all the answers' (perhaps better, all the 'requisite answers' - the answers which are needed). In such steady-state ecologies, pain-related phenomena have their fixed, distinct meanings, locked into the symbolic order of things, they are 'cultivated' within the symbolic order and are thus essential processes for the maintenance of the 'steady-state' (including its fluctuations and cyclical changes - the 'life-cycle' as a participant in the ecological community and the reproduction of the 'steady-state'). Practical, every-day action is not

only rational-purposive for the task at hand, but it is also meaningful in the total symbolic context which is anchored in a cosmology. Not only pain-related phenomena, but all emotional experiences have their place in such an order.

Systems of 'signifiers' (and thus language as the spoken 'short-hand' sequences of meanings) can be used as 'narratives' of occurrences in the symbolic-tautological (self-referential) order. However, once signifiers are ordered by other signifiers, which have no 'referent reality' (i.e. objects, events or experiences), but are 'metasignifiers' and classification systems, then the narratives of this 'attributive, metasignified order' may conflict with the symbolic order and the ecological order which it represents. For instance the classification system of the Enlightenment increasingly conflicted with the 'mysteries' of the Christian symbolic order - and ecology; natives of small tribes will account for a collection of pebbles they have seen in terms of individual shapes and colors (personal communication, Paul Rubiny, in reference to work done by David Suzuki and Stafford Beer). Westerners would merely account for an approximate number and average size. In a small village, such quantitative classification systems have no prominent utility. This does not mean that they are absent or totally useless.

In large societies, because of overwhelming numbers and variety, the capacity to account for individual items is replaced by accounting for classes of items with attributable commonalities. Classes of items are substituted for individual items - at the expense of a symbolic order: the order of classifications has no dynamic, it is relational, it becomes tautological as a system of signs (everything is defined by its attributes, but also by

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the complement of attributes which it is lacking. (For instance: first hepatitis A and B were identified, the complement was named hepatitis non-A, non-B; thereafter hepatitis C was discovered amongst non-A, non-B hepatitis; the balance was called hepatitis non-ABC. A 'delta agent' had been discovered earlier, and, recently, hepatitis E has been discovered; we are now left with hepatitis non-ABCDE).

Once classes are applied to communal life, to social orders, to specialized work, and so forth, a universally meaningful cosmology becomes more difficult to maintain. Thus within such 'classes', the wholeness of the lifeworld may be preserved and remain in some correspondence with the classifications systems used within the class. Inevitably, such a society would exist with multiple 'world views', strung together with some common symbolic systems, consistent with such varieties of classes which may be coercively maintained. (The Greek pantheon is an expression of such a variety.)

The meaning of pain-related phenomena in such a sign-ordered, fragmented worldview would then become fragmented as well, as the judge, the soldier, the mother, the hunter, the slave, the priest, the lawyer, the physician and the beggar may all use different attributes and thus different meanings of suffering.

Late modernity is characterized by additional phenomena. People may participate simultaneously in different 'classes' or 'reference groups', they may draw multiple meanings from different frames of reference for life-phenomena, and be eclectic about their 'draws'. Thus we may select different meanings for different signifiers from different classification systems. This fragmentation is not just manifest socially, but we have

internalized it in our individual internal ecologies. Event reporting by media, with little or no meaning provided, and the extensive use of 'simulacra' (see Baudrillard 1983) will contribute to even more fragmentation. Since coherent, symbolic construction of our lifeworld is lost, pain-related phenomena must be expected to have lost their fixed place and meanings. Stripped of all other meanings, suffering can, at best, be avoided. (I consider the attempts made by 'value philosophers', 'ethics philosophers' and 'discourse philosophers' to construct a classification system of values (perhaps to fill the void of a symbolic order), as futile or worse: they may aggravate the confusion (e.g. Yayyusi 1991).

In summary, there is no contemporary scientific paradigm from which pain-related phenomena can be explored coherently and which could contribute to the construction of a coherent 'meaning' of pain-related phenomena. Meaning continues to be derived from a variety of ideologies, philosophies, religious and cognitive treatments of such experiences. Ecology will be examined as to its capacity of transcending this 'miasma of meanings'.

2) An ecological interpretation of pain-related phenomena

For reasons of feasibility, the 'pleasure side' of the experiential continuum will not be dealt with in this thesis. Only the field between wholeness and 'pain-fully disrupted wholeness'. The view of wholeness and disruption of wholeness needs to be cross-culturally supported. The capacity to inflict suffering by commission or omission, the suffering experience and the empathetic response to the suffering of others (or lack thereof) will be examined. The following discussion will be organized in four sections, consistent with key elements of the human-ecological approach developed in the previous chapter:

- a) Adaptedness, adaptation and adaptability; time-related ecological paradigms**
- b) 'The cycle of meaning'**
- c) 'External ecology'**
- d) 'Internal ecology'**

a) Adaptedness, adaptation, adaptability; pain-related phenomena in the context of time-related ecological paradigms

The definitions are provided on pages 40-41. To recapitulate:

Adaptedness is a state of 'equilibrium' within an organism and between the organism and its environment. Processes oscillate, in small

amplitudes ('normal ranges') around central tendencies, which are optimal for given central tendencies in a given 'ecosystem'.

Adaptation entails the processes which result in a shift in the central tendency within tolerance limits in response to changing boundary conditions (e.g. 'physiological adaptation; 'operational adjustments'; oscillations around a given thermostat setting). If the changes in boundary cannot be adapted to within tolerance limits, the tolerance limits may be adjusted (e.g. 'development'; 'resetting of the thermostat'). If the tolerance limits cannot be adjusted to reach a new equilibrium, then the organism may die (e.g. selective pressure in biological evolution. Organisms with new 'designs' may compete more successfully).

Adaptability refers to the reserve capacity of an organism to change central tendencies or change the tolerance limits. Generally speaking, most organisms can only adapt 'physiologically', within genetically determined tolerances and within given ecosystems (beyond, they are exposed to selection pressures). This includes the animal brain. The human brain is unique as it can adapt within established tolerances, and it can shift tolerances (in other words, it can 'redesign' itself: 'learned skill' - 'kung-fu'). If that does not suffice, it can 'redesign' the conditions of its operating environment (social organization, technology).

This capacity to adapt exceeds the capacity of any other individual organism. However, small animals, in particular microbes and insects, have high enough mutation rates, a high enough rate of reproductivity, and short enough reproduction times, that entire species can adapt. This is why so many species of microbes and arthropods have remained unfettered by horrendous events in biological evolution. A case in point is that the

'immutable' small pox virus could be eradicated, whereas the 'mutable' influenza and HIV viruses remain as big a threat to humans as ever.

The blessings of human adaptability, however, come at a price: with every step in 'design adaptation' the ecosystem in which the adaptation occurs is changed as well, and new adaptations become necessary. Therefore humans are engaged in a perpetual catch-up game with the consequences of their own adaptations (except in low population densities and marginal, subsistence societies). If we consider, as discussed, that pain and suffering, but also the infliction of suffering, are essential participants and motivators in human adaptational processes, one would predict that human suffering, in its totality, would be horrendous, and it would remain so, until some kind of steady-state is reached. Our greatest strength is also our greatest weakness. Such a steady-state may be elusive, as the ecosystem is never at a standstill. Sooner or later, environmental pressures would force changes to the steady-state (or at least we would not be able to resist our adaptational intentionalities and imperatives). As the Genesis story indicates, the journey from Eden has not been an entirely enjoyable one.

There are three human potentials which can mitigate against this 'adaptational frenzy':

1) The same faculties which produce our adaptational processes also increase our capacity to predict the consequences (side-effects) from our adaptational projects;

2) The experience of pain and suffering from such side-effects

may induce us to look for such side-effects, to take time out, and to respond 'empathetically' ('with understanding') to those who have been or would be damaged from our interventions.

3) The first three potential add up to a third, the capacity not only to anticipate and respond to consequences and side-effects, including suffering, but to avoid them.

Mitigation is possible only if we do not, in a maladaptive way, suppress these potentials, and allow ourselves to adapt to our own adaptational capacity; and if we, in an adaptive way, find practical means of achieving this. The most essential prerequisite would be some degree of devaluation of our favorite adaptational (and competitive) preoccupations, something which is not yet on the horizon.

The following discussion, the examples discussed in Chapter 3, and the analysis of the contamination of the blood supply represent searches for such practical ways. Along such paths, we must remain aware that such 'practical ways', inevitably, have 'damaging side-effects' as well.

Relational-Functional interpretation

Experiences of pain and suffering participate in processes which maintain or restore physical integrity. Pain can be constructed as having a 'function' in maintaining, restoring and protecting the integrity of the

physical organism. Suffering can be constructed to have a 'function' in the maintenance, restoration or future protection of the integrity of the sentient, cognizing and acting Self and its constituents.

The functional model of suffering is weak, however, because the 'function' of suffering is not as clearly assignable to a specific physical structure or component part, as is the case with pain ('gate-theory' of pain). Suffering is only generally located in the nervous system. 'Functionality' is thus ascribed to an objectified experiential phenomenon, not to an 'organic entity'. (This point was made by Laughlin et al. in a recent article on emotion. He was concerned with depression, etc.) This functional conception of pain and suffering was adopted by Emile Durkheim, who saw pain and suffering as symptoms of a 'social pathology' (e.g. anomie, suicide, revolution), and the absence of pain and suffering as a state of social health (Steven Lukes (ed.) 1982:85-107). As a contemporary of the German pathologist (and originator of the concept of pathology as 'cellular injury'), Rudolph Virchow, he could not see the adaptive properties of illness (and cellular processes), nor could he see the adaptive properties of 'social suffering' (see Fox 1989:205-240 on 'Leviathan').

Cybernetic interpretation

In cybernetic models, an organism is seen as a system of interlocking and interdependent 'control loops', which are mutually tuned and calibrated to operate as a 'homeostatic', 'resilient', 'balanced' whole. It is commonly

assumed, in particular with respect to the nervous system, that at least some of these controls are hierarchically ordered (with higher order controls, eg. the neocortex, overriding lower order controls, such as the mid-brain). While the nervous system is undoubtedly controlling most other organic systems, the concept of the hierarchical order in the nervous system can be challenged. The relative 'control power' of emotional processes (constructed as 'more primitive' than 'higher' cognitive centres) may be equal or higher relative to cognitive controls and, at times, override them. As will be discussed in more detail, cognitive conflict (in every-day life, as well as in scientific pursuit) is more likely signalled by an emotional, 'dissonant' experience, however subtle, not by 'rational illumination'. Conversely, the absence of conflict may be signalled by 'a sense of comfort' or an aesthetic sense of 'goodness of fit' or 'harmony', not by the 'objective' fulfillment of the rules of logic. Game theory points in this direction. In strategic/tactical games (such as poker), there is considerable reliance on 'guts feeling', not on the rational evaluation of odds. Otherwise, bluffing or calling a bluff would never yield an advantage.

The anthropocentric hierarchical conception of the central nervous system is manifest in granting sign-ordered rational cognition a higher value than symbolic cognition, although many of our every-day life social processes are symbolically ordered, not sign-ordered. It may be appropriate to consider abandoning the hierarchical hypothesis for the central nervous system, and to recognize it as a metaphor derived from the systems of hierarchical (sign-ordered) social organization (which, in turn, may have rather archaic foundations at the neuroendocrine level of brain organization). Instead, relations between various parts of the brain should

be looked at as some sort of ecological balance amongst large, diverse and differently organized cell-populations, with the 'locus of control' - 'intentionality' - shifting situationally from one part of the network to another. There is no recognized 'executive' in the brain, but rather networks are activated according to what is presented by the sensorium (Laughlin 1990:103) or by internal impulse centres.

The classic cybernetic model is useful as long as there is no permanent change in the settings of any of the component controls and in any of the boundary conditions of the system (in other words, it only works well for steady-state conditions). Neuronal networks can be seen as 'control-settings' (control-information), rather than 'function'. The cybernetic model of pain and suffering would be useful for 'reversible' processes, that is a restitution of the status quo after departure from a central tendency threshold for avoidance or aggression (for instance the 'comfort range' in the shower, where we avoid water which is too hot or too cold; or the observance of spending limits, to prevent existential catastrophe; or observance of thresholds of socially acceptable behaviour to avoid social sanctions).

Transformational interpretation

Disordered, transforming systems tend to move towards steady-states, and 'disintegrating' steady-states tend to move towards transformation. The disintegration preceding transformation need not be total: cognitive

crises in human ontogeny (or even cosmic catastrophes) leave 'something' behind which is no longer fully constrained by the former steady state, and which is thus potentially prepared for transformation towards a new steady-state. Sometimes, what is 'left behind' is substantial, even relatively small 'losses' may be substantial enough to trigger transformation, as the boundary conditions may be more affected by a small change in the system of concern than the system itself. (See Waldrop (1992) on applications of the Theory of Chaos).

All cybernetic systems 'drift': they are at all times undergoing 'small-scale, irreversible disintegrations' (one can notice that with the wear-and-tear on a car over a period of years). Transformational models account for the engagement of pain and suffering in irreversible non-oscillatory, transformational changes (partial disintegration, 'loss of integrity') of the physical being, or of the conception of the physical being, such conceptions of the Self and its life-world.

As discussed in the previous chapter, the transformational view, like the relational and cybernetic view, is perceptually selective. By itself, it cannot account for 'rates of transformation' (which are in part constituted by 'resisting' cybernetic processes) and for patterns of 'co-transformation' (relational-functional-structural patterns, which cannot be readily cognized in any other way). Cybernetic processes, transformational processes and co-transformational processes are all confounded in each other.

The idea of experiencing hardship as a prerequisite of attaining a community oriented, empathetic attitude and enhanced understanding of the life-world would constitute such individual 'irreversible changes'. Higher

understanding cannot take place without partial disintegration - or in human experiential terms: without some degree of dissonance, discomfort or even suffering. In this sense pain-related experiences would be engaged in 'complex processes', higher levels of organization arising from states of partial (individual) disorganization. In a 'steady-state community', there may be just enough 'individual disintegration' to prevent disintegration of the community and to maintain the steady state.

In contrast, in late modernity, when the community is continuously transforming from technological and other engineering interventions, individuals may struggle just to maintain a 'steady-state' for themselves. They may try to avoid individual transformation to preserve existing relationships and meanings. A simultaneous loss of reference 'within' and in the lifeworld may overtax individual resilience. The result would be a 'desynchronized' community.

Furthermore, individual transformation is, in part, a high-order biological rhythm, not a matter of rational intention or 'rational choice'. Social transformation coinciding with individual transformation may overtax the resilience of the individual and lead to a higher likelihood of breakdown or other forms of 'compromised integrity'. (Note: so-called stress-scores relate to transformations in the individual or in its life-world).

b) The cycle of meaning

The representation of the cycle of meaning on pages 24 and 26 focuses on two extreme manifestations. The substitutions of the contents of

the cycle across the stages in evolution of civilization cannot be addressed in the format of this thesis. The key-change pointed out was the absence of a coherent cosmology in late modernity. The comparison also shows that the loss of ritual expression, as a change contingent on loss of cosmology leaves life changes, ruptures, losses suffering to become ritual expressions in their own rights and their own symbols. The adaptations and outcomes from these expressions are then feeding forward into further fragmentation and corresponding adaptations, which could be maladaptations and ultimately lead to disintegration. While it has been argued that some disintegration is necessary for transformation, it also carries the potential for catastrophe. There is no way of predicting what amount of disintegration will trigger it.

The late-modern version of the cycle of meaning stresses the role of technology, which cannot accomodate individual disintegration, distress and suffering in a meaningful way. At best, the conditions assumed to have led to suffering are 'problematized' and added to the 'universe of problematics'. In the absence of consistent meanings, fears may gradually transform into increasingly 'amorphous anxiety looking for meaning' (see 'identity crisis', page 14). It is impossible to tell from the quotation of the American Psychiatric Association whether psychiatric illness is actually on the rise. The only indicators may be a rise in suicide, suicide attempts and violence. However, 'tips of icebergs' are not reliable predictors of the shape of the submerged portions. They can only indicate the presence of an iceberg.

Thus the late-modern situation may not be the consequence of a specific constraint inherent in the configuration of human consciousness,

but rather the absence of key-constraints which are not inherited but must be culturally constructed in large social organizations. By the same token, the degree of violence and suffering present in earlier forms of civilization could have been 'bad constructions' of such constraints, rather than a flaw inherent in the consciousness of humans, as Bateson claimed.

The introduction of 'human rights' and other protective codes could be seen as attempt to introduce such constraints. Since they have no ecological basis, they may, in their legal implementation, become part of the problem rather than part of the solution, i.e. another set of 'not-so-well-thought-out constraints'.

It is claimed that spirituality is 'on the rise', in particular in its cult manifestations. This late-modern substitution in the cycle of meaning suggests that it may be co-opted into the sequestered cycle of meaning and actually contribute to the facilitation of sequestration: instead of 'opium for the people', customized cognitive tranquillizers may be offered to maintain the cycle of meaning sequestered by technology. Yet there is considerable hope invested in 'spiritual awakening, reaching into science'.

"One of the hottest topics in the neurosciences, according to Canadian anthropologist Charles Laughlin, author of 'Brain, Symbol and Experience', is interconnectivity: the intricate relationship between consciousness and the lifeworld, the mind of the scientist and what he studies, and the inextricable web of relations between objective information and subjective experience." (Eugene Taylor in Psychology Today, November/December 1994:57)

There are two contenders for the 'cosmological position' to bridge the diversity which exists not only in cults, but also in 'value-systems', 'para-

digms', disciplines and so forth. One is the science of instrumental use of knowledge (which I would summarize as late-modern corporatism). The other is a reflected on, understood, experienced environment (which I would summarize as ecologism). The question is which one can 'run a circle around the other', establishing a cycle of meaning and relegating the other to organizing everyday-life. Ecologism has taken a tenuous position in the cosmology field, but it is being challenged and co-opted by corporatism.

There are three 'weaknesses' of late-modern ecologism which give corporatism the 'ecological edge':

1) The main weakness of ecologism is that it does not control its requisite data, which are controlled by corporatism. Thus corporatism has this 'ecological edge'. I consider this to be the most important practical problem, one which cannot be solved with spirituality alone, but one which requires political engagement. As hinted earlier, this is where I see the future of a new socialism.

2) If all of the potential from human suffering which exists in humanity today is channelled into personal enlightenment and tranquillity, then the energy to struggle against those who do not suffer and are inflicting suffering will be lost. Which, again, would give corporatism an ecological edge.

3) And thirdly, the 'design' of corporatism may have outrun the adaptive capacity even of the 'selfish gene', whereas ecologism has not been able to arrive at a coherent, adaptive paradigm.

Therefore, unless the insights and understanding gained from spiritual practice can be transformed into practical action and broad political engagement, it will either remain 'exiled', 'ghettoized', or it will be 'co-opted'.

c) External ecology

The human organism

Acute suffering

'Objective' acute suffering requires evidence of sudden loss, injury, or any other physical manifestation of a disturbance in the equilibrium between the individual and his or her environment or within the individual. This can be, for instance, a physical injury, loss of a home, a close relative or an acute illness. The acute situation may lead to a struggle, or '*functio laesa*', the loss of operational functioning of the individual, and most importantly, to an expression of suffering, which would alert other individuals and possibly result in a 'compassionate response'. This may be effective even in stopping an aggressor as the source of pain infliction.

(Kaplan and Sadock 1988:93). However, the psychiatric interpretation of such a response is referred to as 'empathy' (and arousal of 'empathy'). This contradicts the meaning referred to in this thesis, which is closer to notions of empathy in use for describing late stages in childhood development. I would suggest that empathy and compassion, although confounded, actually belong to two different classes of experiences ('understanding' vs. 'impulse').

The acute loss or damage experience may be followed by an adaptive ('healing') process, which could be referred to as 'grieving': from denial, to anger, (sometimes bargaining, as in expectation of one's own death or in recognition of other anticipated losses), to depression and, ultimately, to resolution (but not necessarily in this precise sequence, and with different intensity at different stages); (Kuebler-Ross 1969). In fact, all acute changes in one's lifeworld, regardless of their nature, can be constructed as a grief reactions, including the loss of health, whether it is acknowledged by the individual as a loss or not (paradoxically this may include what may appear to be a sudden substantial gain, for instance a promotion or lottery win). The grief reaction could also be interpreted as 'orientation response' (see Laughlin 1990:66-70), or rather the OR ('orientation response') as tip of the 'intentional iceberg' (Laughlin, personal comment).

The acute suffering experience may induce an individual to struggle, or to 'submit', or as in the case of a broken bone, stop further movement (avoiding additional injury). Such suffering 'behaviour' would not be much different from the survival responses of an acutely suffering animal. With the exception of primates, mammalian and avian parent-offspring relationships, there is little 'compassionate response in the social others'

in the animal world (where it exists it is instinctual, rather than learned, however). We know little about the grieving animal. Dogs may grieve over the loss of a master. Monogamous owls are known to grieve the loss of their spouse for up to three years, before they accept a new mate. Hinde (1989) does not discuss grieving in his summary of ethology. In any case, some higher animals appear to be ostensibly grieving, including the pacing tiger in the zoo (who cannot adapt; his grieving response - pacing - is believed to have become 'psychotic').

The compassionate response is probably adaptive. It is most commonly observed in the responses of others to the 'suffering' of an infant: the crying of an infant, in most people, induces a response which is not unlike a compassionate response to a person in acute distress.

The close proximity of violent and anxious behaviour in acute distress (aggression/depression) and suffering can be explained at least in part with Cannon's theory of emotional response (experience and behaviour; Cannon, 1927), the fight/flight conflict, depending on the kind of (perceived or real) injurious agent: if it can be overcome (perceived or real), there may be struggle, anger or violence; if the agent cannot be overcome (perceived or real) there will be depression and resignation. A great deal of violence arises from 'perceived' threats, even when the perceived threat may not be a 'real' threat. Secondary gains (drawing satisfaction from dominating of the 'perceived threatening lesser other' may take over at a later stage.

'Acute suffering' could be considered equivalent to fight-flight-distress response to an injurious situation. The period following an acute loss or injury could be considered equivalent to a grief reaction (denial:-

anger-depression-healing). Both responses are primarily adaptive for the individual to the injury or loss. There may be secondary gains from eliciting empathetic responses to acute distress (intervention) and to the grieving reaction (support, social compensation for the 'functio laesa').

Acute distress (or distress-like states as evoked in certain rituals) make the individual accessible to 'symbolic interjections': the meaning within which the acute distress is experienced will have an important influence on the postdistress 'mindset of the individual'. I would suggest, for instance, that labor distress during the giving of birth could, conceivably, predispose a mother to bonding with the infant, if the contact occurs immediately after birth. If there is a timelaps between the distress of giving birth and mother-child contact, bonding of the mother may not be the same (the bonding of the baby is a separate matter; the baby is also in a state of distress from the shock of leaving the womb). In addition, the birthing experience is highly ambivalent and associated with heightened suggestibility, which is resolved as soon as the baby is delivered and accepted. By the same token, infanticide of a deformed child may only be possible immediately after birth, when the dissonance between the expected and actual appearance still coincides with the labor distress. If the deformed child would survive, the mother may grieve over the deformity, but may find it more difficult to kill the child. Thus it may be difficult for the father, or any other members of the community, to do it. (I am not suggesting here that labor pains ought to be excruciating. Given the long processes of child rearing, it may be more than a mere nuisance. I have not investigated the influence of full anaesthesia during the birth on child-mother relations).

Chronic suffering

Chronically suffering animals would not survive long in the wild and are eliminated by predators. The chronic human sufferer, in general, may depend on social help and support, materially and emotionally, and seeks an adaptive steady-state within the community or family. If the suffering lasts for long periods of time, or is of unpredictable length, the individual can expect to receive some support in the community, but will 'suffer' some loss of status in the community because of his or her reduced value. In such cases the individual is not necessarily in need of a suffering display as in mourning or in acute distress, but rather the individual with his/her demonstrable losses is a symbolic entity by itself. Some chronic sufferer, in trying to maintain social status, may engage in displays of suffering from time to time. (Some psychologist would argue, that in this fashion they would be rewarded for the suffering and are thus setting themselves up for never-ending suffering; they may not account adequately for the suffering of 'loss of status'. Status may be well worth defending. In the long run, however, such status-saving strategies are probably subverted by the family or community, and loss of status occurs.)

Anthropologically, there appears to be comparatively little reference to the chronic sufferer. Infanticide would eliminate much of the chronic suffering which could result from a birth defect. Other chronic conditions may not last, because natural or non-Western remedies may not suffice to bring about a 'chronic steady state'. A shortened life-expectancy is the more likely outcome. Medical-anthropological interest appears to be mainly

focussed on acute, short-term conditions and corresponding healing practices, not on chronicity (which may be simply consistent with what such anthropologists actually found). We know a little about lepers, who were isolated from the communities from fear of infection ('the dreaded skin disease' in the Bible) but kept alive. We know nothing of their life-expectancy in antiquity. In terms of chronic mental illnesses, we can assume that some cases, like in our civilization, ended up in their respective 'criminal system' and were eliminated there. If a chronic condition led to lowered social status and poverty, the 'beggar' comes to mind (including invalids from warfare). Poverty from chronic illness would speed up the process of deterioration.

Chronic suffering in pre-modern civilization is not well researched. If one goes by the accounts of the New Testament, the level of chronic sufferers might have been substantial and the social concern for the chronic sufferer minimal. The Old Testament does deal with 'economic deprivation' and consequent suffering (widows and orphans) and with a peculiar form of chronic suffering resulting from the uprooting of an entire people from their environment, as extensively described by the 'prophets' during the Babylonian captivities.

In late modern societies, the chronic sufferer poses not only an economic burden, but because of accounting methods the perception of the burden is 'distorted'. One schizophrenic in a community of 100 is probably not a great burden. A 'count' of 2.5 million schizophrenics in the United States, on a percentage basis, does not represent a greater burden. Because of overall higher life expectancy, however, there is a large burden of chronic conditions, and schizophrenia has to compete with them. In late

modernity, after a short-lived 'ideal-state', the 'universal right' of care for the chronic sufferer is gradually undermined by the 'universe of problematics', 'priorities' and 'rational choices'.

The infliction of suffering, suffering and empathy in social adaptation

The infliction of suffering

It is not clear whether the deliberate infliction of suffering has any primary adaptive value in small steady-state subsistence societies, not even in sorting out dominance and property conflicts, or acting on sorcery attributions. There are reports of significant dominance related violence in preliterate societies; see McKay 1991:65-81). This includes even the !Kung, who in 1987 reached a homicide rate three times that of the U.S. The meanings of the infliction of suffering have been and still are the means to a variety of ends: extorting information (torture); 'intimidation and blackmail' to get at somebody else's resources; punishment as a form of 'operant conditioning' and exploitation; or violence to facilitate plundering. As suggested, I have not been able to address the phenomenon of 'vendetta', the principle of an 'eye-for-an-eye', and retaliatory punishment, to any satisfactory degree. It may be tempting to rationalize it with 'functional explanations'. However, it seems to be related to specific neurocognitive processes which maintain a level of frustration, which is not relieved

until retaliatory action is taken or some 'force majeure' has taken care of it.

There is a difference in the quality of suffering, when the source of suffering is not a natural circumstance but is inflicted by other humans. A natural injury does not shatter the Self to the same extent as does injury and suffering inflicted by another human being, which is amplified further when the suffering is inflicted by a person of trust.

The use of pain and suffering as an instrument of social conditioning is extended to children as discussed by Naroll, (1983:243-245, quoted in McElroy and Townsend 1989:104): "*with the rise of civilization, punishment of children has tended to become harsher* . (A similar phenomenon has been observed with the !Kung: when property was beginning to be accumulated and family-life retreated into huts and houses as a result of cultural change from acculturation to practices of a neighbouring people, spousal abuse became more prevalent. The rise in homicide may be related to the same transformation of !Kung society.) The use of cruel and painful techniques used in abortion and female circumcision have been interpreted as patriarchal practice to subjugate women (Shear Wood 1979: 104-157). The Skinnerian approach of 'avoidance conditioning' as opposed to 'trust conditioning', and thus the instrumental exploitation of pain-related phenomena in social control still remain dominant in our times. While the instrumental use of pain and suffering on others (including homicide and war) may be a cultural universal, it does seem to be one of the major social effects of civilization, linked with stratification and discrimination (the use of criteria for stratification). Whether the benefits of civilization in reducing pain and suffering from natural conditions by establishing conditions of material se-

curity through surplus production and resource acquisition outweigh the amount of suffering used to produce the achieved level of security, remains to be evaluated - with particular reference to 'security' as privilege of ruling elites.

When civilizations become unadaptive to changes in the boundary conditions, such as shortages of resources, the only available and tested adaptive response to such changes might have been more conditioning and more suffering, including 'heightened enforcement of rules', 'plundering the neighbourhood' and 'depriving the unprivileged'. (We are still doing this in contemporary Western civilization - right now, in this country; it is just not done with physical force).

Since our social-adaptive faculties are limited (with respect to group size), small group social organization has been suggested as a solution (e.g. Fox 1989; Denis de Rougemont 1983). All other measures appear to have re-shuffled the distribution of suffering, either to other societies (e.g. Third World), or within (e.g. antidiscrimination legislation), but they did not, demonstrably, diminish the net-level of suffering.

The Brundtland report shows no concern for this dimension of human ecology because civilization is believed to be 'inherently good'. On page 295-296 the report discusses '*Nuclear War - Threat to Civilization*', a perspective which completely misses the point that nuclear war (like all other forms of technological war) was the product of civilization. The primary threats to humankind are not the outcomes of civilization but the processes of civilization itself.

"... The challenge ahead for us is to transcend the self-interests of our respective nation-states so as to embrace a broader self-interest - the survival of the human species in a threatend world." (Hon. Tom McMillan, Minister of Environment, Government of Canada, WCED Public Hearing, Ottawa, 26-27 May 1986; in the 'Brundtland Report', 1986:263).

Tom McMillan has totally internalized the concept of fighting self-interest with self-interest, without any awareness that self-interest, as evolved under conditions of civilization, may be the operative threat. The groundwork for the Brundtland Report had been done by the IIASA (International Institute for Applied Systems Analysis, a brainchild of Nixon and Breshnev during the Cold War Detente). It is sponsored by the industrial elites of the world. (DOC 27). (Note: G.H. Brundtland just lost her campaign for Norway to join the European Economic Union.)

Empathy

A capacity for compassion arises early in childhood (Hoffman 1987, 1989). Empathy (as used in this thesis), an understanding of another's life-conditions develops late in childhood. Neglect, competition and punitive interventions may modify what appears to be a 'natural tendency'. In two studies (Beatrice and John Whiting 1975, and Whiting and Edwards 1988, referenced in Wade and Tavris 1990) several countries were compared as to altruistic behaviour in children. U.S. children were the least altruistic

and the most egoistic. The most altruistic children came from countries where children make a major contribution to house-hold chores, contribute to the well-being of the family, to the level of dependence of the parents on such contributions.

Empathy, as a significant human behaviour in the context of an 'outer ecology', must be seen against this background. Since civilization depended on the infliction of suffering or at least a threat of suffering for social control purposes, empathy would have been contradictory to the systems of control. Christianity, as an empathetic movement, rose at the height of the Roman system of cruel social control, and its tributaries, such the Hasmonaeen empire, which had a tradition of extreme cruelty. Christianity then used the ultimate threat of suffering to control the controllers (Hell).

At least some civilizations have developed 'observable' forms of empathy. However, charity (alms), and in the case of victims of the contamination of the blood supply, 'compassionate relief-payments', are not a derivatives of an empathy attitude, as they are profoundly disempowering and effective in suppressing a violent expression of suffering. Welfare, in an organized fashion, does the same thing. Hospitals, the outgrowth of such a charitable attitude, require the patient be stripped of almost all powers before help is granted.

On the flip-side of charity is begging. The nature of begging is the induction of an empathic response (or aversive response), by a public display of actual damages, from lost limbs to rags as clothing, and a display or enactment of suffering. The essence of begging is its display in public places. Any large aggregation of public displays of misery would not ne-

cessarily induce empathy or aversion, but rather fear. I should note that empathy and aversion are close experiential cousins, like fight-flight, anger and fear, aggression and depression.

Compassion as a response acquired early in childhood is generally related to projecting one's own painful experiences on another (Wade and Tavris 489-491). Since growing up without frequent occasions for suffering is virtually impossible, we do not know if 'pain-free' upbringing would lead to an absence of empathy. One of the most telling aspects of empathy is, however, that sociopaths, for whom 'lack of empathy' is virtually 'pathognomonic' (the 'tell-tale sign') do display empathy in a peer context (see Kaplan and Sadock, 1988).

The sequestration of suffering and mediated displays

Modernity and late modernity have developed systems of segregating suffering from public places and preventing it from being publicly displayed: hospitals, asylums, ghettos, funeral parlors, hospices, workhouses, jails, old age and nursing homes, notions of non-interference in the private domain of the family, 'non-interference' in the 'management prerogatives in businesses'; lately, the availability of mood-modifying drugs from sleeping pills, diazepam, Prozac and other modern anti-depressives; the institution of pain clinics and the dubious instrumental use of alternative medicine services from herbalism to 'professional psychics'. Thus modernity is characterized by a massive effort to suppress suffering on one hand, and to eliminate it from the public view, if the suppression is not successful.

The maladaptive properties of this late-modern trend lie in the neutralization of responses to 'pathogenic' conditions; in other words, a crucial adaptive response to damages from late modern processes may be eliminated. Late-modern society tries to display itself as 'well-ordered' and 'smooth functioning'. Indications that it may not be as well ordered as it looks are eliminated, segregated, suppressed or denied.

The late-modern variation of display of suffering is closely related to the availability of mass media. Since public places are no longer an accessible place, television has become a public-place substitute where suffering can be enacted, or, as in the case of the 'professional beggar', simulated. As in the case of beggars, it may not be necessary to evoke an empathetic response, as other responses, such as fear, guilt, shame, or extreme discomfort and aversion, will serve the intended goal. The systematic 'management' of this phenomenon is known as 'victimism', and is used by a variety of disenfranchised, discriminated against, neglected, offended and violated groups and their advocates. Two elements were crucial for this form of social adaptation to develop: the emergence of the concept of rights; and media technology, in particular the power of imagery and simulation of television.

Thus, suffering and empathy suppressing strategies are counter-vailed by movements, advocacies and mediated public displays of suffering, which may, at times, be enhanced, at other times be manipulated or even simulated, by advocates of groups which have been damaged and are suffering. Such groups may be comprised of children, aboriginal peoples, abused women, seniors or other marginalized individuals. The apparent intent is to bring about, through mass-media, court rooms, or public inquiries, a

public empathetic response to the plight of the groups concerned.

However, the 'regulating principles' in such confrontations are not necessarily suffering and empathy, but the political and legal skill of leaders and advocates of such groups, aiming for politically rational responses of administrators, politicians or other functionaries observing or being aware of such displays. A widespread, 'popular' empathetic social response and 'public outcry' hardly ever happens. Unfortunately, hyperbolic public displays of suffering are at risk of being reduced to a public relations and legal tactic, rather than being a social process regulating our social consciousness. One can see it in court cases as a rational purposive 'tactical play-acting' and strategic coaching by attorneys, to elicit a 'politically correct response' in judge, jury, commission or media, especially when there is material or political gain to be expected from such displays. (An overreactive account of a variety of hyperbolic, mediated displays of suffering in the U.S. is given by Sykes, 1992.)

Strategic, mediated displays of suffering have little to do with empathy. They are power struggles in which one 'obedience to damaging authority' may be replaced with 'obedience to an alternate authority', which by virtue of being an authority can be just as abusive as the former, except with different targets and goals of abuse. (The 'alternate authority' may continue to make claims of empathetic motives to legitimize its injurious 'collateral damages', e.g. as 'cost of change and progress'.)

In any case, mediated displays substituting for 'communal displays' are for theoretical reasons, at least, unecological. I believe that our 'social brain' can be manipulated by such displays, but not engaged in an ecologically meaningful way. On the other hand, I do not know of any other

method of substitution under conditions of civilization, of very large populations and in the face of highly concentrated state and corporate powers.

From an ecological view-point, pain-related phenomena are significant 'homeostatically or transformationally regulatory processes', which are 'self-limiting' if they are not unduly inhibited. Therefore, excessive 'engineering' interventions from narrowly, non-ecologically defined problematics or political goals may be 'de-ranging' this self-regulation. The net-result could be more suffering, not less: adaptive equilibration (i.e. the return to equilibrium within given control settings), or adaptive transformation (the resetting of controls under changing boundary conditions) could be seriously disturbed. The Western goals of 'eradicating' pain and the techniques of mediated display, as practiced, may be absurd at best, destructive at worst, and dangerous quackery in any case.

Without some pain and pain related experiences and a capacity to respond empathetically to the suffering of others, the representations of our life-world may become (or may have become) distorted, and 'engineering-solutions' from such distorted views may cause severe disturbances in us and our lifeworld. The fragility and possible loss of empathy may have exposed us already to several progressive ecological catastrophes.

The natural and engineered environments

The use of technology for the suppression of the suffering response, in the display of suffering, in scientific-economic reduction of pain-related

phenomena to 'problems' to be solved has been discussed. The use of technology in the infliction of suffering (war and torture technology) is self-evident and need not be discussed here. The evolution of civilization is characterized by a progressive disjuncture between the communal and the natural environment (culminating in today's levels of urbanization) and a contingent disjuncture between the spiritual-reflective and material-analytical aspects of experience and action.

Once segregated, a progressive differentiation of 'material, sign-ordered controls' evolved (which can be referred to as 'administration'), culminating in the paradigm of 'corporate organization':

- 1) Control of the environment, including territorial protection
- 2) Social control (the control of emotions and reproduction)
- 3) Economic and productive control
- 4) Control of knowledge (science and technology)
- 5) 'Boards and executives'.

In the course of this progressive, cumulative process, the 'divine' was gradually transformed, displaced, substituted and eventually sequestered. The material controls evolved into secular paradigms which gradually linked all of these new material controls together into single homeostatic systems. In late modernity, competitive pressures lead to the inclusion of adaptive, competitive transformations through centralized 'strategic planning and development', in the form of late-modern corporatism. Such systems could be seen as 'hypertotalitarian systems', as they control the future, they do not try to predict it (by horoscopes, auspices or other

forms of divination, or in modernity, by 'trend analysis'). The control of the future is carried out by boards and executives, secretively, and with the aid of privileged information - so-called 'corporate intelligence'.

Early civilization granted environmental deities ('Mother Earth', Fertility Goddess, the 'Snake Goddess') control over all material phenomena in an environmental context (Bahring and Cashford, 1993). Environmental-ecological symbolism was predominant. With increasing population sizes, agriculture, advancing metallurgic technology and the growth of empires, the control of the 'engineered environment' would have become more pressing. The signification of deities shifted towards control of human control activities and a 'patriarchal orientation'. This is noticeable, as a transition period, in the Greek pantheon, which was a mixture of natural and social ecologies (Pallas Athena, Mercury, Hephaistos - knowledge, communication and artefaction - were 'social, urban deities'; Demeter and Bacchus were 'environmental, rural deities'. Jahwe emerged as an almost exclusively social control deity). As the need for production and economic controls became more prominent in modernity (either through the accumulation of wealth from production, trade and conquests, but mostly from conquest and plundering), the divine control of the engineered environment was replaced with secular controls (education, coercion, ideology). Finally, so much knowledge had accumulated that knowledge control became a fast growing concern, not to be subordinated to any divine principle. Now the control of knowledge itself is differentiated: as hierarchically ordered fields of control of data, information and knowledge; and as technological fields of data acquisition, storage, retrieval, processing and communications.

As the emphasis and focus of control shifted, the other concerns of

control remained and were modulated by the new priorities. This means that the control of emotions and thus the experience of suffering, the infliction of suffering and empathy would have received their specific modulation from the specific locus of control at the time. (For instance the telephone had a significant influence on the suffering experiences and how it is communicated and displayed.) Conversely, pain-related phenomena would have had context-specific, modulating influences on accumulated controls.

There is cause to be concerned: since technology and science are 'unemotional human preoccupations' (or far less emotional than, for instance, economics), emotions and pain-related experiences may not be able to modulate the technological locus of control at all. Thus it may not be possible to give science and technology meaning from beyond their own tautologies. Based on the same assumption, in the discussion of the cycle of meaning, technology was shown as an organizing principle and locus of control which sequesters human emotional experience and adaptation from the 'every-day' life-world. However, since this is an 'unstable design', new stabilizing paradigms are likely to emerge. The question is whether this steady-state will be 'scientific-technological' (with humans embodied in technology) or 'scientific-natural' (with science embodied in humans), or some 'hyper-controlling' combination of both.

In the following diagrams 'every-day life' (material life) is unfolded as the first four categories of material controls listed above, and synchronized with the shamanic cycle of meaning. First, the shamanic cycle surrounds material life in the inner cycle. Both are arranged around a 'natural ecological centre' (embodied in the shaman - the ecological/spiritual 'authority'). There may be a secondary material focus - or environ-

mental/territorial control in the form of 'chiefs'.

In the second variant, the cycle of meaning is enclosed in a material cycle, and technology is at the 'central locus of control' (embodied in technological/material executives and management boards). There are no clearly circumscribed secondary loci of control of spiritual processes (spirituality is fragmented). In both variants the locus of control is shown as penetrating (and to some extent fragmenting) the inner circle.

These diagrams are 'ideograms', derived from the cycle of meaning, not models which can be readily operationalized for empirical validation. They refer to 'society' as a whole. A corresponding ideogram for an individual agency is discussed in Appendix 2. Some of the combinations and interactions of social control and individual agency are sketched on pages 112-113. I have found ideograms useful in representing highly confounded phenomena or abstractions thereof.

I should stress again that these are not interacting 'objects', but contingent processes: each field shown in these relational ideograms is really a perpendicular projection of the trajectory it represents. It would be of great interest, for instance, to explore a sequence of transformations from the first to the second ideogram.

A third ideogram could be constructed, depicting the two cycles collapsed into one. This would be the ideogram of a 'hyper-controlled' life-world, the implications and feasibility of which cannot be explored here. Ideally, it would arise from an ecological convergence of the spiritual and the material. However, 'hyper-totalitarian outcomes' with a material, technological 'executive centre' are possible as well (this is the trajectory on which we are currently travelling).

THE SHAMANIC CYCLE

Fig. 8

The Relationship Between Material and Symbolic Cultural Processes (1): The Symbolic Process as Locus of Control

THE TECHNOLOGICAL CYCLE

Fig. 9

The Relationship Between Material and Symbolic Cultural Processes (2): The Material Process as Locus of Control

Economistic aspects of pain-related phenomena

Elites and the infliction of suffering

Certain aspects of pain-related phenomena in earlier civilizations and preliterate societies can be accounted for economically, such as child abandonment, warfare, enslavement, actual or the threat of disenfranchising individuals from existential security, the relatively severe punishment of property crimes. They could be interpreted as instrumental to the maintenance of an economic 'steady-state'. The economic view-point is limited, as it does not account for the social adaptations in civilized societies, which seek to maintain primarily a steady-state of the social order for which a steady-state of the economy is a requisite, not the primary 'design'. Elite phenomena cannot be explained sufficiently with economic paradigms. They need to be explored in terms of an inner ecology of the 'empire-builder' or of the 'empire-building elite'. The neurophysiology of economic growth and empire building is in complete darkness, and can only in part be explained from avoidance of material loss and competition for resources. The inner construction of 'hierarchical social control' of humans seems to be the more likely candidate for the 'inner ecological locus of control'.

Late modern paradigms of Western health-care

Late-modern health-economics (consistent with the problematics of

resource-allocation problems in civilization) uses the paradigms of steady-state such as cost-effectiveness (e.g. cost of lives saved), cost-benefit (replacement of a procedures with one which is cheaper and of equal effectiveness); and cost utility (cost of convenience; e.g. in the care for a hemophiliacs). Today, 'cost-saving' is accepted as a 'moral good' with little challenge, therefore the trade-offs underneath the superficial economic construction need not be revealed. (The real trade-offs are between patient-care and health-commodities; in other words, between human care and technology. This is not only more lucrative for corporations, it also removes human empathetic interference from the process.)

The cost of suffering 'inflicted by omission'

Typically, in Canadian medical malpractice litigation, compensation is granted for direct costs arising for the victim and opportunity (for revenue) lost (see *Pitman vs. The Canadian Red Cross Society*, D0C12). Years of misery, anxiety, loss of a spouse and companion, loss of a father, a devastating period preceding death (such as reported by AIDS victims) are not accounted for. The most significant consequence from discounting the suffering experiences is that malpractice becomes a limited 'cost of doing business', a 'calculated and calculable risk'. Such forms of compensation do not lead to an increase in risk avoidance but to a legitimization of risk to be taken by the patient as long as it remains an acceptable cost to the system. Once this is accomplished patient-risks can be upwardly adjusted, as long as the revenues can be upwardly adjusted as well, or production

costs can be reduced. (Similarly, in warfare, the 'kill-rates' can be upwardly adjusted, as long as the revenue generation can compensate for the losses of human life; or if the loss of human life is irrelevant - like the loss of life on the 'enemy-side'.) Questions and problems dogging the ecological debate on the environment extend into the ecology of the human organism. Western environmental science tries to account for 'unintended', damaging consequences from its economic 'problem-solving' operations which, in particular by its capitalist definitions, can all but disregard such side-effects. They cannot be expressed in economically meaningful equivalents, unless they show up as cost of litigation. Accounting for incommensurability of economics with other, ecologically relevant paradigms leads to conditions of undecideability, in multiple, incomparable options, as well as economic and political 'impalatability'. In situations of undecideability, people and decision makers will return to the original dominant problem-solving paradigm, the 'cycle of meaning' remains 'encircled by the material cycle'. Technology remains the 'locus of control', disrupting the cycle of meaning:

....."The counting gets more complicated still if entirely intangible values are to be included - which, arguably, they should be for some purposes. Economists have been unable to agree even in principle on how exactly to measure the value of assets such as the beauty of a wilderness or the splendor of a blue whale. 'I don't see us trying to put aesthetic values into economic accounts,' comments Carol S. Carson, director of the Bureau of Economic Analysis. When it comes down to hard numbers, sustainability remains an imprecise data.

Economists may be getting greener, but they will not anytime soon be able to lead the way to a sustainable future. Difficulties arise above and beyond the measurement challenges, Hamilton argues. Many governments would probably not look after the long-term interests of their people even if green accounts would show them how to do so. Environmental accounts are unlikely to have much influence on leaders who do not want to hear." (Beardsley Tim, 'Green Economics' in Scientific American, July 1994: 102).

Popular attention is still focussed on the 'natural environment', and secondary effects on the human organism from environmental degradation. (See for instance Gordon and Suzuki 1990.) However, Suzuki (1991) begins to point to more direct invasions into the human organism via the human genome project. The cognitive invasion of the human brain is not yet widely recognized as an ecologically significant process.

The epistemic adjustment from 'commission' to 'omission' has already been discussed in the first introductory chapter. Omission in an economic context can be legitimated by uncertainty and increasingly 'fiscal restraint and limited resources', 'expert consensus', and 'collegial communication', by the avoidance of some other 'evil', or the pursuit of some greater 'social good', no matter how contrived and insignificant.

I suggest that the inability of our culture to protect the environment extends into the protection of the human being. To believe otherwise would not just be naive but stupid, in face of the massive precedent: pain and suffering will be inflicted in the interest of short-term goals and will be constructed conveniently as omission rather than commission.

Corporate interest in pain-related phenomena

The Western construction of pain-related experiences as 'problems' makes them inevitable targets of problem-solving and control. After the development of major pain-killers(!), anaesthetic drugs and mood altering drugs, the medical interest in the phenomenology of pain almost disappeared. During the latter half of this century, a renewed interest in the

phenomena and the treatment of pain emerged in Western industrialized nations. Superficially, this interest seems to be motivated by economic problem-solving, such as the avoidance of the 'cost' of pain: productive hours lost, cost of social services etc. At another economic level, pain and suffering represent product 'markets' for drugs and various 'pain-management technologies' and employment opportunity. A third interest exists in the systematic avoidance of litigation. Corporations will go to great lengths to avoid blame for any suffering they may have inflicted. Therefore, the suppression of the suffering experience itself, the suppression of public display, of compassionate response and coherent ecological awareness ('empathy' in its widest sense) are of considerable interest to corporations.

Note: Corporate omissions resulting in human suffering are usually settled in civil litigation, although the nature of some of such omissions may be criminal (as an example consider the recent coal-mine disaster in Nova Scotia). Consequently, the cost of suffering can be financially discounted. Suffering can be inflicted as deemed 'affordable'. Lawyers have more to gain from civil litigation than from criminal charges and may thus be colluding in the maintenance of a virtual corporate immunity from criminal charges.

'Atomization' of the construction of our lifeworld, with the exception of the corporate paradigm is in the best interest (or 'adaptive' for corporatism, as it generates highly plastic, malleable boundary conditions for corporate operations. It is probably not necessarily in the best interest of society (see for instance d'Aquili et al. 1979; chap. 1; discussed in Laughlin 1990:69):

" The human brain is capable of modeling the environment sufficiently complex and remote from the immediate stimulus field that the 'cognized' world of individuals in a group can potentially become discrepant. If this discrepancy becomes too great, the processes of cognition may become antithetical to adaptive social action. In tacit recognition of potentially atomizing effects of discrepant cognition, human societies everywhere expend a great deal of effort controlling the development of the 'cognized' reality of their members".

We are now spending a great deal of effort in atomizing the 'cognized social reality' of members of our society. At the same time corporatism is propagated into every aspect of our life-experience. Late modern civilization is no longer willing or able to expend the energies necessary for controlling the development of the cognized reality of their members, except in the shape of the 'corporate, material reality'. Unless something else 'adapational' occurs, this is the end of 'society as we know it'. The 'cohesion' offered by the corporate paradigm and its cognitively manipulative or chemically manipulative devices are potent attractors. Also, those who have suffered from earlier 'total social cohesion' and 'false consciousness' may have the greatest interest in the atomization process, and at the same time be most readily seduced and co-opted into the paradigm of corporate cohesion. By co-opting the leadership of marginal and oppressed groups, the organization of collective resistance to corporatism becomes virtually impossible.

d) The inner ecology of pain-related phenomena

Neural structures of interest

This discussion is restricted to a few highlights. A full discussion of relevant neuro-cognitive processes cannot be attempted here. These highlights are intended to point to some urgency for a better understanding of the cognitive processes which underly our 'external ecological processes'. It is also important to show the necessity for the identification and protection internal and external ecological spaces, which are 'organizationally meaningful', and from where individual and collective resistance remains possible. The unfolding material technologized life-world is increasingly compressing and even closing these spaces: 1984 has arrived, ten years later than predicted, but it is already accepted as 'normal' and 'natural'.

Temporal structures

The neurophysiology of a variety of conscious processes are addressed by Laughlin et al. (1990), and cannot possibly be summarized here. The following discussion addresses neurocognitive phenomena which were not explicitly discussed in that account. They may be of some 'inner ecological' significance for pain-related phenomena. There are some striking simi-

larities (not identities) between temporal (epilepsy related) syndromes and practices resulting in transpersonal experiences, spontaneously arising transpersonal experiences and 'psychotic' reactions (not to be confused with psychosis). Psychotic reactions and spontaneously arising transpersonal experiences ('para-normal experiences') are situational responses of the brain to inner or outer conditions; 'temporal syndromes' are ictal (epileptic) events; transpersonal practice is a controlled mode of experiencing such or similar phenomena. If we look at the symptomatology of temporal syndromes: religiosity, interest in 'worldsystems', preoccupation with issues of morality and philosophy, euphoria, dreamstates, hallucinations, dissociative experiences (Kaplan and Sadock, 1988:59), we can recognize some associations with transpersonal practice and the kind of learning and knowing it induces. Epilepsy has been recognized to be associated with unusual individual performances. It also has been referred to as 'morbus sacer'. I would suggest that the temporal lobe may be the site of perhaps more archaic, and perhaps more 'symbolic' associative (adapational, 'learning') fields than adjacent frontal and parietal regions. The expansion of the occipito-temporal portions of the neocortex appears to have preceded the fronto-parietal expansion (see diagrams in Ganong 1989:-212). Besides, deep temporal structures, such as the hippocampus, the amygdala (in which many 'avoidance' reactions and controls of social behaviours appear to be located), the olfactory brain, face recognition (central to visual social culture) and higher order visual cortex are all located in and around the temporal region. Fundamental fear and rage responses are integrated with the limbic system and neocortical structures (Kaplan and Sadock 1988:63).

A structure of particular interest is the amygdala. It is usually accounted for as part of the limbic system. It is also located at the lower end of the caudate nucleus. Thus, in terms of the gross architecture of the brain it is positioned similar to the basal ganglia of the brain and, functionally, it shares the general characteristic of 'constraint' (and thus 'organization') with the basal ganglia.

There are two aspects of the limbic system (cum amygdala) which are relevant to wide ranges of emotional experiences and behaviours:

1) There are few connections between the limbic system and the neocortex: emotions can not be turned on and off at will. (Nauta: the neocortex is like a rider on a horse without reins). The emotional responses outlast the stimuli which preceded them. (Ganong 1989:213)

2) Socialization processes may condition emotional responses by inducing avoidance behaviour. Once synaptically fixed, avoidance behaviour is difficult to change (e.g. phobias). The amygdala plays an important role in avoidance conditioning: 'avoidive synapse formation' has been verified (LeDoux, Joseph, 1994:50-57). If there are 'executives' at all in the brain, a sort of 'ghosts in the machine', then the amygdala is the 'avoidance executive', debating with the categorical-planning executive, the 'categorical brain'. However, the categorical executive may only rationalize the avoidance executive's dialogue with even deeper 'impulse executives' in the brain stem. (I would suggest that extensive meditative practice transforms the bickering of all three 'executives'. There is no 'chief executive

officer' in the brain, however.) The caudate nucleus seems to have significant constraining roles, as it is the anatomical location for attention deficit disorder (which may lead to forms of sociopathic behaviour).

Frontal structures

One of the most important cognitive additions in homo sapiens sapiens may have been the cognition of time, which appears to be associated with prefrontal lobe development (Ganong, 1989:229). Neanderthals may have lacked this faculty: they were 'encounter' humans rather than 'planning' humans. They may have been at a significant cognitive disadvantage vis-a-vis Cro-Magnons because of it, even if all other faculties were the same (but of course the addition of a single cognitive faculty would modulate all the others). The incorporation of time-vector and time-scalar cognition may also have changed the 'modelling' capacities and practices of homo sapiens sapiens and be responsible for the technological progression ('possible futures construction', 'inventing the future'), perhaps at the expense of wider, more inclusive, relational fields. However, the full employment of the faculty of time cognition (such as calendar development, or intentional, planned migrations) may have become fully evolved (and necessarily so) under social conditions of civilization. Time cognition would have made the requisite adaptive capacity available. There may be a need to explore why small steady-state societies have not fully utilized this faculty.

The sign-symbol dichotomy

The neocortex is asymmetrically organized, with language functions on the 'categorical' (so-called 'dominant') side of the brain and image processing on the 'representational' side of the brain (Ganong 1988:222-230). Destruction of the corresponding frontal lobes leads to impairment of responses to language and to pictorial stimuli, respectively. It remains a mystery, however, how the temporal fields interrelate with the representational-categorical functions, and how language modulation is controlled in the use of language as expressive/ representational, as a narrative/representational and as a categorical/analytical tool. (See Donald 1992, on the cultural evolution of human cognition.)

Imagerial cognition appears to be more closely related to emotional responses than categorical cognition. The image of a rose obviously triggers a different response than the botanical classification of it. (I should at least acknowledge here that this discussion applies to the dominant visual culture, not to the culture of blind people). In combination with 'enactment' and auditory symbolism (music, rhythm), imagerial cognition is far more penetrating into emotional processes than analytical language use. Logical-classificational elaboration of an emotional experience seems to 'pacify' or 'tranquillize'. Thus cognitive therapy ('talk-therapy') may act like a 'tranquillizer'. It is confounded by similar effects from transference to the therapist. Books written by authorities can have a similar, combined tranquillizing effect. The singularly most effective intervention for a frightened, distressed individual may be the authoritative assignment of a name, label, cause or blame to the distressing condition or circumstance.

'Symbolic categories' of illness (sorcerers, witches, spirits, mean-spirited ancestors, demons) are hardly 'tranquillizing' and call for a more profound, penetrating intervention (shamanic healing). The implication of 'symbolic categories' are encompassing the spirit world and the community, not just the individual.

In a shamanic context, the experience of illness and suffering are 'ecological disturbances', 'symbolic dissonances', perceived as external, already 'explained' by the patient. In a Western context they are 'categorical disturbances', 'categorical dissonances' (lack of category), unexplained by the patient. This aspect of suffering would thus be qualitatively different in sign-ordered and symbol-ordered societies. If all aspects of 'healing' from suffering and illness (not 'disease') from both orders were to be combined, the following 'non-specific treatment' effects would be accumulated (expanded from Fletcher et al. 1988:142):

Specific treatment

Non-specific effects:

- Autosuggestive**
- Placebo**
- Hawthorne**
- Categorization**
- Symbolic intervention**
- Transference**
- Increase or decrease in stimuli**
- Removal from noxious environment (social or natural); e.g. 'bed-rest'**
- Natural history (getting better anyway)**

However, if there is 'cognitive conflict' between these 'non-specific treatments' and if dissonance arises from such conflicts, the effects could be lost.

The issue is important also with respect to the infliction of suffering. Authority can exploit both forms of cognition to achieve compliance with actions towards deviant goals. The goals may be rationally-morally deviant (they do not make 'sense', they are 'illogical'), or they may be symbolically-ethically deviant (in contradiction to some internal symbolic order). The most significant example is perhaps Nazi Germany, where the leadership utilized the morality of 'Deutscher Gruendlichkeit' ('efficiency'), together with a massive mystical propaganda to achieve total compliance with the goals of the leadership. Most of the residual resistance was handled with 'basic conditioning by reward and punishment', and the 'panopticum effect' (Foucault, 1975). Corporatism is about to embellish all these paraphernalia of social control.

'Deep structures'

Stress physiology will not be discussed here (see McElroy and Townsend 1989:241-289; Selye 1976). Post-traumatic stress-disorder, neurosis, anxiety states, grieving, home-sickness, menopausal syndrome, cognitive dissonance, shamanic experiences, break-down, suffering, compassion, violence, the somatization of such processes (as, for instance, experienced during menopause), which are not associated with any 'organic' cognitive defect, are all varieties of the same processes of cognitive adaptation to significantly altered boundary conditions of the individual. Menopause is a classical example (Lock, 1993:33-34).

Lock compares menopausal women in Japan, Manitoba, and Massachu-

sets and lists more than 50 complaints or symptoms. I can attest to having experienced all of these symptoms (with the exception of those which are strictly related to female anatomy and physiology) in the course of what I would classify as 'chronic culture shock' after my arrival in Canada. Thus these 'menopausal symptoms' are most likely 'non-specific' (unrelated to the metabolic effect of female hormones). Instead, they are an expression of frustrated, deep adaptational processes in the 'inner ecology' to conditions in the 'outer ecology' - which are not providing for cultural ritual support. (As Lock points out, seeing a doctor for estrogen supplementation is not a good adaptation). The depressive features of menopausal syndromes may be signs of 'exhaustion' in the course of a frustrated adaptation. Some symptoms are classic physical symptoms of depression.

Note: Lock believes that most Western menopausal syndromes are the result of 'medicalization' and cultural discursive practice - consistent with Foucault's notion of the discourse writing itself into and onto and exerting power over the human body. Unfortunately, discourse analysis is so dominating Western social sciences, that it is becoming exclusive of alternative explanation. Even if one stays within the discursive analysis, there are other discursive practices which may play an equal or even greater controlling role than medicalization and gender discourse. In Western society, men and women in great numbers have no longer any role to play after 45 and latest at 50. In some engineering professions obsolescence starts as early as 10 years after graduation. 'Experience' of many kinds is of little value as it may imply a risk of resistance and critique of administrative practices. Thus the 'aging population' is growing in two directions from the point of the official retirement age of 65: towards the forties (loss of meaningful role, using up any accumulated assets); and towards the eighties, towards possible poverty and compromised health. I would suggest that such conditions are sufficient to create a situation to which adaptation is not possible (and will thus be frustrated). A frustrated search for meaning is as stressful as 'culture-shock', or perhaps worse, since it arises from one's own society which one trusts. Therefore, a tendency to ease the chronic experience of distress through pharmaceutical symptomatic relief does not have to be created by 'medicalization'. Hypochondriasis is known to increase before and around the menopausal age, in men and women. It is not the result of medicalization or gender.

I am suggesting that textual analysis, by excluding contingent and contingent controlling processes may have locked itself into its own 'metatextual constraints'. Locke is faced with the paradoxical proposition that with false consciousness Japanese women are suffering less than Massachusetts women. If the consciousness of Massachusetts women were to be implemented in Japan, not only could women be predicted to suffer more during menopause, but their removal from the 'source of meaning', looking after the elderly parents and living grandparents would result in heightened distress for the elderly. Thus a distressful menopause would be followed by distressful old age. This vexing problem cannot be explained textually with gender and medicalization alone, but needs to be explored from a broader, more inclusive, ecological frame.

Medicine, and in particular psychiatry, can be accused of having chopped this continuum of processes of adaptation into distinct clinical syndromes, the handling of which aims at symptom specific intervention and at the suppression or manipulation of such processes. Rarely are the interventions aimed at the conditions which produce them. People suffering from menopausal symptoms are shown how to cope with 'aging', people suffering from stress disorders are shown 'how to cope with stress', while the stressors are not critically examined. Yet there is little more psychiatry can do, since it has no referential framework from which it can understand the external and social environments. The psychiatric intervention aims primarily at the 'inner ecology': at the 'emotional' biochemical level or at the 'cognitive level'. However, at the 'cognitive level', cognitive processes are not clearly explicated. There is some kind of a division between 'symbolic' and 'rational intervention'. Besides rudimentary 'transference', there is no ritual enactment of anything in so-called symbolic interventions. Psychiatry is based on 'schools of therapy' rather than on 'schools of understanding'. Consistent with targeting the 'inner ecology', relatively too much attention is paid to past experiences, and not enough to current,

external ecological circumstances. A notable exception is Victor Frankl's school of thought (e.g. 1977:80-84), which considers the 'loss of meaning' ('Sinnlosigkeit') of late modernity as a central source of 'suffering'. As a psychiatrist, however, he shies away from confronting the pathogenic contributions of the externally constructed and ill-constructed human ecology.

Note: many 'mental disorders' have organic substrates, including head injuries. However, the underlying 'anatomical disorder' may be too subtle to be accessible to identification. Some mental disorders may thus be individual adaptations - and maladaptations to these disorders. The social Umwelt adapts to these 'maladaptations'. Thus conditioned, the Umwelt, in turn, feeds its adaptations into the individual. The 'deviation amplifying' influence of such anatomical deviations was evident in the fate of individuals with Down's syndrome some decades ago. This needs to be accepted with great caution, as biomedicine is almost entirely focussed now on finding the microanatomical substrates of mental disorders, and is diverting attention to 'external human ecological pathogens'. In other words, bioscience is beginning to propagate the myth that all mental disorders can be identified as of genetic, developmental or traumatic/infectious origin, meaning that there will be a biotechnological solution for everything. (PET/MRI + genetic map = 'lesion'; receptor + designed drug = 'solution').

The deep structures of the pallium, the basal ganglia, have important connections with the limbic system and the associative sensory fields. Organic lesions (Huntington's Chorea, Wilson's disease, Parkinson's disease) destroy the individual as 'culture bearer', with manifestations of depression, psychosis, dementia and movement disorders, including gesture and facial expression, key-elements in 'symbolic enactment'. Ganong (1989) states summarily that the basal ganglia are engaged in the processes by which an '*abstract thought is converted into voluntary action*'. This is only

possible if their organization is correlated with the organization of abstract thought as well as the organization of voluntary action. Basal ganglia dementia occurs with intact cortical areas: e.g. without aphasia. This would indicate that speech (in particular categorical-classificational language) is a 'superficial adaptational faculty' rather than 'deep organization' (Kaplan and Sadock 1988:65).

Another large grouping of nuclei is the thalamus, which is connected with just about everything else. It has a critical role in pain perception. In the vicinity of the thalamus there are concentrations of structures with high large numbers of opiate receptors, which can interrupt the pain sensation. Thus the entire complex of the central brain is involved in the processes of pain-related experiences. Without better understanding of the role of these centres, it will be very difficult to arrive at neurognostic theories of emotions and pain-related phenomena (Kaplan and Sadock, 1988: 290).

Superficial and deep adaptation

The deeper centres may represent the patterned process which we refer to as symbolic construction of our lifeworld, 'archetypes', the locus of our routines and habits and background-understandings. They may also contain our future images, expectations and worries. Dreams, fantasies, rituals, habits, myths are all organized as experiential and action sequences. Instincts of animals are also fairly constant actions or behavioural sequences. An action sequence requires co-ordination beyond relational

organization at any 'action-moment', as each organizational moment stands in a meaningful relationship to the preceding and following moments (dreams may violate the laws observed in waking experience, but they are not 'chaotic'). Since the neocortex seems to be organized into relational maps rather than sequences (pictorial or categorical), the deep centres may be good candidates for sequential organization. (This is purely speculative at this point; the pre-enkephalization organization of instinctual behaviour would be consistent with such a concept. Also, the lag between short-term memory and long-term memory integration, and the difficulty in breaking 'habits' of thought and action could be explained with a resistance of deeper centres to integrate elements which would disrupt sequential organization.)

Accordingly, I would suggest that the central brain complex is the 'steady-state' complex in our brain, whereas the neocortex is the adaptational, superficially transformational portion of the brain, which must fulfill the imperatives, intentionalities, meanings, and motivations which arise from deeper centres. After all, each new action taken is meaningful in the context of all past actions.

I believe that there is an overlap between 'cognitive dissonance', 'orientation response', and 'intentionality', all aiming at restoration of 'wholeness', 'balance', 'correspondence', and 'steady-state', whenever such states are disrupted, or challenged by changes in the boundary conditions to the 'cognized environment'. (The process of achieving steady-state is the most fundamental intentionality of all living organism; humans have acquired the capacity to accomplish a "future steady-state". Thus older parts of the brain would maintain 'adaptedness and 'implicit knowing', some of

which may still be inborn. The newer parts would be engaged through their associative fields in 'adaptations and explicit learning' towards a future steady-state.)

Those 'adaptational fields' are themselves, to some extent, in a state of adaptedness, as perception is highly correlated with the total steady-state of the individual. I would deduce that the associative fields provide an opportunity to 'pre-adapt', i.e. produce 'preliminary behaviours' which are not yet integrated into the deeper centres. Language provides an exquisite faculty for such 'pre-adaptations'. By the same token, language is also a faculty which can produce 'incoherence', fragmentation and 'atomization'.

Thus language may be a truly 'double-edged sword'. Because of the possible pre-adaptive nature of language, dissonance arising from language constructs are less severe than discrepancies in 'encounters'. 'Language-adaptations' (e.g. 'lip-service'), are faster and more easily accomplished than profound adaptations of, for instance 'personality'. Parole boards have to deal with these 'two levels of adaptation'. Accordingly, a sign-ordered social organization would be 'pre-adaptive' as well. Consequently it can be easily changed and transformed. It is easy to introduce new social policies in corporations, it is near to impossible in non-Protestant churches; a characteristic of the Lutheran Church is its lack of symbols: the Eucharist is a 'sign' to trigger a memory. In the Catholic Church it is a ritual enactment.

The engagement of inner ecological processes in pain-related phenomena

Temporal phenomena: It could be suggested that the temporal lobe and its adjacent structures are the locus of 'ecological cognition' and adaptation, perhaps best characterized as 'inclusiveness'. One of the signs of a 'temporal syndrome', moral preoccupation in combination with 'over-inclusiveness'. Most corporate decisions are now made about the future (future viability of the corporation). If this occurs at the expense of depth and of contingencies considered, the tendency towards infliction of side-effects may be inherent in our (now accelerated) future inventing processes. We can cope with the relational dimension of cognition or the time dimension, but we have difficulties doing both at the same time. Therefore, without the assistance of computers, we may be 'ecologically handicapped'.

Extreme 'goal-orientation' in management is known to lead to a high degree of 'ruthlessness', including towards the Self. 'Excellent managers-to-be' are being taught to pay the same attention which is paid towards goal achievement to the 'customer', the 'boss', the 'Self' and the 'employees', to avoid major errors. In other words, they are asked to become more 'inclusive'. However, it is not known how successful such consulting interventions have been. Corporatism still favors the 'clearly defined goal' in combination with 'control of contingent processes'. (Universities prefer the 'clearly and narrowly defined research question', or the construction of a 'discipline specific theory', and lately, 'training students to solve the problems of the community' - utterly unecological preferences. Universities may encourage Bateson's 'imagination and rigor', but they would rather not deal with the 'imaginative' part and 'knowledge for the sake of knowledge'

- that would be 'inefficient'. The 'annoying scrupulousness' of the temporal syndrome may thus be a cultural label of modernity - in particular of late modernity - of Western managerial style and habits, rather than a 'true handicap' (also consider Dostoyewsky). In order not to be suspected of pathognomonic 'overinclusiveness' I shall keep this discussion short.

Frontal phenomena: Superficial goal construction in combination with a deep authoritative relationship can inflict suffering. The engagement of time-cognition in the infliction of suffering has been introduced. The engagement of time in causal/relational cognition of disease has also been discussed. Time is critical in Western medical intervention, as all therapy plans are elaborated on a timescale, e.g. diagnostic procedures, diagnosis, preparation for surgical intervention (e.g. sedation), postoperative care, follow-up). This sequence is strictly structured around the 'repair procedure' and, in principle, does not differ, for instance, from the sequence used in car repair. The shamanic sequence, on the other hand, is organized synchronously around transformations of the patients (and possibly the community), as well as transformation of the shaman him- or herself. In Western health-care, the transformations which the patient undergoes are not registered at all. Instead, the patient is being organized around the technical procedure. An array of specialist consultants (the 'multi-disciplinary team') may be added to the main procedure. The more the main process is being rationalized (made 'efficient'), the more compressed and desynchronized from the patient these interventions become.

Symbolic and sign-orders: Symbolically ordered world-views model

individual, social and environmental life-processes in their totality, they represent the familiar, the taken-for-granted. Sign-ordered models represent states of fields of things or objects (including 'objectified processes') for quick orientation when encountered. Illness and suffering are experiential processes in which the 'taken-for-granted' can no longer be taken for granted, it scrambles the 'loom of life-processes'. The shaman enagages symbolically and adjusts the 'loom'. Western medicine explains and sign-orders (classifies) states of the organism (the fabric) and the environment (injury, pathology, pathogenicity), not experiential processes, such as illness and suffering. It mends the 'fabric'. (Note: while 'grieving' may be recognized as a process, in practice, medical interventions target a 'state' of the person such as 'depression' with, for instance, anti-depressants, which leave the 'loom' scrambled.)

Deep experiential symbolic knowledge and empathetic understanding, internalization of communal harmonies and disharmonies are essential for the shaman's healing powers. Biological, functional-relational, sign-ordered knowledge is essential for the Western doctor for 'repair' to make 'rational choices'.

Implicit in this difference are all the diagnostic and therapeutic limitations of either approach. The rational construction of health and disease 'solves problems' sequentially. It aims to reconstitute a match between the classification of the 'normal' and the classification of the state of the patient. Since the problem statement is relational (at best 'cybernetic'), 'problem statements' and 'problematization' do not fit into a comprehensive representation of our life-processes. New contradictions, conflicts and problems may arise with every problem-solving step. The

symbolic construction of illness, on the other hand, is embedded in the totality of life-process and 'harmonizes' the disrupted 'dissonant' whole. However, the 'harmonization' may be ignorant of or in disregard of many relevant detailed material and relational aspects of life-world, which would be better treated in a relational 'repair-mode': killing deadly pathogens with antibiotics effectively interferes with a given 'natural harmony' of which bacteria are part; yet in a state of sepsis one would not want to rely entirely on 'harmonizing' symbolic interventions. The shaman also has a repertoire of 'objective' material interventions (e.g. herbal remedies). He or she does not rely on them primarily and exclusively like the Western doctor. Western doctors, on the other hand, do not have the requisite knowledge, communal access and cosmology, shared with their patients, to 'harmonize' the patient's life-world.

Holistic, processual understanding is difficult to explicate logically or numerically, to be 'documented', to be communicated abstractly (it shares some properties with 'ecological understanding'). 'Problems and solutions', on the other hand, can be articulated, documented and communicated, yet remain unsatisfactory in 'making sense of it all'. (Of course they can be 'analysed in court').

Superficial and deep adaptation: Small discrepancies between the cognized expected (cognized) and then encountered (sensed) can perhaps be handled with adjustments in the sign-order. Major discrepancies, like the death of a family member, invalidity, change in life-circumstance, may affect the deeper organization, which is more resilient and resistant to change. (Long-term, 'committed' employees may be undesirable for the

'adaptive, sign-ordered' corporation. Their activities may be integrated at a deep level, which may be the source of resistance to corporate transformation.) By the same token, by changing systems of signs continually, little may ever be committed to deep organization. A cultural environment which relies on such a continuous manipulation of signs may be flexible, but also increasingly malleable, suggestible, and ultimately confused and corruptible. The high level of short-term adaptability may come at the cost of loss of long-term adaptedness.

Accordingly, profound changes need profound adaptations and symbolic intervention. Small changes can be accomplished with 'reordering the labels' and 'rational choices'. Mistaking one for the other could lead to wrong interventions and maladaptive results.

Finally, excessive reliance on a symbolic order could lead to a degree of rigidity which would render the individual (or an entire society) undaptable to even minor changes in boundary conditions. (The Aztecs were defeated by a handful of Spaniards; Chinese technology froze in its symbolic meanings; almost all the European Monarchies collapsed at the same time; the symbolic homeostasis of small societies may also limit their adaptability).

The role of authority in distancing and sequestration

The power of 'authority' in legitimating ('authorizing') actions which could be damaging to others, and dehumanizing others as objects or targets of 'authorized' action has been addressed in three classical social

experiments (the 'prison study': Haney, Banks & Zimbardo, 1973; the 'hospital study': Rosenhan, 1973; and the 'obedience study': Milgram, 1963 and 1974). All three studies describe the pre-eminent role of authority in the (inner) distancing of 'authorized' actors from the suffering which authoritative action may produce. How authority (or better: dominance) really works we do not know.

"The key to the behaviour of subjects (of his obedience study)" says Milgram, "lies not in pent-up anger or aggression, but in their nature of their relationship to authority. They have given themselves to the authority; they see themselves as instruments for the execution of his wishes; once so defined, they are unable to break free" (Milgram, 1974, quoted in Wade and Tavris 1990: 658).

One might suggest that if 'sequestration of the immediate experience is a problem mostly related to authority, then 'sequestration of authority would be an appropriate counter-strategy, in particular when authority is damaging and abusive. It rarely happens, and if it does, then it takes the form of rather violent (or at least aggressive) collective actions. They do not arise 'spontaneously' but are always 'led' by an alternative authority (like Lenin's 'Party Vanguard'; the French Revolution). The surrender of control to authority cannot be explained by some 'disembodied' power concept and fear of damages from disobedience. In particular the Milgram experiments show that this kind of 'blind obedience' occurs even when there is no tangible or significant consequence from disobedience. The only explanation would be some form of transference of relations with parents and avoidance conditioning and the recreation and exploitation of these ('entrained') conditions in various adult social situations. That would

seriously challenge 'rational choice', 'free will', 'personal responsibility', 'agency', and push 'society' into responsibilities which it stubbornly and ever so eloquently refuses to accept.

The following four ideograms and the concepts associated with them represent the organization of internal ecologies in different enactments of authoritative power, cognitive organization, and different levels of autonomy of the individual.

There is some connection between the ideograms and the discussion of 'inner authenticity and public accountability' in Appendix 2. The ideograms are suggestive that reliable 'inner authenticity' is not just a 'gut-reaction', as the gutreaction may have been induced by authority. By the same token, public, rational accountability may also have been induced by authority. Thus inner authenticity should not be considered authentic at all, if it is not acquired through personal quest, reflection and action, in a sense through personal suffering, rather than reliance on authoritative inducement. Those who have never challenged the established order (or disorder) may not have a valid claim of 'inner authenticity'.

This is a central problem in our hierachies: one does not get to the top by challenging the established order and a quest for inner authenticity. On the contrary, the systems select individuals who are compliant. Yet one should think that those who have gone through challenging ordeals would be best equipped to move into leadership positions, once their inner authenticity has 'settled in'. The democratic multi-party system, because of the 'party-platform', achieves exactly the opposite. The same applies to the 'company man'. The current decay in democratic systems of government and their loss of credibility may be rooted in this problem. As political

parties are becoming more and more 'the same' ('corporatized'); this problem may become even more acute. The systems of democracy and its institutions cannot achieve the aspirations for which they were designed. Only their incumbents can. If they are selected on the basis of collages from 1) personal appeal and appearance; 2) prepared and rehearsed speeches; 3) impressive resumes; then we may be selecting the wrong people. Somehow, along the road to democracy we missed paying attention to the most important requirement: how to prepare and select our leaders. The media may have the right idea, but they are looking for trivial details.

Concepts: rational reinforcement of rational response by obedience: 'authorized rational action', 'rational authority', 'problem solving', 'rational choice', 'rational transference to professional competence', 'bureaucracy';

(Example: Holocaust; contamination of the Canadian blood supply)

(Movie: "Judgement at Nuremberg")

Rational authoritative distortion moving towards functional psychopathomimetic distortion

This pattern can be found in bureaucratic, corporate, scientific and legal rationalization of strategies with significant damaging side-effects. The most powerful rationalization takes place when it is demonstrated that the benefits outweigh the damages ('discounting'). If the benefits reach the person thus influenced (or a threat is averted), the 'rational block' is even more effective ('reward', 'bribe', 'security'). A variant is 'state paternalism': the state knows best what is best for you; or 'professional paternalism', observed in the medical profession, the legal system and in the semiological and engineering professions.

Fig. 10 *The Authoritative Rational Attenuation and Block of Symbolically Dissonant Experiences*

Concept: symbolic re-inforcement of 'symbolic action' by obedience: authorized symbolic, emotional action, 'symbolic authority', 'problem dissolution', 'spontaneity, impulsive action', 'symbolic transference to symbolic authority', 'movement';

(Example: Inquisition, Rwanda, Crusades,.....)

(Movies: "Scent of a Women", "A Few Good Men" - at opposite positions on so-called "honour codes").

Symbolic authoritative distortion moving towards functional psychotomimetic distortion.

This pattern can be found in movements, cults, charismatic leadership. The pattern can be 'rationalized' at a later stage (for instance, the Inquisition was eventually rationalized with the 'Hexenhammer', or it can be inserted into a rational strategy to break rational resistance (e.g. antisemitism and Nazi mysticism as vehicle for economic, predatory strategy). Military training uses 'patriotism' first and then rationalizes it into 'a-job-to-be-done'.

Fig 11

The Authoritative Symbolic Amplification of Legitimizing Meanings and Block of Rationally Dissonant Experience

'Shamanic' authorization; both forms of authorization are accessed in the cycle of meaning. The shaman figures in this pattern as an experientially centred, autonomous authority.

The shaman uses two access points: the ritual enactment and the interpretation in the cycle of meaning. If the shaman is an autonomous individual, embarked on a life-long personal vision quest, there is no problem. If the shamanic individual leans to one or the other side, possibly under the influence of another authority, or is constituted in one or the other direction (as it happened with the various priesthoods in civilization) the shamanic authority will drift in the direction of one of the previous configurations and their abusive variations and combinations.

Fig 12 *The Shamanic Resolution of Dissonant Experiences*

Autonomous (self-) authorization; personal quest. A very difficult position to take because the dissonance reducing processes of transference to authority, in either mode, have to be abandoned.

Fig. 13 *Evocation and Resolution of Dissonances in the Autonomous Individual*

All of these variants can be reconstituted in the 'cycle of meaning' and the cycle of material processes mentioned above, or fragments thereof. It should be obvious that any authority has multiple options to insert itself into the cycle of meaning, from specific, purposive positions. Therefore the 'atomization' of our social life-world makes us particularly vulnerable to less than ethical, purposive agenda, which are never required to enter into a cycle of meaning (materiality encircling the cycle of meaning). While 'symbolic authoritative interventions' make us susceptible to 'impulsive ruthlessness', 'rational authoritative interventions' make us susceptible to 'calculated ruthlessness'.

If we return to the notion that all living systems seek to maintain a steady state, and emotional experiences (including pain-related experiences) are a disruption of the steady state, then whichever process is most likely to bring about a 'steady state' will become the preferred mode. If the symbolic process is not cultivated, then the other mode is the only one available to achieve 'steady-state'. In our civilization, where emotions are not 'cultivated', the symbolic relics do not provide a frame in which this could be achieved. Rational abstraction and logical resolution of dissonances is the more likely path to be followed. Logical explanations of any kind of trouble normally tend to be 'abstractions' and higher level classifications of the trouble experienced.

The reaction to the death of a friend becomes a 'grief reaction'. This experience is fitted into a preformed (learned) logical classification system. Since it makes sense there, the dissonance experience is diminished, and some steady-state is achieved. Of course it will not work that well with grieving, but the emotional reaction to lesser dissonances can be effective-

ly attenuated; conversely, children and adults who do not have a classification system to 'hang their grief on' seek comforting 'symbolic' attention rather than 'explanation'. In earlier times we may have been 'symbolic addicts'. In modern times we may be 'rational addicts'. Because of the plasticity of the rational system it may be easier to become a 'rational addict' ('to customized explanations for every occasion').

The 'uncoupling' of rational processes from temporal processes may be the 'distortion' which Bateson was talking about. For instance the rational 'tit-for-tat' process lead to the escalation of nuclear armament. However, the threats from such stock-piling reached bizzare proportions before an 'emotional response was allowed to kick in'. 'Tit-for-tat' is an inherently 'rational system' (like 'an eye-for-an-eye'), and the public was led to great lengths to accept this horrendous threat.

The ultimate threat to humankind could be that people with a particular capacity to split rational-reductionist cognition from temporal-inclusive cognition could not only be culturally but also genetically selected. (This is not be confused with the Mensa Club, it is not a selection of exceptionally high IQ's.) It would be sufficient that stabilized elites interbreed and then inbreed, and only retain individuals with high 'uncoupling capacity' in their ranks. Inbreeding has been a pattern of all elites of civilizations ('dynasties'), however the selective pressure was never in the direction of this 'uncoupling capacity'. This possibility is enhanced by possible effects of decoding of the human genome, which will inevitably be linked to 'desired phenotypes'.

The 'autonomous individual', on the other hand is not likely to be the product of genetic selection (although some predisposition may be

necessary), but rather of cultural ('human ecological') provisions which support the achievement of inner authenticity. It is not a matter of granting more and more 'freedom', but of creating conditions under which an inner and outer struggle with established constraints as well as freedoms can take place. Individualism must not be mistaken for 'inner authenticity': individualism is exclusive, inner authenticity is inclusive - empathetic.

Suffering as loss of integrity of the 'Self'

Suffering can be constructed as processes of the Self. I am using here the term 'Self' as others may use the term 'ego', and 'ego' as part of the 'Self', as Freudians would - see Appendix 2. Pain is the conscious phenomenon of disturbed physical integrity ('wholeness'), suffering is the conscious phenomenon of a disturbed integrity ('wholeness') of the Self. We may not be able to comprehend what the 'whole' Self is, just as we do not know what the 'physical whole is': the whole may not be revealed to us, but we know when wholeness is disturbed. Many of our approximations of the whole are derived from observations of its injuries and violations (a notion which became Francis Bacon's scientific paradigm of getting to know nature; much of science indeed works that way).

Since the whole ('the operational environment is transcendental') is unknowable, our inferences from the 'injured detail' to the whole or parts of the whole contingent on the injured part must remain flawed. We can, from the experience of suffering and associated life circumstances, make

some inferences as to the kind of whole Self we are observing or experiencing - but we cannot generalize from such observations or experiences. The 'objectively observable' and the 'subjectively experienced' have this weakness in common. Therefore, action from either position alone, the 'subjective' or the 'objective' is risky. Only action from synthesis of both, through the engagement of the mediation of the unknowable 'whole' (which is an unconscious process), can give rise to an understanding beyond objective observation and subjective experience arise. Modernism, post-modernism, or even dialectics between them are cul-de-sacs. This is not a surrender of self-control, but rather a matter of allowing the whole self (not the ego!) to be in control.

This is not without problems. The adaptive response to injury of the Self may range from the rigidity of an 'emotional scar' (a 'bad adaptation') to disintegration of the Self. However, there is room for a wide range of 'adaptive' transformations' between these two extremes, some of which may bring us back into the 'range' from a 'de-ranged' status, some may move us towards the two extremes, while others may move us towards a more complex understanding and mastery of the phenomena of our life-world. (This is where derivatives of the theory of chaos could find their 'pathological'/social-ecological applications. For an introductory explanation of Langton's 'phase transitions' analogs: solids - complexity - chaos, which are alluded to here; see Waldorf, 1992:198-240.) Neither the biosphere nor the human organism are infinitely adaptable. The plasticity and malleability of the cognizing human being looks like a mixed blessing so far: in one way it makes us uniquely adaptable, in another it enhances our tolerance ('anaesthetizes' us) to injuries to the Self, to Others and to our natural

environment beyond our adaptive capacity.

These aspects of suffering should lead us towards seeking a more profound understanding of our inner ecological processes and a realization that the suppression of suffering and of empathetic responses to it are ecologically wrong. Healing ought not to be merely the termination of the suffering experience, or of the material effects of the experience, but a transformation for the benefit of the individual, of society and, ultimately, for the whole of humankind.

3 Examples of Human-Ecological Analysis of Pain-Related Phenomena

This small selection of examples and discussions is intended to give a sense of the kind of context which the paradigm of human ecology can provide. Much of the 'internal ecology' will still be presented as 'modes of thinking', 'strategy', 'belief' etc. Hopefully, the need for an understanding of the neurocognitive processes underlying such phenomena can be seen to be a matter of urgent concern.

The following examples will be discussed:

- 1) Azande culture and !Kia healing as examples of integrated internal-external ecologies;**
- 2) The Holocaust as a process contingent on processes of maintaining the survival of elites;**
- 3) The parallels between the origins of Christianity and the construction of the contamination of the blood supply, as examples of 'strategic myth construction', designed to 'conceal truths which cannot be told':**

4) 'The blood bankers' dilemmas' as examples of how adaptive strategies of corporatism may scramble and confuse 'meanings';

5) The Emperor Ming as an example of making a good assessment of the 'state of affairs', but choosing, situationally, the wrong intervention;

6) The Roman Republic as an example of differentiated routine and emergency responses to external environmental pressures; and

7) The Canadian leadership in the contamination of the blood supply: knowingly choosing the wrong strategy.

With the exception of the first two, all of these examples are dealing with phenomena of civilization. The first two examples of 'whole ecologies' and the role of pain-related experiences were extracted from Barber's (1993) discussion of illness and cosmology.

'Whole ecologies'

The experience of hardship being necessary for individual development and for gaining an empathetic attitude towards others and the community are discussed for instance by Katz (1982), with respect to !Kia healing amongst the !Kung by Morinis (1985), in the context of ordeals of initiation. Vestiges of such concepts are still recognizable in elements of Western military training such as 'boot-camp' ordeals, in preparation for

the 'supreme self-sacrifice'. (I am referring to my own infantry boot-camp training. It is done under coercive conditions.)

The example of Azande culture

In Azande culture, chronic, persistent pain and misfortunes are interpreted as the product of witchcraft, or, if the illness or pain is acute, as the product of sorcery. Breach of ritual prohibitions and 'natural causes' are in use as explanatory concepts as well. Illness ascribed to witchcraft is healed by treating the witch. Witches are aware of their capacity to inflict misfortunes, not of the specific occurrences or their human targets. The condition of being a witch is an inherited property of the soul. Sorcerers, in contrast, use their purposive consciousness, their 'will-power', to inflict acute pain. Together, witches and sorcerers constitute a system of 'institutionalized blame' (and 'explanation').

Both, witchcraft and sorcery, are believed to operate through non-physical means of communication and intervention: as a phenomenon of unconscious connectedness, in the form of intentional psychokinesis (not unlike what has been labelled in our culture as 'psi-phenomena'). It would be wrong to challenge these notions on the basis of 'proof'. If the cosmology of the sufferer includes witches and sorcerers and their respective influences and powers, then the healing must take place in the context of the same cosmology, regardless of whether such 'causes' of illness are 'real' or not. The cognized life-world is embodied in the 'culture bearer' as a physical reality.

Furthermore, the belief in some non-material connectedness of

individual members of the social group (of which the sorcerer, the witch and the sufferer are part) means that suffering individuals represent disturbances in the community to which they belong. Indeed, suffering and healing, in particular when a witch is involved, are public events in Azande culture. By transforming ('healing') the witch, the sufferer and the community are healed.

Thus publicity is a fundamental, requisite condition for the ecological role of pain, suffering, the infliction of suffering and healing interventions to unfold. (It is interesting that those who are presumed to inflict suffering are considered troubled people, and need to be healed; in a perverted manner, this emerged in witch-burning, to 'save the souls' of the witches; the criminal justice system attempts 'rehabilitation', but its methods are 'retaliatory': one cannot pursue such conflicting goals at the same time.)

The shamanic healing process is not a procedure which can be meaningfully performed in an 'office' or 'clinic' setting. Ecologically, pain, suffering and healing are engaged in a complex ecological process, in which the witch, the sufferer, the community and the shaman operate in 'contingently' transforming processes. This puts into question whether shamanic healing practices can be effective at all in Western communities which do not provide the requisite 'cosmological' and community - and thus ecological - conditions. (For details on the community ritual of healing see, for instance, Shear Wood 1979:303).

The example of !Kia healing

The initiation ordeals of the !Kung San, as shamanic initiation rites

in general (Katz, 1992, discussed by Barber, 1993), consider the suffering experience to be essential for the passage to adulthood and the empathetic and epistemic capacity of the healer (Morinis, 1985): they are essential for the healer to obtain access to the spirit world and the unconscious of the sufferer.

The !Kung San are (or at least used to be) a highly communal, almost egalitarian society, with Selves's unusually modulated by being conscious of the other. Shamans undergo a long training process to acquire their knowledge and healing powers, not as 'professionals', or 'functionaries' within a sort of communal division of labor, but with the view of gradually acquiring knowledge of the total life-world (Shear Wood, 1979:291-334).

This comprehensive understanding (and experiencing) of the life-world differentiates the shamanic healer from the Western physicians. As products of Western culture and the Western education system (even if trained in specific practices of alternative medicine) Western physicians may suffer from the same kind of 'social sequestration' and 'epistemic fragmentation' as their patients. Having no apparent self-awareness of such limitations, and since there is no communal participation in the Western 'healing ritual', their 'healing power' other than through transference, Hawthorne and placebo effects may be limited, if not totally lacking. No learned assembly ('concilium') of specialists of orthodox or heterodox branches of medicine can replace the wholeness which is incarnate in shamans. (Holism in Western culture means the 'sum of everything'; in non-Western culture it is everything and thus has properties which are not contained in the sum of the parts).

Also, shamans are continually legitimized by the community they serve. Our medicine people, as other professionals, merely legitimize each

other ('peer review'). Some of the shamanic experiences are best described as 'suffering', as they can be quite terrifying and go hand-in-hand with massive sympathetic/parasympathetic stimulation. Shamans may have adapted to voluntarily inducible 'post-traumatic distress'. 'Survivors' with post-traumatic stress disorder express persistent guilt feelings vis-a-vis victims left behind, which could be interpreted as maladaptively persistent - and effectively frustrated - compassionate response. Since they are not given the facility of passages through the 'cycle of meaning', and without a cosmology to accomodate such traumatic occurrences, the suffering itself cannot bring about adaptive transformation. Such individuals remain arrested in a rationally unresolvable conflict and still grieve decades after the event.

The two examples show the cohesiveness of all life experiences and practices as a 'total ecology', maintaining a steady-state for the community and accomodating transformational changes of the individual, without permanently disrupting the communal steady-state. The shaman provides the requisite body of knowledge, the ritual intervention and the 'empathetic self-sacrifice', to make multiple individual transformations possible within the communal steady-state. His is a bearer of a special inner ecology, which is acquired (possibly with a certain 'temporal' predisposition see page 120-121 on temporal neurocognitive processes).

Other members of the community could be expected to have corresponding inner ecologies in order to be able to respond to the shamanic intervention, including a dream-life, which is a form of experiencing one's inner ecology. In contrast to the shaman, whose domain is the 'inner ecology', the chief's domain is the outer material ecology and its sign-order. However, the sign-order is embedded in and constrained by the symbolic

order, and would normally not exist outside or sequestered from the symbolic order (see page 26).

2) The Holocaust and similar events

The Holocaust ranks as one of the most extreme examples of 'horrendous death', but has not been the only instance in the history of civilization. The crusades and, in their wake, the Inquisition, trench warfare in World War I, or the Turkish assault on the Armenians, the skull pyramids of Timur Tamerlan, the Meso-American human mass sacrifices were just as horrendous, in particular if taken relative to population sizes and densities at the time.

All of these events had some kind of economic motivation, all of them engaged members of society to carry out the atrocities, in all cases the balance of members of society co-operated or acquiesced, in all cases an elite had the most to gain from such measures to establish a controlling position or to protect an achieved steady-state. The 'survival of a society' was never a true issue. In all cases the elites claimed some religious or ideological legitimation from beyond their own instruments of power, which included the 'dehumanization' of those targeted for death, sacrifice, exploitation or suffering.

Bauman (1989) discusses specific processes which made the atrocities of the Holocaust possible: such as 'distancing' (which can be spacially - e.g. long range weapons; temporal - the killing of the North-American buffalo; or hierarchical - the 'chain of command'; - or 'inner ecological' by authoritative legitimation - see also ideograms on pages 141-142); the

modernist faith and blind belief in problem-solving (including the achievement of 'efficiencies'); and the exclusive use of 'rational choice', as phenomena of modernity. He even implicates modernist sociologists (but he does not see postmodernism as the conditions under which the consolidation of late-modern rationality can evolve, undisturbed).

The 'aesthetics of a solution to a problem', its seductiveness, and its role in childhood socialization as an inner-ecological process worth investigating. It would augment 'the physiology of problem-avoidance' with the 'hedonism of problems solved' and as the inner ecological basis for 'problem-solving'. 'Functionalism', 'balances', 'pyramids' (hierarchical or architectural), 'control' appear to be closely associated with a kind of aesthetic sense in their accomplishment, whereas transformation seems to have the opposite effect (but one person's transformation may be another person's sense of control). The theory of the 'hedonistic neuron' (Klopf 1982) may be of relevance here.

Bauman does not pay enough attention to the economic processes. Antisemitism gave the convenient pretext and seductive racist ideology to grab the Jewish assets which were essential for the 'war-effort', then to utilize the Jews for cheap labor and expertise, and, finally, to utilize what was physically left of them. The German 'efficiency machinery' could only go into full gear once the issues were 'scientifically' (eugenics) and economically defined. Goals and legitimations were not of the same kind. A purely racist ideology alone would have led to massacres, plundering and other atrocities, but not to the kind of systematic, progressive 'problem-solving' which characterized the Holocaust.

Such atrocities seem to come about under three conditions:

- 1) the survival imperatives of a power elite;
- 2) the establishment of requisite economic conditions and goals to make the survival possible; and
- 3) forms and methods of public legitimation and compliance with economic goals, including the manipulation of 'inner ecologies'.

The same pattern is apparent in Marxist interpretations of class society, in American slavery, and the same pattern will be shown as an explanation for the contamination of the blood supply. The pattern is even discernible in the current trade-negotiation of the Canadian Government with countries of the Pacific rim. The novelty is that economic goals are now openly used as legitimation to counter concerns with respect to doing business with countries which are deeply entrenched in human rights violations. At the same time, human rights concerns are sequestered ('separated') from economic strategy. The feeble, contradictory ideologic legitimation is that an improved economy will improve human rights conditions. While in earlier days crude exploitive economism needed to 'mask' itself with 'ideological aesthetics', other violations of nature and the human organism can now be 'masked with economistic aesthetics'. 'Capitalism has become beautiful'. (See also the relationships between the 'economic cycle' and 'cycle of meaning' - page 112-113, and the sequestration of the suffering experience - page 26).

The inner and outer ecologies of members of power elites need to be urgently examined. The social sciences have shied away from such analysis and exploration, in particular with respect to inner ecological phe-

nomena amongst elites. The relevant power elites are not necessarily the visible politicians or leaders, but the invisible economic, bureaucratic, scientific/technocratic and religious elites. The German industrialists were the ones who had the most to gain from the success of Fascism. The churches co-operated. The bureaucrats were willing instruments. The intelligentsia acquiesced (e.g. Heidegger). Since our future depends on what is happening in the heads of such elites, and bearing in mind the ways in which authority engages in our own cognitive processes, we ought to find out.

3) The 'mythification' of what is too horrendous to become public knowledge

Vaccines (which use animal cell cultures) and transfusion and transplantation have been celebrated successes of Western medicine. They were also opportunities for pathogens, in particular viruses, to spread through human populations. The issue that HIV originates from green monkeys, and that their kidneys may have been used for tissue cultures in the production of polio vaccines has not been thoroughly investigated (See DOC 3). Transmission of Creutzfeld-Jakob pathogens (a disease similar to Kuru) through preparations of somatotrophic hormone from human hypophyses has occurred (possibly several hundred cases). Human organ transplantation is a fast growing reservoir for transmission of viruses, in particular when such organs are obtained from 'black organ markets' (e.g. in China). Thus some of the biggest successes of medicine have become its worst nemesis. All along, these successes had been glorified as 'miracles,' 'break-

throughs', 'triumphs' (over nature), as 'heroic ventures'. (A recent ad of the pharmaceutical giant Glaxo Laboratories plays on that theme; the actors are no longer struggling with nature, but with a computer which presents them with simulated puzzles of nature to be solved: the heroism is depicted as going back to the computer terminal instead of going home for dinner). The propagation of viruses through biotechnologies constituted a major rupture of the 'myths' and 'miracles'. The 'mythical adaptation' to this rupture has been as follows:

1) the myth of 'heroic medicine'; 'heroism' legitimizes 'occasional' failure;

2) the myth of the 'alien agent' which overwhelmed human know-how until 'science triumphed'- again; (the heroes had a temporary setback);

3) the myth of the transcendentality of the operational environment: 'nothing is 100% safe'; and

4) the myth that new technology (recombinant and other technologies, such as new virus laboratories and virus banks) will prevent similar disaster in the future. The 'new elixir' is being delivered by the 'heroes'.

Of course these myths are contradicting claims of the 'scientific' nature of medicine. There are not supposed to be any 'miracles' and 'heroes', but only cold, rational calculation. The subtext beneath the myths

is approximately as follows:

1) Wrong-doings have occurred, but they are more than balanced with all the good that has been done;

2) When the consequences of the contamination were recognized the know-how for stopping the spread was there. But there was cause not to stop the spread, 'for a greater good', which only the leaders (or 'insiders') can understand and appreciate, they are not suitable for public consumption;

3) Technology cannot predict the consequences of its implementation. Since we cannot abandon technology, we can always blame nature.

4) The scientific myth is powerful enough already that new technology can be hailed in the same way old technology was. Nobody will notice that the precedent would predict a similar or even greater disaster, some time in the future. (It is a good strategy, however, to 'celebrate technology and science' and to indoctrinate children at the earliest possible age).

I suggest that the subtext underneath these subtexts is that corporate survival legitimately overrides all other concerns, and that, ultimately, the survival of corporations, industries and large conglomerates is paramount. This 'truth is so horrendous' that the 'whole truth will not be told'. Barbara Thiering (1992) argues that the New Testament, although meticulously 'accurate', has two very distinct meanings, one which was inten-

ded for 'public consumption' (for the '*babes in Christ*') and one for the '*insider*' (who has '*ears to hear and eyes to see*'). For the insider, the Gospels were an account of a political process as seen by the 'peace-party', which differed from the militant Zealots, the 'war-party', in that they tried to achieve their goals through religious movement and conversion (baptism): the re-establishment of the Jewish empire. (The 'figtree', which was cursed by Jesus (why did he?) was the code name for the Zealots. The 'vineyard' was the code name for the peace-party). The peace-party movement resulted in horrendous death (the persecution of Christians for the sake of establishing a secular kingdom); the war-party perished in defeat (Masada). The original goal was lost, but vestiges survived in Southern France.

The horrendous sacrifice of the peace-party (later Cristianity) needed to be legitimated. The legitimating myth of Christianity was constructed from Old Testament prophecies and from various terminologies ('Son of God', 'Son of Man', 'King', 'Father', 'Virgin' etc.), which had once been a set of meanings for the 'insiders' of the Essene sect (the predecessors of Christianity), but came to mean something completely different when encountered in the Gospels by 'outsiders'. The contradictions which arose from the 'outside interpretations' of the Gospels are still referred to as 'mysteries'. They are explained as 'supernatural, unexplainable'. A central piece of insider knowledge was that Jesus did not die or was not even meant to die. This is a potential 'whole truth' which could never be told, as martyrdom would have lost its legitimacy. The prophecies provided the necessary religious legitimation. The commonality between the myth of the contamination of the blood supply and Barbara Thiering's analysis of the gospels is as follows:

- 1) an 'ultimate good' is considered unassailable by an 'insider elite';
- 2) the achievement of the good requires 'strategy and means' which cannot be made public as such;
- 3) the means are justified with the unassailability of the 'ultimate good';
- 4) the 'evil of the means' must remain hidden from the public, or else the strategy will be challenged and may fail;
- 5) 'insider elites' still need to communicate and account;
- 6) the story is told with 'insider signifiers', which are taken at 'face-value' by the public; the 'insiders' know what it 'really' means.
- 7) after a while, the insiders die and with them the 'inside-meanings'; the 'outside meaning' survives as myth;
- 8) the myth takes on its own life and generates its own meanings and value systems, initially in the interests of 'insiders,' but eventually without them. Contradictions become 'mysteries' and central to 'faith'.

Christianity, once implemented, established its own value systems, many of them quite inconsistent with the Gospels. The myths of the contamination of the blood supply are already spawning new 'value systems'

which will be addressed in Chapter 9.

This particular form of myth construction may be a universal phenomenon of civilization. It has a corollary in an apparent inability of a society to take the leadership to task for their horrendous actions, in particular when large segments of that society benefited, participated and acquiesced. Butchers become heroes and mythical benefactors (Napoleon, Djenghis Khan, Stalin, Ceasar, the French Revolution, Bonnie Prince Charlie, Mao). Failing that, the truth may be suppressed and denied. Societies may find it even more difficult to put such leaders on trial. Some doctors who were given prison sentences during the Nuremberg tribunals had their sentences drastically shortened. A few years later they were going back to practice (Hoedeman 1991). Attempts in Germany to deny that the Holocaust ever happened had to be curtailed with legislation, declaring such denials as crimes. The mystification and heroification of some very dark episodes in human history may have been a common social coping mechanism in past and recent civilizations. Whatever could not be built into the myth may have been suppressed and eventually forgotten. (The reaction of WW II veterans to allegations of unnecessary bombings of the German civil population is a typical example, as are the suppressive tactics used for the Kennedy assassination in the face of filmed and widely viewed evidence to the contrary. The false story is still avidly defended by the American Medical Association).

It is difficult to construct 'heroism' in the face of the contamination of the blood supply. Thus suppression and denial are the prevalent strategies, until all the victims have died, participants have died or are retired, and the 'new heroism' of science has taken front-stage. The 'discovery' of

HIV is still celebrated as an American heroic event, although Dr. Gallo's story and controversy with Dr. Montagnier remains unclarified, obfuscated and fraught with 'anomalies'.

Myth construction seems to utilize ambiguity: one cannot be sure, there is no 'proof', there are different 'perspectives', etc. Once ambiguity has set in and dissonance is aroused (as is also done effectively through various means feasible through a fragmented cycle of meaning), new interpretations and new mythologies may become more readily accepted.

The production and propagation of ambiguity as the hallmark of active myth construction is evident throughout the proceedings of the Krever Commission. The only real obstacles in this mythification process are the surviving victims, not unlike the surviving victims of the Holocaust. They are the 'eye witnesses', and they tend to interfere with the production of ambiguity, myth and the mystification of 'cause'.

If we accept such myth constructions as a common coping mechanism (which may or may not meet the needs of elites, but most likely does), which is still manifest in our time, we should seriously concern ourselves as to 'who' is producing the myths. In preliterate and pre-modern societies this may have been poets, bards, troubadours, shamans, priests, magistrates and the people themselves. In our time, this is done by 'sociologically trained' public relations specialists and technicians in the employ of specific commercial and political interests. (The Red Cross has such a firm under contract for three years at 1 million dollars.) While this issue may be of some anthropological interest with respect to older techniques in myth construction (like the 'peshar' technique used by Hebrew scribes, see Thiering), the use of public relations and lobby firms, as well as that of other consultants in the 'double-hermeneutic processes' of late modernity

must be exposed and critically analysed. This may be a good place to quote Joseph Campbell again:

"Without arguing the point as to whether a state can survive without compelling its subjects to accept as 'Absolute Truth' whatever system of belief the dominant elite may have decided to put forth as divine revelation [or judicial revelation, as in the Kreyer Inquiry], we shall observe only that in the history of the Levant this pseudo-religious form of sociology can be studied in variety and, so to say, in purest style. And where once allowed to prevail, it only grows in force and terror as the violated, coerced factors become increasingly intractable through the operation of a second natural law, namely, that gods suppressed become demons; which is to say that psychological factors and sociological factors neither assimilated nor recognized by the consciously controlled system become autonomous and must ultimately break the approved system apart". (Campbell 1991 (c):405)

I should note that I found this passage after I had written this chapter. I consider this highly advanced, intuitive 'human ecology', far more advanced than Bateson's ecology of mind. Earlier in the same book, he raises another human-ecological issue, which I have not addressed anywhere in the introduction. This may be politically incorrect or at least politically impalatable, as it can be applied to phenomena of multiculturalism or post-modernity. I will apply it to transnational corporatism: it represents the destructive force of gods suppressed turning into demons, and also the destructive force of an ideology which is disengaged from 'the local sector of body politic' in which it thrives. Without any other argument, the contamination of the blood supply would have been predictable, if not inevitable, from the combination of these two circumstances.

"Now it is simply a fact, signally illustrated in the history of the Levant and particularly in Judaism and Islam, that when religion is identified with community (or, as we have expressed the idea, with a consensus), and this community, in turn is not identified with an

acutal land-based social organism, but with a transcendental principle embodied in the laws of a church or sect, its effects on the local secular body politic, within which it thrives but within which it does not identify itself, are inevitably and predictably destructive. The Old Testament Book of Kings describes in detail the terrible effects of such intransigence in the history of the Monarchy of David, and we are to watch it once again come into play - with cumulative fury in the calamitous disintegration from within the state so bravely fought for by the Maccabees" (predecessors of the Essene sect). (Campbell 1991 (c): 227; Campbell refers to the period when Zoroastrianism was forced upon the Levant as the first fanatical and persecuting religion).

Case in point:

"Drug Giant forms research network".

Rhone-Poulenc Rorer Inc., an arm of a giant French drug and chemicals corporation, has agreed to collaborate with a number of international institutes and companies to form a research network dedicated to development of cell and gene therapies.

PRP, based in Collegeville, Pa., said yesterday that it is investing \$300-million (U.S.) in the venture. The project will involve organizations ranging from the Rhone-Poulenc affiliate that controls Toronto Based Connaught BioSciences Inc. to the Lawrence Berkeley Laboratory's Human Genome Centre in California.

PRP, an arm of Paris-based Rhone-Poulenc SA, pointed out that the figure cited includes some financing for deals that have already been announced.

The company also said it has formed a cell and gene therapy division, Gencell, that will focus initially on oncology, cardiovascular disease and neuro-degenerative disease.

Companies involved with PRP in the network include its sister Company, Pasteur Merieux Connaught, and its Virogenetics and Transgene subsidiaries.

A spokesman for the Connaught BioSciences said the company expects this initiative to lead to better co-ordination of research and development efforts, without affecting the autonomy of the Canadian operation or the role it plays within the Rhone-Poulenc group. (Reuters and staff; Globe and Mail November 15 1994).

4) The blood-bankers dilemmas

In 1983 and part of 1984 medical directors of the Red Cross were not allowed to exclude donors on grounds of sexual orientation; on the other hand, some appeared to be reasonably certain that blood from the homosexual group had a higher likelihood to be HIV contaminated. Some had difficulties in negotiating 'self-exclusion' with gay donors (for whatever reason), and resorted to letting clinic staff mark units for destruction, if they thought that the donor was gay. A number of 'ethical dilemmas' were mentioned during the inquiry: a choice between risking the life of a patient against offending some members of the gay community by overtly excluding gay donors from donating; a choice between risking the life of a patient and taking the blood of a donor fraudulently and discarding it without him knowing; a choice between instituting an unreliable and unverifiable self-exclusion program (and still putting patients at risk) against offending some members of the gay community.

For most of us, a 'gutfeeling' response to acute danger to others (checking the alternatives and measuring one's 'degree of comfort or discomfort') would probably have been in favor of the life of the patients, combined with negotiating the least offensive way of excluding gay donors from donating - even if some gay individuals would still have been upset. However, the matter was not resolved in this fashion at any level of the organization of the Canadian blood system. Instead, dilemmas were created between obeying orders and putting patients at risk, or disobeying orders and putting one's career and economic existence on the line. The principle of protecting the public from a serious risk was never authoritatively enunciated.

Thus the original ethical dilemma had become a computation of relative powers and authorities. Which left a decision between insubordination and protecting the public on one hand and following policy and thereby leaving the public at risk on the other. Most medical directors followed the policy, and the actual responsibility was left with the gay donors (through self-exclusion, which was later shown to be of limited value only). Some medical directors attempted some partial or devious solutions out of the dilemma (such as the above noted elimination of units).

The situation was an emergency, a profound change in the boundary conditions to the blood system. However, the problem was defined question of powers and authority and resulted in a sequence of very superficial 'solutions'. A profound solution, with strong 'symbolic-authoritative' political interventions might have destroyed the viability of the commercial blood industry. The controlling influence of these interests was able to out-power what might have been there as 'inner authenticity' on part of participants in the blood system. The sequence of 'rational arguments', amplified with authority provided enough 'sedation' and blockage. Those who tried to organize resistance (e.g. Dr. Gail Rock, former Medical Director of the Ottawa Blood Centre) were removed and/or had their credibility destroyed.

From an outer-ecological point of view, the crisis was handled like a routine occurrence. Consequently, today, nobody, anybody or everybody is blamed for the results. The Inquiry on The Canadian Blood System itself is a 'routine process', pretending that the entire calamity was a 'routine-occurrence', the sort which occurs when 'there are not enough facts', and which can be fixed by 'reorganizing' the sign order. The routine-process was one of maintaining a steady-state in boundary conditions for the com-

mercial blood industry, for a period of 10 years, during which it could accomplish its own profound adaptations (a switch to recombinant technology). The so-called 'confusion' was not the result of limited facts, but of the particular kind of cognitive processes deployed and used in the process. The industry succeeded - at the expense of the health and lives of thousands of people.

Those testifying claim that with 'hindsight' things might have been handled differently. I am saying that 'foresight' was at work, and that available knowledge did not make any difference. It just was not made public. The 'inner ecology' of 'leaders' of the commercial plasma industry and allied government 'officials' and of medical 'professionals' and 'scientists' (who acquiesced) needs to be explored with some urgency.

Note: The Federal Government's mandate, although not explicitly stated as such, is to intervene 'explicitly' in situations where routine assumptions cannot be made (such as in the licensing of products and in the prevention of public health hazards). Not to regulate in such situations is as negligent as, or worse than, not to enforce an existing regulation.

5) The Emperor Ming

In a Chinese musical treatise of the second century we read:
(Cambell 1991a:453-455)

"If the Note, Kung [C=the tonical], is disturbed, then there is disorganization, the Prince is arrogant.

If the Second note, Shang [D], is disturbed, then there is deviation: the officials are corrupted.

If the Chiao [E] is disturbed, then there is anxiety: the people are unhappy.

If the Chi [G] is disturbed, then there is complaint: public services are too heavy.

If the Yu(e) [A] is disturbed, then there is danger: resources are lacking.

.....In periods of disorder, rites are altered and music is licentious. The sad sounds are lacking in dignity, joyful sounds lack calm...."

The Chinese metaphor can be interpreted as referring to various inner states (of the members of the ruling class and the ruled) and their relationship to the 'outer ecology'. Campbell gives an example of a deep and real anxiety in the words of the Emperor Ming (227-239 A.D.) following a solar eclipse of the year 233.

.....We do not therefore consider it a part of Our duty to act in accordance with certain memorials advising that the Grand Astrologer be instructed to offer up sacrifices on this occasion. Do ye gover-

nors of districts, and higher officers of the State, seek rather to rectify your own hearts; and if anyone can devise means to make up for Our shortcomings, let him submit his proposals to the throne.

He did not ask his officials for legal advice or administrative rational solutions (which would have included astrology). Rather he realized that something was 'off' in the routines in which the middle kingdom acted and that this could have disastrous consequences. This dissonance could not, in his view, be handled by the manipulation and reshuffling of signs within given administrative algorithms. Rather, the algorithms of the Empire were in disarray and could not yield a state of harmony. The distorted algorithms were embodied in his administrators and the disharmony which they represented. Consequently he asked them to contemplate their inner processes and his. Of course the 'heart to be rectified' was in their 'heads'. He was right in his analysis. In his choice of action he was not. He should not have asked his governors and administrators to 'contemplate', nor should he have asked for advice (they were the problem and already far too 'troubled'). He needed to make a 'symbolic intervention'. Instead he appeared troubled, anxious and indecisive. Thus he became the selffulfilling meaning of the solar eclipse. He had come to power after the collapse of the Han dynasty, at the beginning of troubled times which lasted for four centuries.

6) The Roman Republic

The Roman republic clearly distinguished between normal business and 'emergency orientation'. For emergencies, a single 'dictator' was

given all the powers, while the powers of the Senate were, at least partially, suspended - but only for the duration of the emergency. This pattern prevailed, until Julius Caesar turned 'emergency orientation' into a permanent condition and was promptly assassinated - but too late. Today's business management also distinguishes ordinary (routine) business from extraordinary business, but it carries out both at the same time. Extraordinary business is normally assigned to a (time limited) project manager, it is not given to operating managers (see DOC 38; Beer 1972). One of the positive aspects of the Krever Inquiry is that it is conducted by a one-person commission, not a 'democratic, representative panel'. Not all 'dictators', however, are 'true' dictators. Justice Krever is part of the 'senate', he does not stand, empowered, outside of it. This amounts to a conflict of operational mode, and he must at least pretend that he is a dictator (which he does). The symbolic character of the Commission is one of a 'ritual fake' (it serves the elite not the damaged public).

7) The Canadian leadership and the contamination of the blood supply.

An as yet unspecified 'crime against humanity by omission' was committed by those who had an awareness that the contamination of the blood supply was not a routine occurrence, who had an awareness of the 'social adaptational processes' which would take place in absence of a forceful emergency intervention, who had the power to exploit and control

them, and who made the public believe that it was all routine. The consequence was 'horrendous death'. The Chinese Emperor understood the nature of the disturbance in his empire. He did not understand that it was upon him to undertake a deep symbolic intervention to bring about a 'change of heart'. The 'governors and officers' of the HIV crisis were the producers of the disturbance. They could not have done this without the 'emperors' above being aware of it and not making the necessary symbolic interventions. As long as I have been in Canada, no Prime Minister has ever spoken (meaningfully, that is) of epidemics, or of those who are handling or mishandling them. It is therefore very significant that the Commission of Inquiry on The Canadian Blood System was appointed by the Prime Minister, but not announced by her. Thus there is no intention of bringing about a 'change of heart'. Rather, the intention is not to bring about a 'change of heart' amongst the 'governors and officers'. What could one infer with respect to the 'Canadian emperors'? Which notes of the Chinese musical metaphor are disturbed? Why are the same 'grand astrologers' who advised on the epidemics still being listened to, or even consulted? And how long can the 'inner boundary conditions' be simultaneously disturbed (by 'spin-doctors and lawyers) and controlled (by bureaucrats and the Commission), before the 'adapting systems' of government and industry are overwhelmed?

4 Methodology

In the first two chapters I made an attempt to build a theoretical foundation for the exploration of pain-related phenomena. The four chapters following the one on methodology present data sets on the events and circumstances of transfusion-related infections. These data were considered relevant to informing the theories developed in the introduction:

- 1) a summary of events and issues surrounding the contamination of the blood supply; a discussion of hypotheses on the processes and conditions which led to this catastrophe;**
- 2) a letter to the editor of the Globe and Mail from Dr. Hershfield;**
- 3) a selection of legal and public relations interventions and outright oppressive methods which were used in camouflaging contamination of the blood supply and its subsequent cover-up. Some U.S. references are provided.**
- 4) Summaries of five histories of victims and their families.**

A fifth data set, autobiographical data, has been added for the benefit of the reader, providing information on my involvement in the circumstances surrounding the contamination of the Canadian blood supply.

3

**PM-1 3½"x4" PHOTOGRAPHIC MICROCOPY TARGET
NBS 1010a ANSI/ISO #2 EQUIVALENT**

PRECISIONSM RESOLUTION TARGETS

My background is obviously closely associated with the choice of topic and the particular theoretical approach taken. Although I am drawing on existing theory, theory development was an autobiographical account of my own epistemic processes. It is a reflection of the current state of experiencing, modelling and organizing of my lifeworld. Since I am making the claim that this kind of autobiographical account may be of interest to others as to how they may 'organize' their life world, I am obliged to disclose the specific autobiographical data. While this disclosure was difficult and, in part, embarrassing, have no choice in the matter, since I wish to remain 'intellectually honest', and since I am severely critical of the 'system' which produced the contamination of the blood supply and its consequences. Witnesses testifying at the Inquiry on the Canadian Blood System are not required to provide such personal details (those who were fired by the Red Cross are not required to disclose the firing or the circumstances of it).

I have stressed that this paper does not constitute a legal analysis. Rather, it is an attempt to explore the 'internal and external processes, conditions and constraints' which made the contamination of the blood supply possible, in the context of the larger 'human processes and conditions' from which we may have become and are becoming to be what we are. The thesis deals with 'inner ecology': this was another reason why it became obligatory to declare my personal 'inner ecological processes'. I do not feel that my background and involvement has introduced any important distortions in the interpretation of data and the use of theory. On the contrary, much of what is being presented also represents a rejection of the kind of 'distortions of view' under which I used to carry out my various professional activities. Thus the writing of this paper is also a description of a process of overcoming and extricating myself from such distortions. I did

this, not by selecting a specific alternative viewpoint, but by integrating viewpoints, accounts and realities of other individuals into my own world view. There is some hope that this process can lead me to 'better, more inclusive, and thus more comprehensive models of the truth of things', from which a 'better reality' may arise.

1) Summary of events

The summary of events was developed on the basis of a Federal Government summary which was filed with the parliamentary subcommittee looking into issues of transfusion-related HIV in the first half of 1993, under the chairmanship of Dr. Stan Wilby, then progressive conservative member of parliament. (DOC 22). This summary is commented on and critiqued with additional data from other documents and publications.

The summary is presented in two parts. The first part, as Chapter 5 of this document, focuses on the role of the most important parties, the Federal Government, the Red Cross and the pharmaceutical companies, as the group of institutions which were primarily responsible for the safety of blood and blood products. An economic-ecological hypothesis is advanced by explaining the delays in implementing preventive measures, and later, in informing the public of the consequences. These explanations included: avoidance of costs and revenue loss (if safety measures had been implemented) resulting in a severely constrained use of products and services; avoidance of liability cost once the damage was done; the use of assured revenues to build up blood screening and product decontamination technologies to maintain the system in the short term; most importantly,

in the long-term, to develop, engineer and market recombinant technology to replace some of the conventional, hazardous human plasma products.

The leading roles of the Federal Government as the primary safety regulator and of the Red Cross as the primary manufacturer in the crisis are explicated. This is not to be read as legal proof of liabilities, but as the use of accessible information and circumstantial evidence in the evaluation of the social and cultural processes ('human-ecological factors'), which came to bear in the contamination of the Canadian blood supply and made it possible. Proving or disproving liability may still take several years of court battle. However, where, in my opinion, the possibility of such liabilities exists, I have said so, without laying the blame on any one specific individual. Not to disclose such opinions would be hypocritical and 'intellectually' dishonest'. However, laying specific blame on individuals could result in libel charges. It is my legal understanding that institutions cannot sue for libel.

The second part is compiled as Appendix 1, where a Federal Government summary is quoted verbatim and augmented with additional documents, references and publications. This Appendix provides additional detail and items which will be referred to in the main body of the text. Chapter 5 is a very high level summary and cannot do justice to all the facets and events which took place during and after the contamination of the Canadian blood supply. I am drawing on my work experience (in particular in hepatitis B, and corporate planning and quality assurance) to lend credibility to the fashion in which I highlighted what I consider to be the most significant aspects or 'loci of control' in the crisis.

On purpose, I chose to present a report which was designed to support the message to the public that everything humanly possible was done

at the time - given the knowledge available at the time: while there is little doubt left that the decisions, with good cause, could have been made on the side of caution and in favor of protecting the safety of the public. This summary is an important element of this thesis, as it provides the necessary correlates to the victims' experiences and their interpretations. That which appeared 'unexplainable' to the victims becomes 'explainable', if one views their experiences in the light of specific government action and inaction and possible motivations.

2) Accounts of victims

I taped almost all of the hearings of the Krever Commission from January to September 1994, including the testimonies given by the victims or their close relatives. I had originally planned to interview victims face-to-face. But this would have been difficult, while legal actions were in progress. Besides, the recall of painful experiences causes additional pain in some circumstances which, with one exception, I could not justify with the purpose of this thesis. The data from the Inquiry and other documents provided an opportunity to do this work without undue infliction of suffering on my part.

I have followed the testimonies of almost all the victims who were testifying before the Commission. The length and depth of these testimonies differed greatly. Therefore, my initial intent to provide summary tables of characteristics of their experiences was of doubtful value. The absence of a characteristic, recognizable form of the testimonies did not mean that it did not exist. But rather than accounting for all the possible personal and

statistical biases and for incompleteness of accounts, I chose to select a group of five individuals who represent a common bias: they are all activists. They went through the full process of experiencing the damages, denial and a process of learning and understanding, culminating in political engagement. In many instances their accounts do not just speak for themselves, but also for many other affected individuals with whom the activists have been in contact.

Three accounts are related to HIV, one is related to HIV and hepatitis C, and one account to hepatitis C alone. One case is related to hemophilia (it is rather paradigmatic), three accounts are related to blood transfusion, and one case is not clarified as yet. Four accounts are from Canadians, and one account is from an American. In two instances, infected spouses are involved, in one case a non-infected spouse. One account includes an infected child. One account was taken from a taping of the Inquiry, one from documents submitted to the inquiry, one from a book which the individual has published, one from the notes for public speaking engagements and one from an interview given to a CBC reporter. In none of the accounts was I engaged as 'interested researcher': there is no 'observer bias'. There may be bias in the selection of data. Activist accounts also provide an opportunity to examine the issue of 'victimism' (media enhanced display).

I suggest that this mix of individuals, circumstances, and forms of accounting provided for a fairly 'thick description' of the victims' experiences. The accounts are probably amongst the most informed which can be obtained from victims. The analysis of these accounts could provide the basis for a more comprehensive study of victims. I felt that this would not be advisable until the Commission has closed its proceedings and until liti-

gation is completed. To conduct such interviews now could interfere significantly with any process of justice individuals may be contemplating, as the questions would certainly have an impact on their thinking and orientation.

Over the last few years, victims had opportunities to be in touch with each other, a lot of information was exchanged and opinions were formed. While this produced some homogeneity of view amongst the victims, it also produced a population in which individuals are no longer 'independent', but are linked by their shared understanding of what had happened. This, however, does not change the independence of their infection history and their subsequent encounters, most of which occurred before they knew each other.

The case presentations will include a summary of the history, an exposition of the salient issues and of aspects specifically relevant to the hypotheses developed for this thesis. I felt that, given the statistical problems with sampling, and given the complexity of ecologically explored issues, case studies (as is being used in anthropological ethnographic research) would be the most suitable format of data presentation. Similar approaches are used in media, management, and medical research: they usually start with the compilation of case histories and their interpretations (e.g. the Harvard Business Review). As the traditional boundaries of contemporary culture are increasingly blurred, it may no longer be possible to use a 'circumscribed culture' as the 'case boundary' or 'locus', and other forms of 'case study' may need to be developed.

The Ottosen case provides a glimpse at the situation in the U.S., which is of particular interest, since Canadian policies were strongly influenced by American policies.

Note: The patterns of the propagation of the epidemics through the blood supply were common in most Western industrialized nations, such as Canada, the U.S, France, Germany, Switzerland and Austria. Belgium, because of its former colonial relations to Zaire, had early warnings of the epidemic and may have been the most 'forsightful' of all countries. While the international picture is important for the context of a transnational plasma industry, it cannot be explored here. It should be noted, however, that in a 1990 WHO survey, Canada ranks amongst the countries with the highest infection rates for hemophiliacs. Some countries, like U.K. and Austria did not participate. Countries are ranked by estimate of % hemophiliacs infected: Brazil (55%), Spain (49%), U.S. (47%), Canada (47%), France (45%), Japan (40%), Costa Rica (40%). Germany showed only a small sample. Belgium, in comparison had only a 6% infection rate. (Note: there are some biases in these data). Brazil, Spain and Costa Rica may have been importers of infected product (the WHO report does not address the issue). The WHO report does not address the rate of infection in transfused hospital patients (!) (Mann et al. 1992).

3) A letter from Dr. Hershfield

A letter to the editor of *The Globe and Mail* from Dr. Hershfield is used as an example of the medical profession going through a profound major 'dissonant experience': the result of the contamination of the blood supply combined with the adaptations and new compromises the medical-scientific 'superstructure' is seeking. (Dr. Brill-Edwards described them as behaving like "*somebody who has just hit a deer on a dark foggy road while driving at high speed*"). Dr. Hershfield was not directly involved in the contamination of blood products, but was a prescriber of such products.

The 'products of adaptation' of the medical profession and the main participating specialties are limited value in the understanding of the inner ecology of health professionals, as they are, at this point, legally constructed. Dr. Hershfield's letter is a much better window into the 'inner ecology'

of medical practitioners.

4) The 'medical semiotic jungle'

The entire thesis is based on very simple assumptions, namely that the commercial plasma industry was mortally threatened by the AIDS epidemic, that it needed time to adapt and transform, and that it had to seek ways of sustaining its revenues and generating enough capital to finance the transformation. The chosen strategy required continued sale of infected product, to conceal this from the public, and then to avoid litigation cost as long as possible. The strategy was horrendous because of the human cost. It required extensive efforts in 'spin-doctoring', control of dissenters, and legal preparation. While Dr. Hershfield's letter shows an individual 'symbolic reaction' to a persistent and highly dissonant experience, spin-doctoring ('myth fabrication') is a more mundane and strategic undertaking. It was briefly discussed in the chapter on 'Examples'. It is important to show that the locus of control of 'myth fabrication' was not Canada, but the U.S. This section on myth fabrication provides some insights into the processes in the United States. It also shows how the legal preparation (which is legitimate 'conspiracy') may have contributed to the choice of strategies, which were aimed at producing legal 'invulnerability' of the interested parties (the blood industry and government). Finally, the medical-governmental network is pointed out as a collective of individuals who might benefit from effective myth production.

5) The anthropological approach

I believe that my past participation in the blood system makes me an 'observing participant' rather than a 'participant observer'. 'Transfusion medicine' is a complex, global subculture engaging blood donors, patients, medical professions, industries, para- and non-medical personnel, government and public health departments, lawyers, 'ethicists', public relations specialist, economists, computer specialists, theoretical scientists, universities.

It is organized (or 'structured') by a specific technology, a phenomenon which has precedents throughout the development of human civilization in other fields of technology. It is also an indicator of world-wide changes in the epidemiology of infectious diseases by migration, immigration, refugees, travel and trade. It has become a debating ground for human rights, public health practices and policies. In other words, transfusion medicine has become a technological subculture of a very special kind, in that most if not all tendencies in the cultural evolution of late modernity, and Western Medicine in particular, have become manifest and observable. It is thus a confined field in which the ecological model proposed can be tested in a number of different dimensions.

This 'multiparadigmaticity' presents opportunity but also great difficulty. Of all academic disciplines, anthropology has been the most exquisite 'multiparadigmatic'. Therefore an anthropological approach appeared to be the most suitable for such an undertaking. 'Participant observation', perhaps even 'observing participation', becomes essential for such a level of complexity.

It should have become apparent from the discussion of 'suffering' in Chapter 2, that structuralist and semiological analyses are important

tools for this kind of exploration. While a full semiological analysis cannot be attempted here, many issues have been and will be tacitly discussed 'semiologically'.

This thesis can only initiate the exploration, addressing a specific aspect ('suffering') of the entire field. The approaches and methodologies developed here should and can be extended to the entire field of hemotherapy, then to medicine and healing and, finally, to the larger issues of 'human well-being'. It can be of interest to anthropological inquiry in late modernity, as health, illness and healthcare are perhaps the most important contexts in which culture contact takes place (others may be armament, democracy, market economy, feminism, exploitation of human and natural resources and industrialization, which in turn are all more or less contingent on healthcare and the well-being or suffering of humans).

The risk to the population from late-modern health care which can be observed in Western industrialized nations and should be of even greater concern for developing nations. Because of their lower educational levels and because of poverty they are far more vulnerable to manipulation by commercial interests.

One of the most challenging aspects of the contamination of the blood supply is the extent and depth of individual and institutional networks involved in the production of 'incomprehensibility', which I believe can be overcome by identifying 'loci of control': trajectories of individuals, groups, events, texts, technologies and so forth, which are transforming other, contingent processes more extensively than they themselves are being transformed. Once these trajectories are identified ('cognitively discerned, differentiated') in the overall 'noise', very complex processes become comprehensible. Late modernity is characterized by ever increasing 'noise'.

However, if one tries to find the sources of the noise (some are louder than others), even noise analysis can be used as an aid in comprehension (see also the comments on 'myth fabrication' above).

5 Summary of Transfusion-Related HIV and Hepatitis Infections in Canada.

Appendix 1 contains (verbatim) a summary provided by Health and Welfare Canada Media Relations (Fax: OCT 13 '93 12:55PM HWC COMM/MEDIA RELATIONS). It had been entered into evidence with a 1992/1993 parliamentary subcommittee of the Standing Committee on Health and Social Services of the federal legislature. Chairman of the Subcommittee was Dr. Wilby of the Progressive Conservative Party. It had representation from all three political parties, as well as from Quebec, and dealt with transfusion-related AIDS during late 1992 and the first half of 1993. I testified before this committee and submitted a written submission - DOC 45).

The federal document was prepared by senior officials of the Health Protection Branch Bureau of Biologics and was presented to the subcommittee by Jan Hopkins, Executive Director of the Health Protection Branch. At the time, Dr. Boucher was Chief of the Blood Products Division of the Bureau of Biologics (Health Protection Branch). This particular federal government document was chosen because, for better or for worse, the Federal Government was and remains the highest authority in the land on such matters: all blood, blood components and plasma derivatives are drugs by definition of the Food and Drug Act and fall under the jurisdiction of the Federal Minister of Health. Administratively, as a matter of public protection, licensing and enforcement they fall under the jurisdiction

of the Health Protection Branch and, specifically, its Bureau of Biologics. Therefore the actions (and inactions) of the Federal Government must be seen as the most significant and influential circumstances for the contamination of the Canadian blood supply with HIV and hepatitis B and C viruses, regardless of what other parties and institutions may have done or may have omitted to do. I have no indication or cause to suspect that any of the details given in the summary are inaccurate. While the document provides an overall sketch of the events, the selection of events appears to be such that:

1) It attempts (and would be expected to attempt) to show the Health Protection Branch and its Bureau of Biologics (and implicitly four ministers of health: Begin, Epp, Beatty, Bouchard) in the most favorable light possible. This is very significant, as at the time of writing of this thesis several government officials of the former French government are under criminal investigation of complicity with respect to the same issues.

2) It attempts (and would be expected to attempt) to show the Canadian Red Cross Society in the most favorable light possible. The Federal Government was the regulator. The Red Cross as the sole distributor of all blood, blood components and plasma fractionation products was one of the primarily accountable 'regulatees' - notwithstanding that regulations were not enforced by the Federal Government in the late seventies and through most of the eighties, until 1989. In that year the Bureau of Biologics began to license its

facilities, production processes and products.

3) It shows the pharmaceutical companies, the other group of 'primary regulatees' as almost neutral to the entire process. Industry and commerce (profit or non-profit) appear to have a degree of immunity surpassed only by the government itself.

4) The Canadian Hemophilia Society is painted as the main responsible agent in the distribution and use of contaminated fractionation products (despite the fact that the CHS is a 'consumer' organization which depends heavily on government and private subsidies and on the advice from outside experts, such as those of the Red Cross and the Federal Government). The physicians treating hemophiliacs are painted as the group ultimately responsible (I believe they were the designated 'scape-goats'. See entry for February 8, 1983, in Appendix 1. They may not have been aware of such a 'designation').

5) The Canadian Blood Committee (and thus the provincial governments) is not painted favorably, but the Federal Government document makes no mention as to the role, actions or interventions of the federal member on this committee. In addition to the member, the Executive Director of this body was an employee of the Health Programs Branch of the Federal Ministry of Health. Thus there were two important federal liaison positions associated with this committee.

In summary, based on the evidence of this document, the Federal

Government appears to be protective of itself, the Red Cross and the commercial plasma industry, at the same time implicating the Canadian Hemophilia Society, the Canadian Blood Committee, provincial governments and the hemophilia treaters as groups and agencies responsible for the carnage. In other words, the Federal Government (with the exception of the Canadian Red Cross Society) effectively blames groups of its citizens for its own regulatory failure. The document is not flawed in what it says, but in what it does not say. Some notable events and circumstances which shed a different light on the Federal Government and the agencies referred to are missing in the document. (See Appendix 1).

The paper ends with the year 1989 and a 'compassionate financial assistance package' from the Federal Government (with a 'positive note regarding compassionate action on part of the Federal Government', so to speak). It does not discuss why it took another three years before the provinces were willing to discuss compensation, before the Federal Government agreed to have an inquiry into events surrounding the contamination of the blood supply and before any serious attempt was made to find blood-infected individuals. It also does not mention the waiver of further litigation which victims were forced to sign in order to be eligible for the package.

The most important events between December 1989 and November 1993 have been extracted from a document filed with the Commission of Inquiry into the Canadian Blood System by Mr. Jerry Freise of the HIV-T (Transfused) Group, a group of individuals who were infected by blood or blood components, and from a compilation of Hepatitis-C related information, prepared by Dr. Alan Powell (President of the Canadian Association of

Transfused Hepatitis C Survivors) - see DOC 19, 1994.

Neither the government document nor the additional comments can do justice to issues related to hepatitis B and C virus contamination of the blood supply in the late seventies, which has remained unattended to this day (with the exception of some representations before the Krever Commission). Both kinds of infections were ignored by the Health Protection Branch and are thus not presented as associated issues in the government document. Hundreds of hemophiliacs were infected with both kinds of hepatitis, but so did tens of thousands of Canadians who received blood and blood products in the course of their medical treatments. The risk-factors for hepatitis and AIDS are very similar: sexual life style, transmission via blood, including blood-contaminated needles. Appropriate and called-for interventions to prevent hepatitis B transmission in the late seventies might have, without any additional measure, prevented a large number, if not the majority of transmissions of HIV and Hepatitis C via blood and products (Aledort in Madhok et al. (eds.), 1987).

Unlike HIV and hepatitis C, hepatitis B was not a 'new or poorly understood' condition, but it was well understood and researched, and tests which could detect hepatitis B at any stage of acute or chronic infection were available.

The argument that in 1982 and 1983 one could not be sure about AIDS is totally contradicted by actions which were taken: hemophiliacs who were thought to be infected already were given suspected infected product. The suspicion was strong enough not to give newborn hemophiliacs infected product but cryoprecipitate, while at the same time it was claimed that there was no risk. Thus the patients were asked to play 'Russian

Russian roulette', while the levels of sales of products was maintained. The nature of the events between 1982 and 1985, when few people in responsible positions (including our government, see Appendix 1, entries for 1982) would have had any serious doubt that the epidemic would enter into Canada and into the Canadian blood supply, are summarized as follows:

o Despite its regulatory mandate, obligation and statutory power, conferred to it by the Food and Drug Act, the Federal Government did not exercise its regulatory responsibilities and powers. Instead it restricted its interventions to recommendations, consultations, a few public messages and the licensing of pharmaceutical products. At no point in the early eighties were the pharmaceutical manufacturers (for-profit and the Red Cross) given specific regulatory directions, nor was the Food and Drug Act enforced and dangerous product recalled. Therefore, the entire blood industry in Canada remained effectively unregulated with respect to the spread of hepatitis B, C and HIV. This resulted in the issues being 'managed' from strictly economic interests by federal and provincial governments. Similarly, the Red Cross, although it had the obligation to act in compliance with the Food and Drug Act, did not act in such a manner, it chose to make few policy decisions of its own and relied on consultation, 'consensus' and a few media appeals as well. The same applies to the pharmaceutical companies which were subcontracted by the Red Cross for the fractionation of Canadian plasma or the supply of U.S. manufactured fractionation products. It must be noted that the pharmaceutical manufactures were separately licensed.

The Red Cross, as an independent corporation, should have made its own decisions, including the acceptance of product from commercial plasma fractionators which were under contract with the Red Cross.

o While the Federal Government is ultimately to blame, the Red Cross and pharmaceutical manufacturers, regulated or not, were in non-compliance with the Food and Drug Act. The omissions of the Red Cross are amplified by the context of its humanitarian mission: its own 'Principles' require it to act as 'auxiliary to government', but also 'independently' of government. This is of great importance, because there are occasions, for instance in civil strife, when a nationally organized Red Cross Society cannot ally itself with the actions of its government. It must try to make humanitarian relief available regardless of government policy. In the late eighties, the board of The Canadian Red Cross Society finally may have reached an awareness of this circumstance: the 'Principles' were read at the opening of every board session.

Furthermore, the Red Cross held a monopoly for the distribution of blood products in Canada. It had a unique role, the strategic clout and the public support to do what was best for the public. However, national Red Cross organizations have been vulnerable to political pressure and political appointments in the Red Cross. For instance, two of the highest ranking Nazi physicians were heading the German Red Cross in World War 2. One was executed following hearings at the Nuremberg tribunals (Hoedeman, 1991) for his

participation in medical crimes against humanity committed in concentrations camps.

o While it must be assumed that the Red Cross acted under federal direction, there remains a question why the Red Cross did not even attempt to follow a course in the interest of the public. While the top volunteer decision makers in the Red Cross may not have had the expertise to evaluate the situation technically and scientifically, the Red Cross had ample expertise available amongst its medical staff. The medical group (including the Scientific Advisory Committee, of which its chairman Dr. Bienenstock, then Chairman of Pathology at McMaster University, and later Vicepresident the Medical Faculty at McMaster), could have redirected the Red Cross at any time: not just at the beginning of the crisis, but at any later stage - unless the medical leadership was no longer acting in an autonomous professional fashion. In other words, the volunteer board of the Red Cross may not have received or sought the advice and persuasion it needed or should have expected. Of course it did not help that in 1983 a high-ranking federal bureaucrat was (volunteer) president of the Canadian Red Cross Society: Huguette Labelle (she is currently head of the Canadian International Development Agency, a position formerly held by Mr. Lindores, currently Secretary General of the Red Cross). It also did not help that the National Commissioner (highest staff officer in the Red Cross) in 1982-3, Henry Tellier, was a retired Major General of the Canadian Armed Forces. In this context the resignation of a member of the (volunteer) Executive

Committee of the Red Cross in 1983, Mr. Michael Worsoff, serving as counsel, has a very high significance, as he saw the Executive Committee of the Red Cross acting against ethical as well as legal norms (and, I presume, against the 'Principles' of the Red Cross).

o There was one party to this 'process' which had the most to gain from such an unregulated, yet federally controlled state of affairs, and the most to lose if protective regulations or emergency measures had been put in place: the pharmaceutical industry. It would have incurred massive losses (product quarantine, product recall, product destruction, cessation of production), until more became known about AIDS and improved technologies became available. This could have translated into an undeterminate number of years of loss of production and sales, and even the demise of the plasma industry. In short, I suggest that the safety of the Canadian public (and the public in other countries), including the lives or the majority of severe hemophiliacs were sacrificed for the interests of the plasma industry.

o Once the size of the damage was established by HIV testing (hepatitis testing was still deferred), it became necessary to avoid lawsuits which, in the worst case, could be expected to be in the hundreds of millions, if not billions. No serious inquiry commenced until 1993. The life-expectancy for AIDS in the early eighties was estimated to be two to ten years after HIV infection. A considerable number of potential claimants could have been expected to die before

the nineties. Also, the individuals most seriously at risk were multi-transfused people, many of which were suffering from conditions which would have drastically reduced their life expectancy. (Several hundred hemophiliacs have died from AIDS in Canada).

o The final containment of the total liability was achieved by two compensation packages, one offered by the Federal Government in 1989, and one by provincial governments in 1993. Both packages stipulated (implicitly) that the recipients could not file civil lawsuits or lay criminal charges. The pharmaceutical industry, insurance companies and the Red Cross contributed very little. Most of the compensation burden is borne by the Canadian tax payer through provincial and federal taxes. Thus the industry did not loose money during the crisis, and it lost hardly any money in the aftermath from civil liabilities. The only loss consisted in loss of 'product market' from hemophiliacs who had died and a very small quantity of infected product which was eventually withdrawn (but not formally 'recalled' by the pharmaceutical manufacturers or the Federal Government). The provincial governments would not only have saved money from the death of hemophiliacs as a reduced liability burden, but also in the reduction of medical treatment costs. (This may sound cruel and insensitive, but these are the brutal facts of the 'economistic ecology' of this example of 'horrendous death'. I made this point before the parliamentary subcommittee to 'encourage' provincial governments to pay compensation when the federal assistance package was about to expire).

o Pharmaceutical corporate and/or federal money is flowing in the direction where some kind of returns can be expected. 1 billion dollars was pledged towards medical research (This was announced in a newspaper advertisement by Judy Erola, President of the Canadian Pharmaceutical Manufacturers Association and Dr. Henry Friesen, head of the Medical Research Council). Some of the money will likely be used for a virus banks and laboratories in Ontario and Manitoba, the home province of Jake Epp Federal Minister of Health between September 1984 and February 1989. In 1983, the Red Cross started planning the new head-office in Ottawa (I was the planner), and was granted funding by government in 1985 (20 million dollars; I wrote the request for funding). The Red Cross, as of 1989, received substantial refunds from its preferred contractor for plasma fractionation (Cutter/Miles-Canada/Bayer, Germany). Its investment portfolio, which was in the order of 20 million dollars in 1985 and could have been used as collateral to bridge-finance an earlier start for HIV testing in 1985 (but was not used), has grown to the order of 50 million dollars. The interest earned from this portfolio was traditionally used to finance non-blood operations of the Red Cross at its head-office. Finally, the Red Cross has a joint venture agreement with Cutter/Miles/Bayer to build a fractionation plant in Nova Scotia. Notably, Nova Scotia was the first province to pay compensation to the activists Janet and Randy Connors and did not require them to sign a waiver of further litigation.

o The tactic of delaying the discovery of infected individuals

between 1985 and 1994 saved expenditures but claimed additional victims: infected people were not aware of their condition and subsequently infected spouses and sexual partners. Some women infected their children during pregnancy or childbirth. People infected by such secondary or tertiary transmissions have still not received any compensation. (There may be an exception in Quebec, as it was mentioned in the hearings in Montreal that the Quebec government had promised a package to infected spouses beginning 1996).

o There is no compensatory action at all for victims of hepatitis infections by the federal and provincial governments. Many sufferers from chronic Hepatitis C are in dismal financial condition, require expensive treatment with Interferon, are severely restricted from normal activities (severe fatigue), but are not getting any relief.

The aforesaid can, in part, be reconstructed from the data provided in Appendix 1. The main argument which could be used against the hypothesis of commercial interest is that nobody seemed to protest, and that everybody agrees that the best was done with the knowledge available at the time. Two explanations can be offered:

1) In 1982 AIDS was new in North America and had shown up only sporadically in medical practice. In other words, the epidemic was still invisible to the public.

2) Most medical practitioners and the public relied on the pronouncements and actions of the national authorities, which were scant, ambiguous and not compelling. By the time practitioners might have realized that they had been misled, it was too late. A great number of them would have been implicated in various modes of transmission of the disease or in not having contributed enough to prevention. Subsequently, an onset of a 'collective guilt' (justifiable or not), of pressure from legal departments of various hospitals and agencies could explain the silence which followed the catastrophe - which became a complete 'wall of silence' for the victims later (see also Chapter 7, on the Irving Memorial Blood Bank in San Francisco, and the seminar on how to defend against AIDS related litigation).

The main sign of a 'collective guilty mind' is, of course, that the medical profession as a whole, without any controversy, is in agreement, not only in Canada, but also in the U.S., and even in Austria. There I found out from a former colleague that exactly the same rethoric is in use.

Arguably, government and the industry may have underestimated the total casualty and death rate which would follow from their actions and inaction. However, not even 'some casualty and death rates - meaning considered 'tolerable' - as a cost of doing business (in terms of subsequent financial settlements) are justifiable. All along the way, there was plenty of opportunity to change course and to influence the outcome in a positive direction. The problem was 'studied' by the Federal Government and 'bandaged' by Federal Minister Beatty with an Emergency Assistance Package in 1989.

There is additional support for the 'economic hypothesis'. The AIDS crisis (following the spread of hepatitis) signalled a decline of the traditional blood technology, and there was a need to develop recombinant technology to substitute for the older, hazardous plasma fractionation methods. This needed large research and capital investments and a ten-year period to build up the technology from design to production. Cutter (now called Miles Canada), the preferred supplier of plasma products to Canada, has this technology now, but did not have it in the late seventies and early eighties. Without sustained revenue protection throughout the eighties this might not have been possible.

I recall a comment by my former supervisor in the National Blood Transfusion Service of the Canadian Red Cross Society, Dr. Roger Perrault: *"You don't think that the government will let an X - billion dollar industry go down the drain!"* Like many of his remarks, I could not understand their meaning at the time, since I was not involved in the AIDS related decision making processes. Other ominous remarks were: *"The whole truth shall never be told"*; *"Once in a while we stumble over the truth, but most of us keep on walking"*, and *"After Stalingrad, the German industry knew that the war was lost. They just got on with planning the future"*. He repeated the last one many times. All of these remarks point in the direction of major engagement of the industry and government in the salvage of the industry. These remarks stuck in my mind at the time, since they seemed to carry some significance, but they did not make sense in the context of knowledge I had at the time: which was close to nothing with respect to AIDS.

I also discussed the threat to the plasma industry with Mr. Heisig,

President of the Austrian Hemophilia Society, and Dr. Braun, President of the German Hemophilia Society, on March 29, 1994. They both confirmed that the hypothesis of survival of the plasma industry applied in Europe as well and that 'dirty deals' had been made. (See DOC 46). Mr. Heisig actually told me that in a televised interview, a senior officer of the Austrian fractionator, Immuno AG, Dr. Eibel, admitted that this was the case. Mr. Heisig's response to him was, "*that is too bad, then you just should have gotten into something else*". In France, where the fractionation industry was a government monopoly, the medical officials were imprisoned for delaying issuance of a safe, heat-treated product and for delaying testing for HIV. (Ottosen, 1993:280). (Responsible politicians, up to the level of prime-minister, went free initially, on grounds of a statute of limitations, but have been charged recently).

The effectiveness of governments remains questionable to this day. For instance, in 1994 inspectors of the U.S. FDA - Food and Drug Administration - found that the Bureau of Biologics in Canada had inspected below FDA standards. The American inspection of blood centres in Canada took place because Canadian plasma is crossing the border to be fractionated in the U.S. It remains to be explained, why the FDA did not inspect in the early eighties, when the same conditions of operation existed. The phenomenon of this 'delayed inspection' is the strongest indicator that the links between the American and Canadian drug administration were far more profound than we will ever be allowed to know.

In 1994, in Austria, a blood product (Beroplex) had been quarantined by the Ministry of Health and was illegally subsequently shipped to hospitals. The company declared it to be 'a result of error by a

temporary employee.' (Vienna, Austria, *'Die Kronenzeitung'*, August 19, 1994; page 8-9). The response of the Austrian Ministry of Health was that *'the hospitals should have double-checked with the company'*(sic!) (government has learned something from the AIDS experience: to pretend that it is not responsible and to pass its own responsibility onto others).

In 1982, The Canadian Government had the information; the virus had entered the blood supply in the U.S.; latest during the fall of 1982 it was known to Dr. Gallo of the National Cancer Institute that it was probably a retrovirus - because it left a 'footprint' in white bloodcells - an enzyme called reverse transcriptase; see Shilts 1989:201-2). The Canadian government had the rationale and the means to avert the worst: all plasma product could have been recalled, hemophiliacs (with hemophilia A) could have been switched to cryoprecipitate, with loss of convenience only and within no added threat to their physical health; the use of blood and blood-products could have been restricted to emergency and life-saving circumstances; blood tranfusion for elective surgery could have been converted to 'autologous transfusion'. Three tests could have been used: 1) lymphocyte counts - introduced by Dr. Engleman at Stanford, CA, in May 1983 (Shilts 1989:307-309); a liver enzyme test (ALT), available since the sixties; and Hepatitis B core-antibody testing, available since 1976). In addition, a full education and self-exclusion program (not to attend the clinic, to self-exclude at the clinic, and to designate a donation for research) could have been implemented to protect what needed to be retained as essential supplies; and with good will and intention, a direct exclusions program by sexual preference could have been implemented, at least until more was known about the disease.

All of these measures could have been implemented on short notice, until further notice. The only obstacle that stood in the way of such measures were the financial losses of the blood industry, in particular the commercial sector. However, concerns over financial losses extended to the non-profit sector in the U.S. (See Ottosen 1993; see also Shilts regarding the Atlanta blood-banking meeting in January 1983 (1989:220-223), in particular Dr. Aaron Kelner's (of the Greater New York Blood Programme) position of 'unaffordability' of surrogate testing for the exclusion of blood suspected of transmitting AIDS). (His resistance was closely copied by the American Red Cross.)

There is no shortage of other explanations offered by the industry and by government, (such as 'scientific uncertainty', an unco-operative gay community, an unwillingness of hemophiliacs to surrender the convenience gained with the newer Factor VIII preparations). None of them are cogent or even relevant in comparison with the threat which the epidemic presented. Early measures would not only have prevented some infections, but they would also have speeded up heat-treatment technology for plasma products, which was already available from Germany since 1980, as 'wet heat-treatment', the most effective method of sterilization. The American industry started with 'dry heat-treatment' later, to avoid some activity loss of Factor VIII, which could have affected revenues. It had to switch to wet heat-treatment later and withdrew some dry heat-treated product.

All of the above mentioned measures were within the operating mandate of the Canadian Red Cross Society as an independent corporation and the primary and sole manufacturer and distributor of blood and blood products in Canada, regardless of the level of regulation exercised by the

Federal Government. As regulator, in a situation of a serious health-hazard from a drug, the Federal Government had the ultimate responsibility to ensure that the appropriate steps were taken, and if necessary, to order and enforce them. The Red Cross and the Federal Government cannot put the blame on each other, as both were independently in default.

The pharmaceutical industry is 'hiding behind the Red Cross and behind the Federal Government'. The companies were operating under separate licenses from the Federal Government, but were equally compelled to operate according to the Food and Drug Act and to ensure that the products which were sold were not unsafe for use. "Just because a speed-limit is not enforced does not mean that speeding is permitted."

The suggested interventions are not a matter 'hindsight', but a response appropriate to a situation which, in the governments own words, was a "*serious potential public health problem*" (see Appendix 2, entry for October 13, 1982). The 'hindsight' argument is particularly problematic, since the risks from hepatitis viruses were ignored before the AIDS epidemic was even in sight. The signing of the waivers by the victims to get their compensation packages is at least an indication that the possibility of civil and criminal liability exists from the government's point of view, the manufacturers and the insurers.

Since the hindsight argument has been used so extensively as a legal defence (and is being used again with respect to hepatitis C during recent testimonies), it needs to be given more detailed attention. The following is quoted from the 'Pitman case'. The plaintiff, Mrs. Pitman, was infected with HIV by her husband, who was infected by a unit of cryoprecipitate in November 1984). (Pitman Judgement, 77-78, DOC 12)).

"Counsel for the Plaintiffs argued that once it had been established by the Gallo announcement, that the causative agent of AIDS was a blood borne virus, it became a matter of simple common sense to screen out donors at high risk of carrying the agent. It would have been a simple matter, he says, to have immediately introduced procedures where every donor was asked directly whether he had sex with another man, and to have excluded his donation if he gave a positive answer. It would have also been a matter of common sense at that point not requiring scientific expertise, to distribute a form whereby a donor could confidentially indicate, without fear of embarrassment or identification, that his blood should be used only for research but not for transfusion. The implementation of such simple measures, and additional measures such as further donor education, written screening, privacy stations and surrogate testing, could have saved some of the lives then threatened by the risk of TAA (transfusion associated AIDS).

This is an attractive argument, particularly from a 1994 perspective. We now know with certainty that had some of those measures been implemented, lives would have been saved. It is natural from a 1994 perspective to feel that those whose lives were damaged because these measures were not implemented, should be compensated in law. The test, however, is to look at what those concerned knew in 1984, not what we know in 1994. It is imperative to avoid the temptation of evaluating measures taken or not taken in 1984 according to our knowledge today. In Lapointe V. Hopital Le Gardeur, supra, Madam Justice L'Heureux-Dube, for the Court, placed great emphasis on the importance of avoiding hindsight:

"Courts should be careful not to rely on the perfect vision afforded by hindsight. In order to evaluate a particular exercise of judgement fairly, the doctor's limited ability to foresee future events when determining a course of conduct must be borne in mind. Otherwise, the doctor will not be assessed according to the norms of the average doctor of reasonable ability in the same circumstances, but rather will be held accountable for mistakes that were apparent only after the fact. (at 362-363)

The importance of avoiding hindsight is critical in this case, which involves not only conflicting medical theories and practices, but also changing levels of knowledge and understanding of both rapid and controversial developments in medical and scientific knowledge. The procedures of the Red Cross should be reviewed and judged according to the state of knowledge as it prevailed at the relevant time and not at some later date when such knowledge has increased, advanced and developed: ter Neuzen v. Korn, supra, at 496; see also E. vs Australian Red Cross Society, 105 A.L.R. 53 (Fed. C. of A.) per Lockhart L. at 75."

My comments:

I would not refute the hindsight argument on the basis of a single case, or of a single procedure which may or may not have prevented infection. Rather, I am looking at persistent pattern of now almost 20 years (1976 - 1994), without there being a single instance when the blood system had 'erred' on the side of safety for the public (hepatitis B testing, warning of hemophiliacs of chronic hepatitis and liver cancer as possible sequelae from hepatitis B, warning of non-A, non-B hepatitis, switching from concentrate to cryoprecipitate, promoting autologous transfusion, effective self-exclusion program for donors, early implementation of effective selection procedures, recall of presumed infected product, warning patients of transfusion risks, earliest possible start of testing, surrogate testing for hepatitis C, trying to find transfused infected individuals). In every case the decision was to the disadvantage of the public, and when action was taken, it was still not on the basis of scientific proof and incontrovertible evidence! Thus the Pitman case needed to be argued in the context of the overall responsibilities of the players in the blood system. My specific comments are as follows:

- 1) The first lawsuit ever settled out of court in favour of a plaintiff affected by transfusion related AIDS was the case of Frances Borchelt, in San Francisco. She was transfused in November 1983 and died in 1985. (see Randy Shilts, 1989, passim. Mr. Pitman was transfused in November 1984).

2) The staunchest opponent of surrogate testing in the U.S., Dr. Joseph Bove (see also Chapter 7), became an advocate of surrogate testing in August 1984. At that time, AIDS had already become the leading cause of death amongst hemophiliacs in the U.S.

3) The people who embodied the 'state of knowledge at the time' in Canada, Dr. Roger Perrault, National Director of the Canadian Red Cross Blood Transfusion Service, and Dr. Davey, Assistant National Director, did not take the stand in this trial as witnesses for the Red Cross. They were the only individuals in the Red Cross who had the relevant and requisite international connections, in the U.S. and in Europe, to represent the 'state of knowledge'. (It was their job to know).

4) In May 1984, months before Mr. Pitman's transfusion-related infection, the state of knowledge was such that it was convincing enough for the diagnostics and blood industry to transfer ELISA HIV testing technology from the scientific lab to industrial engineering and production; and that the test was implemented by all blood banks in the U.S. within a year without proving that the test would actually diminish transfusion-related AIDS. The test was uniformly used in the U.S. by July 1985. (If the 'hindsight hypothesis' is true, then there would have been no compelling reason for the transfer of testing technology at a massive industrial level in May 1984).

5) The quotation (as well as other quotations used by Justice Lang) apply to clinical medical practice, not to a manufacturing operation. It is therefore totally irrelevant. From the perspective that blood and blood products were drugs it is also very dangerously distorting and misleading. The decision of the Red Cross (under orders or voluntary) not to screen donors, not to test, not to restrict the use of blood and blood products, and not to advise the use of autologous transfusion were not a matter of 'weighing medical risk and benefits' but purely economic decisions. If there is doubt - and again, there was no longer any relevant doubt - in a serious public health crisis, the public should expect that decisions are taken in the direction of their safety, not in the direction of possible damage, in order to find out how big the damage might actually become!!! Otherwise, it would be better to close Health and Welfare Canada, because that department may be the greatest risk to the public.

The Red Cross knew of a wide range of means, albeit not ideal, but affordable' and in no way putting the life of people at risk. It had a legal and moral obligation (not a choice) to minimize the risk to the public with these means - until better means became available. Thus the 'choice' was not between one risk (transmitting AIDS) and another (letting people bleeding to death), but between high risk of transmitting AIDS and low risk combined with some temporary inconvenience.

Unfortunately, the issue was never presented in this fashion. To apply ruling from precedents concerning clinical medical practice to a manufacturing operation is a caricature of justice, not justice.

The court decision was delivered a day before the deadline imposed on the victims for the signing of the waiver of civil and criminal claims in order to receive the provincial compensation package. They had no time to read, let alone analyse the judgement. Next to the Federal Government, the Red Cross and the pharmaceutical industry, the role and integrity of the justice system, as it pertains to medical practice and technology is a significant factor in the AIDS crisis, its aftermath and now in the inquiry. The following are examples of incidences which put in question whether the justice system serves the people or some other purpose:

- o The Pitman case (as discussed).
- o The non-application of the Food and Drug Act in the Pitman case.
- o The offer of 'bail-out by the Justice Department (see page 213).
- o Justice Krever, who held two important positions in the Royal Society project, as co-chairperson of the project and as chairperson of the committee on legal and ethical issues, did not recommend the tracing and notification of patients with transfusion related AIDS.
- o Commission counsel (M. Edwardh), being a criminal defence

lawyer, with a record of having successfully defended a former federal minister under criminal investigation; the public does not need criminal defence expertise, but prosecuting expertise. Since the Commission reports to Cabinet, perhaps the government needs criminal defence expertise, with specific experience in defending ministers.

- o The emotional blackmail of victims through deadlines and signing of waivers, in order to receive 'compassionate assistance';
- o The granting of standing before the Commission without funding to the only national organization representing hepatitis C infected individuals.
- o Upon request of the Red Cross, Justice Krever's threatened the cancellation of the National Hemophilia Society's standing before the Commission: because they had made public a hepatitis C study of the Red Cross which they had obtained through Freedom of Access to Information.
- o Justice Krever's announcement in a CBC Radio interview with Mike Hornbrook of the CBC: "that *we may never know who was responsible*" (which was quite prejudicial and unbecoming for a judge).

- o The early resignation of the intitial, experienced, RCMP investigative team, attached to the Commission of Inquiry. Within weeks they had established the Federal Government's failure to order a recall of infected product (see DOC 13). The excuse was an alleged dispute with the Treasury Department over compensation. The new investigative team was young and far less experienced.

- o Other examples:
 - . The protection of Sick Children's Hospital management through the 'Grange Commission' (DOC 26);

 - . The handling of the victims of Dr. Cameron's brain-washing experiments at McGill University (reference);

 - . The handling of the victims of thalidomide. (Presented as CBC documentary (1989) 'Broken Promises');

 - . Canada's record of handling Nazi war criminals; ('it costs too much');

 - . Government control of the RCMP fraud and corruption unit (Palango 1994: '*Above the Law*').

It should be noted that when the Federal Minister of Health Beatty dealt with the 'financial bandage' for AIDS victims, the thalidomide victims were dealt with at the same time (three decades after they had incurred the damage).

The government's default vis-a-vis the public complemented the actions of the industry. There was no need for 'conspiracy'. The elaboration of the 'prisoner's dilemma' and 'tit-for-tat' strategies (Axelrod, 1984) show that co-operation can arise without written understandings and without any verbal communication: by making decisions and taking actions (or choosing not to act) under the assumption of co-operation of the other party. In this fashion, if co-operation arises for less than ethical reasons, there is no paper trail or even a memory track of meetings or conversations. In the case of HIV and hepatitis, however, there is a paper trail of 'understandings' in the Federal Government. Three examples are given here:

1) From the Minutes of the May 15, 1985 Meeting of the National Advisory Committee on AIDS (advisory to the Federal Minister of Health, Mr. Jake Epp at the time).

Page 13: Considerable discussion took place whether the impact will be limited to "donors" or whether "recipients" could be included. Dr. Perrault [National Director of the Red Cross Blood Transfusion Service] felt that because the issue arose out of CRCS (Canadian Red Cross Society) screening, that 'donors only' should be adhered to but that the wording of the motion could involve recipients. Dr. Allen [from the CDC in Atlanta] pointed out that the issues regarding recipients of blood were very different from that of donors who produced it and agreed with Dr. Perrault that maybe the issue should be handled separately. Mr. Starkman [of the Federal Justice Department] indicated from a legal point of view major concerns may be related to donors but there was a growing swell of additional concerns on part of the recipients. [Consequently recipients were not included in the motion, which called for a consensus conference

which would deal with sociological, ethical, legal, medical and any other relevant issues regarding donors found to be HIV positive].

Page 14: A further motion was introduced by Dr. Perrault which read:

"that the Canadian Blood Committee be informed of the eventuality of non-insurability of the Canadian Red Cross Blood Transfusion Service in matters related to the issues of AIDS." The motion was seconded by Dr. Soskolne.

Dr. Wainberg wanted to know if this possible withdrawal of insurance had a more global approach than AIDS related issues. [e.g. hepatitis]. Dr. Perrault, however indicated, that the companies were prepared to take other risks. (!) Mr. Starkman [of the Justice Department] felt this was really a big problem and something should be started in the near future as far as discussions with insurance companies were concerned. He felt that such discussion would lead to some degree of satisfaction on the part of companies that insurance coverage continue but the possibility of government intervention might be an alternative methodology. ['Government intervention' methodology turned out later to be the so-called 'compassionate' assistance packages]. (The motion was approved).

A particularly hideous aspect of this discussion is that it pertained not only to victims who had been infected, but also to people who were about to be infected. This discussion took place in May 1985. The U.S. completed the implementation of the HIV test in July 1985. In Canada the test was not implemented until November 1985).

At the 8th meeting of the Advisory Committee to the Canadian Blood Committee on June 19, 1986, Dr. Perrault indicated that approximately 450 recipients of blood annually might be involved in a look-back procedure alone, which tracks recipients of all donations from donors identified as HIV positive. This kind of manoeuvring is clearly indicative of an intended 'cover-up', and serious liability concerns on part of the Red Cross, the Justice Department, also on part of the American counterparts, to the extent that insurance companies wanted to terminate current policies. A

disturbing part is that the *'industry was prepared to take other risks'*, which would have been, at the time, a continued contamination of the blood-supply with Hepatitis C. Apparently, future compensation of hepatitis C infected individuals was not planned to be granted.

2) In May 1987 Health and Welfare Canada commissioned the Royal Society to prepare recommendations on AIDS in Canada. The project was chaired by Mr. M. Chretien of the Institut de recherche clinique de Montreal, brother of the now Prime Minister Jean Chretien, and co-chaired by Justice Krever, sole Commissioner of the current Commission of Inquiry. Project manager was the current National Director of the Blood Program of the Canadian Red Cross Society, Dr. Aye. The report (published in 1988) implicitly estimates the number of transfusion-infected people. No action is recommended in the report to find them and to limit the spread of HIV to others. Justice Krever was also chairperson of the subcommittee dealing with legal and ethical issues. The study did recommend assistance to known infected individuals. In June 1988, the McDonald study was commissioned by Health and Welfare Canada, the results of which did not surface until 1992 (See Appendix 1). Effectively, every effort was made to delay the finding of infected individuals as long as possible. Ten years have now gone by, and hospitals can now claim that they no longer have the transfusion records, or that a search for transfused people would 'not be cost-effective'. (See Dr. Hutchinson, interview with Mr. Freise, page 157). The civil liability from not informing transfused infected persons who, in turn, infected their spouses or sexual partners was established by the decision in the Pitman case; it acknowledges liability of the doctors, the hospitals, and the Red Cross, but not of the Federal Government as regulator of

blood products).

3) In 1988 The Program Audit and Review Directorate of Health and Welfare Canada conducted a program evaluation study under the leadership of Dr. Overby. (*"Premarket Clearance of Drug Products, Technical Report no. 4. Program evaluation study of the Drug Safety, Quality and Efficacy Program. Health and Welfare Canada. November 30, 1988, revised April 19, 1989). Page 82:*

"Owing to the expense associated with the production of biologics products, the complexity of the production processes, and the potential for widespread health risks (foot note 171: particularly with blood products and vaccines, which tend to be used on a large scale) both the Bureau and the industry have mutual interests in not making mistakes. Discussions with Programme and industry officials and the absence of major complaints from other stakeholder associations suggest that licensed biologics products in Canada are safe, effective and of high quality [sic!].

Footnote 172: The Canadian Hemophilia Society (CHS) claims that 48% of Canada's 2300 Hemophiliacs have been infected with HIV, the AIDS related virus, through injections of contaminated factor VIII, a blood product. The study team had not met with the CHS; we first learned of this claim from press reports on March 22, 1989, too late for inclusion of this topic in our study [!]

The report gives the Bureau of Biologics a 'clean bill of health' and then had to cancel it in an added footnote later. The report of the Royal Society had been published April 27, 1988. It dealt with the hemophilia issues including compensation, but obviously had not been pointed out to the auditors. The audit team learned about the catastrophe from the newspapers in 1989. The fact that the Bureau of Biologics managed to keep the auditors' attention away from anything related to HIV indicates some attempt of 'cover-up' by 'programme and industry officials'.

An additional issue should be raised, one which I consider to be even more serious than the contamination of the blood supply itself. Dr. Bove, advisor to the U.S. Food and Drug Administration, by announcing authoritatively the risk of getting AIDS from a transfusion as '1 in million' - even in August 1983 (Shilts 1987:361), effectively minisculed the threat of AIDS transmission in general and fuelled the propaganda of bath-house owners and the supporters of the gay press. If the risk of catching an infection from a blood transfusion was 1 in a million, and at the time the average number of products transfused was between 3 and 5 products per patient, the probability of transmitting the infection would have translated into 1 in 3-5 million. At such a low level of risk, being gay would not have triggered an alarm. The same agencies (FDA - Food and Drug Administration; NIH - National Institutes of Health; CDC (Centre for Disease Control); American Red Cross; CCBC - Council for Community Blood Centres; AABB - American Association of Blood Banks; ABC - the American Blood Commission; and also the Reagan administration), which were involved in the contamination of the blood supply, were also the key agencies in the handling the AIDS epidemic in general and down-playing its significance (with the exception of the CDC perhaps). Thus the blood industry (advertently or inadvertently) may have influenced the handling of the entire AIDS epidemic. In other words, not only hospital patients, but also the gay population and the public in general may have been led into false security, received the wrong message or no message at all, for at least two years (late half of 1982, 1983, early half of 1984). Thus, during the most critical years, a golden opportunity to keep the spread of the epidemic to an unavoidable minimum was missed. We will never know how many hundreds of

thousands or even millions were infected unnecessarily because of the 'one-in-a-million' propaganda of the American blood industry. This may remain forever speculative. However, if one studies Randy Shilts' account, one can see how the blood industry story is woven into the spread of the AIDS epidemic. From an 'ecological perspective', and given the exponential spread of the epidemic (which was known), a small change in early policy direction might have made a huge difference later. This may be the most cruel consequence of the blood industry's 'gamble for survival' yet.

I am suggesting this possibility because I am not aware that it has been considered. It is virtually impossible to 'prove' it (a great number of the early victims have died and can no longer be asked), but the possibility cannot be excluded. It is important to make such propositions, as a warning that the 'unintended consequences' from 'a relatively small problems solved' (saving the blood industry) with disregard of important boundary conditions can generate an 'avalanche of problems' (perhaps millions of deaths), in particular when the models used in 'problem-solving' are economic and not ecological - in the broadest sense, as discussed in the introduction.

Worse than that, there is a good possibility that, instead of helping the gay community through a catastrophic and frightening period, their anxieties, panics and human rights preoccupations may have been actively exploited and used later as an excuse for not having intervened in a timely and appropriate manner. The role of the gay community in the AIDS crisis has been and is being used as a giant smoke screen.

Finally, if one compares the time tables of the American and Canadian activities surrounding the contamination of the blood supply, one can see

that, initially, the Canadian actions simply paralleled the actions of the American regulators. Later, additional delays set in. The delays in France had been 6 months (see Ottosen 1993). The delays in Canada were of approximately the same length for donor selection, in replacing infected product and in implementing testing. Surrogate testing to prevent the spread of hepatitis C in Canada was never implemented. The most difficult aspect to prove will be to show that this represented an opportunity to sell substandard (by U.S. norms) product in Canada, when it was no longer acceptable in the United States, without any intervention from the Canadian Federal Government. There have been such sales of product by Cutter (predecessor of Miles Canada, subsidiary of Bayer of Germany) to Costa Rica.

I would like to insert a personal opinion here. Having 'lived' in the blood system, or near it, for nearly 20 years, and 15 years in the Red Cross environment, I find it unconceivable that the Red Cross had the requisite orientation and the power to consistently operate against the best interests of the public, and that the regulator merely would have been 'looking the other way'. The Red Cross's actions or inactions could have occurred only if they were carried out under orders, under threat or under promise of reward (or under all three conditions), from authorities not only powerful enough to give the orders but also to enforce them and to deal with the consequences. These fundamental conditions have surfaced in France (which included the level of the Prime Minister of France). The possibility that the same thing happened in Canada cannot be excluded. The pattern of events and of the specific behaviours of the Health Protection Branch rather support this hypothesis.

That no paper trail of high-level direction and facilitation has surfaced so far does not diminish the possibility, in particular if one takes into account that a 'forensic audit' which had been conducted in the Bureau of Biologics prior to the Inquiry. The suppression of full disclosure of how the AIDS crisis was managed could be worse than the crisis itself. Non-discovery would establish precedent and methodology for continuation without risk to the perpetrators. Together with the ongoing manipulation of the issues of liability and 'reasonable regulation' (as the industry calls it), the HIV-hepatitis C scandal would then have resulted in a model of how to handle such occurrences, how to cover them-up, how to get away with it, and how to handle it even better the next time (with respect to liabilities of governments and the pharmaceutical industry).

This personal opinion is intended to be some measure of defence of the Red Cross - as an institution, not of its former or present incumbents. The National Office of the Red Cross, today, is populated with former federal employees or obedient followers of the Federal Government. The symbolism of the Red Cross institution and its emblem have been and are still being abused by the Federal Government and Miles Canada, masking their strategies and actions with the foremost humanitarian symbol. Additional data and discussions are provided in Chapter 7, in particular with respect to the North-America-wide cover-up and white-wash tactics and concealment of the truth, and the fabrication of 'simple explanations' for public consumption. This may extend to other industrialized countries such as France, Germany, Japan, etc., and even to the G-7 nations and antecedents of that alliance. This renders not only victims but also electorates almost powerless in most of these locations.

I would like to add that I have sent a letter to the editor of the *Globe and Mail*, in reference to a speech given to the Empire Club by the former Secretary General, George Weber (I had drafted the speech for him). In this letter, I am suggesting that the Red Cross has been 'hijacked' by the Federal Government and the pharmaceutical industry, and the Canadian people should kick both of them out. Of course I never received a reply. (DOC 48. 49).

Hypocrisy, Hippocrates or?

The following addresses euthanasia. It is not intended as an argument against euthanasia, but as demonstration of how well-intentioned medical policy initiatives become vulnerable to the contingent circumstances in which they are practiced. And further, that we may be moving along a trajectory of social (material) values which can pervert the outcome any number of such policies. The handling of the HIV crisis and the nature of the debate on euthanasia (not the occurrences themselves) can be taken as indicators of such tendencies.

Thus, on this general level, the current debate in Canada on euthanasia (the Rodriguez and Latimer cases) has become a growing concern for me: what was a crime in the Nuremberg context is in the process of being 'normalized' in Canada. (It has been 'normalized' in Holland). The following is quoted from '*Hitler or Hippocrates*' by Paul Hoedeman (1991:96-119), chapter on euthanasia.

From a math textbook for primary schools printed in 1935:

"Lunatic asylums cost the state DM 6,000,000 per year to maintain. How many working-class cottages costing DM 15,000 each could be built with this money?"

On 28 July 1933, the Minister of the Interior, Dr. Wilhelm Frick, gave a lecture concerning national and racial politics. According to Frick, from the standpoint of genetics, twenty percent of the German population was inferior and he also stated that these people's children were undesirable members of the Third Reich. He demonstrated that the cost to the state of...

"...all the insane, the mentally retarded, the ill and the criminal was, to his reckoning, on average of four and a half marks a day per person. However, uneducated workers and petty officials could, in most cases, command only two and a half marks a day".

From this fact, Frick concluded that Germany had to spend too much time looking after the social welfare of the individual, and that no account had been taken of the insights provided by genetics and studies of 'racial hygiene' and improvement.

In October 1939, Hitler drew up, on private notepaper, a decree, the so-called 'Erlasz', in which he empowered Bouhler and Brandt

"with the responsibility of enlarging the authority of certain physicians to be designated by name in such a manner that persons who, according to human judgement, are incurably ill, may, upon the most serious evaluation of their medical condition, be accorded a mercy death."

Dr. Menges (in his thesis on German Euthanasia):

"It is strange that such a radical decision, a state-organized mass-murder, should be set in writing on Hitler's private notepaper. Hitler decided, not as Head of State but as "father" of the German people; he wanted full responsibility for this rather share it with state authorities"

Dr. Walter Schmidt, later condemned to life-imprisonment, referring to one such meeting in February 1940:

"...The discussion then turned to the work we were expected to do - submitting medical opinions on institutional patients, that is mental patients. The other physicians assembled were all gentlemen of mature years, including some eminent figures, as I learned later. Since all these gentlemen consented without hesitation, I joined in this decision and offered many services as a consultant..."

Form letter for completed euthanasia:

"Dear....., It is with deep regret that we must inform you that, a patient in our institute, following a suddenhas passed away. Medical attention proved, alas, of no avail. It may be of some reassurance to you, however thatdied quickly and painlessly in his/her sleep. Considering the grave and incurable illness, death came as a relief.....Heil Hitler. (false name of the doctor)."

Dr. Brandt testifying in Nuremberg:

'But Dr Brandt, there were a large number of people who were weak-minded but non-the-less very happy? 'I do not believe that it is possible to suppose that a weak-minded person can be happy, nor that the life of a weak-minded person holds anything of any human worth. The deciding factor was the suitability of continued life'.

Again Dr. Brandt:

"It is possible, as has here been frequently claimed, that euthanasia has something inhuman about it. But this is merely an outward appearance and lies mostly in the application. Euthanasia was there to help the sufferer, alleviate the pain. These considerations can hardly be called inhuman, and personally, I do not find this unethical or amoral.

I am convinced that if Hippocrates had lived in our age, his oath would have been cast in a different mould.....If one wishes to make a judgement on euthanasia, one must first spend a few days in an institute for the mentally ill.....

I have just read a book in which it was stated that it had been possible to keep a child, who was congenitally insane and brain-damaged alive for three and a half years. The child had certainly cried for three and a half years, anyway I am sorry . but I cannot detect anything humane about this."

Under the Direction of Dr. Brandt 60,000 Germans were euthanized. At the Nuremberg Tribunals he was condemned to death and executed. According to Dr. Menges:

"Euthanasia presupposes a kind of treatment in which relief or prevention of suffering is of primary importance. The alleviation of fear and pain at a death bed, true euthanasia, is part of the daily work of a practicing physicians and poses no problem at all. But other forms of euthanasia (the withholding of drugs should complications arise during an incurable illness, passive euthanasia, and the curtailment of a prolonged illness, active euthanasia) require that the doctor concerned has a love for his patient and that he is honest towards the patient or towards his family.

With "Nazi euthanasia" none of this mattered. The patient's wishes did not count, only those of the State. There was no question of openness; bogus organization, the use of false names, disgustingly hypocritical letters, of condolence and even the misleading or the doctors concerned, ensured from the very beginning that a veil of deceit was drawn over the whole affair. The facts alone condemn Nazi Euthanasia and demonstrate that this was not so much a salvation but murder. (J.Menges: *Euthanasia in het Derde Rijk*, Haarlem 1972, p. VII.)

Bauman (1989) points out that it does not take conditions of the Third Reich to produce phenomena like the Holocaust or euthanasia. Menges' fallacy is an ecological one, in the context discussed in the introductory chapters. To uphold his thesis he must (tacitly) make a number of assumptions:

- 1) that doctors will always be guided by the highest ethical, unselfish standards;
- 2) that families will always be guided by the highest ethical, unselfish standards;
- 3) that there will always be an environment in which doctors and families will maintain their highest ethical standards;

4) that an individual can separate the compassion for the other from his her own suffering produced by the circumstance of the suffering other;

5) That what is best for society can be separated from what is best for the individual.

6) That Nazi Germany was unusual or an aberration.

All six assumptions are false. Having studied Dr. Brandt's history, I have no doubt that he meant what he said, which does not differ, in principle, in any way from what Dr. Menges said. There are only differences in methods and in the social circumstances in Holland and in Nazi Germany. I agree with Prof. Summerville of McGill University, that the risks of crossing the line of legitimizing the killing other humans are so horrendous, that it must remain a line that must not be crossed.

Hoedeman and Menges do not recognize that the main incentive for euthanasia and the Holocaust was the search for financial and human resources needed by the German industry for the war effort (consider, for instance, the movie '*Schindler's List*'). Hitler's 'mission and political program, spelt out in '*Mein Kampf*', were to mobilize and acquire these resources, such as: confiscating Jewish property, using Jews and others as cheap labor and expertise, by euthanasia, by asking the German people to surrender some of their assets ("*I gave gold for iron*", was the slogan used when Germans handed over their golden wedding band for bands made of iron); by retaining only 'productive people' (see comment on

Sandra Panem in Capter 7).

By labelling economic arguments as 'economic determinism' (anything that is unwelcome to analysis can be derogated as 'determinism' or 'essentialism'), economic aspects of human ecology may be left dangerously ignored. Yet the driving force in Nazi Germany was corporate interest, the driving force in the AIDS crisis was corporate interest as well. Any kind of political party or movement can be used to create the desired economic conditions for corporate interests. It then depends on the party or movement in power and their ideological platform to choose the requisite rationalizations: racism, euthanasia, eugenics, but also IQ, full employment, 'social contract', 'globalization', 'human resources' etc.

If we consider the circumstances of the contamination of the blood supply described by the victims in Chapter 8, then none of the above assumptions can be accepted as true with any degree of security. In principle, the rational choices which were made are similar to those made in Nazi Germany (perhaps more cleverly and deceitfully disguised - 'spin-doctored'). The new and added danger is that the corporate interests are no longer national but those of transnational corporations (as was the case in the 'blood industry'), which have no loyalty whatsoever to local populations.

I am suggesting here that the circumstances surrounding the contamination of the blood supply, including the full co-operation of the Canadian intelligentsia (barring a few dissenters) during the crisis, during the cover-up and during the Inquiry, resemble the conditions of Nazi Germany. An elite which made the contamination of the blood supply possible can also make a rational discussion of 'rational criteria' for euthanasia possible -

and vice versa. The post-modernist deconstruction of 'hegemonic values systems' may have started with noble intentions. When all values are deconstructed all at once, anything becomes possible. Feyerabend's "anything goes" means that anything goes. This, in combination with transnational corporatism, as it was and is still being played out in the contamination of the blood supply, should have been a rude awakening. Unfortunately, it will be thought of as an 'aberration' - like Hitler's Germany. The dangerous concurrence of late modern corporatism with postmodernism is perhaps epitomized by a ceremony given for the British philosopher and political theorist Isaiah Berlin. He was a key resource for some former Communist states on their road to capitalism. He was given an honorary doctorate by the University of Toronto on November 24, 1994. Conrad Black and Barbara Amiel then gave a dinner in his honour. Amongst the invited was an 'admirer', Bob Rae, Prime Minister of Ontario. The reporter, John ALEMANG, summarizes Berlin's capitalist vision as follows: (*Globe and Mail*, November 25, 1994, page A11).

"Capitalism may be wicked, it may be oppressive, it may be exploitative, it may be vulgarizing culture and destroying moral values, but there is more freedom in it, more variety, more self-expression".

He is anti-Marxist and abhors the nightmares of Maoism. But:

"For all that Marx fascinates him as does Hitler, Mao, and anyone else who connected ideas with events on a huge scale. For someone who has made a life out of political theory, Mr. Berlin is intrigued by the great men of politics. "A great man", he has said, "is a man who gives history a turn which it could scarcely have taken without him".

Isaiah Berlin has given history a turn - for the better".

Under such tenets euthanasia could be seriously considered, and the contamination of the blood supply would be a normal, to be expected occurrence. Perhaps Berlin has discovered that postmodernism is at least in part a late-modern by-product of and in part a resource for corporatism: corporatism has no longer a need to be visibly coercive. And that might have earned him an honorary degree from the University of Toronto. He also has provided the crowning explanation for the contamination of the Canadian blood supply. If the contamination of the blood supply itself is not a wake-up call, this ought to be.

6 Letter from Dr. Hershfield

This is a Letter to the Editor by a Professor of Clinical Medicine from Alberta (June 6, 1994, Globe and Mail):

"It would appear that we are going to witness another barrage of lawsuits related to the transfusion of blood and the transmission of yet another viral disease - hepatitis C. What about the other unknown disorders that may be transmitted - disorders that are yet undiscovered such as hepatitis D, G, ad infinitum? Does this mean, when confronted with a patient who is bleeding to death, and I deal with many of them, I will attempt to reverse the shock and organ failure with infusion of water and herbs? There is no treatment that is without possible side-effects - even the lowly Aspirin can kill you. Blood-transfusion has saved countless lives, and has allowed the miracles of modern surgery to be accomplished.

Certainly, becoming ill from treatment, be it blood transfusion, surgery complications, or a drug reaction, is tragic. But think of all those hemophiliacs whose lives were prolonged beyond our wildest dreams even 20 years ago. Think of all those transplants that were accomplished with expansion of quality of lives - totally impossible without the technology of transfusion of blood and its products. I for one do not buy the argument that the tests for AIDS (or hepatitis C for that matter) were available or accurate enough at the time to be reliable, and I think this will be clear as the Krever inquiry proceeds.

It is of interest that the great American Arthur Ashe did not even countenance blaming anyone for his transfusion-acquired AIDS. He simply moved on and used his not inconsiderable talents to further the research into this tragic disease and also to fight for the principle of equality of all races in the world. He did not even consider suing anyone - he was thankful for his 'Days of Grace'." (N.B. Hershfield, MD, Clinical Professor of Medicine, University of Calgary)

I do not know for sure if Dr. Hershfield prescribed any blood or blood products which resulted in hepatitis or AIDS. Chances are that some of his patients contracted hepatitis C, something he has to come to terms with, on a personal level and on a level of possible litigations. As I have

implied earlier, I do not include prescribing physicians as a group to be held accountable for having infected patients - with one exception: when they prescribed blood and blood products unnecessarily. Unnecessary treatment or medication cannot be justified (after due consideration of the 'hindsight ruling', see page 205; DOC 12). The risks of infection with HIV was minisculed by the blood industry, and the risks of infection with hepatitis viruses were never communicated by the blood banking establishments, other than to say that this matter 'was under study' (Feinman 1988, Blajchman 1994).

I am not aware that patients are ever given a complete, detailed and quantitative explanation of all the possible (and reported) side-effects of any treatment or medication. (In Austria, patients who buy their drugs at the pharmacy would get a 'specialty package' with an insert which lists all known risks side-effects. A typed summary is given to patients in Canada). I am suggesting, therefore, that hospitals and prescribing physicians, were entitled to assume that the risk associated with products received from The Canadian Red Cross Society was indeed miniscule. With respect to the hemophilia treaters, I have suggested that they were misled, deceived and quite frankly, set up as scape-goats by the responsible agencies. They were led into decisions which were never theirs in the first place. (see Appendix 1, *passim*).

All hospital physicians in the country (and the public, of course) should have been informed and directed by the Health Protection Branch. The ruling of negligence by Judge Lang against Dr. Bain (Pitman vs. Dr. Bain, DOC 12) became possible only because the duties and responsibilities of the Health Protection Branch were not invoked in the trial, and he was

left to his own judgements and advice received when it never should have been a matter of his judgement. (Dr. Bain withheld the information on infection with HIV from Mr. Pitman). Personally, I consider this to be a miscarriage of justice. As it stands, Dr. Bain's case is an example of 'scape-goating'. It is also an example of a justice system which protects the status quo (or 'steady-state') of an elite in power. (See also the examples of the influence and abuse of authority in Chapter 2, pages 141-142). One also has to take into account the opportunity for manipulation of 'causality', if damages arise from omission.

Dr. Hershfield's letter must be seen in this context. Given the pretext and precedent of the Pitman ruling and the modus operandi of medical-industrial-political networks, he may find it difficult to resolve his own conflict with available 'superficial' rational explanations. 'Left in the dark', he resorts to deeper, symbolic, archetypal adaptations for himself to make sense of his life-world to which he suddenly finds himself 'unadapted'. Partially decoded, his letter reads as follows:

The medical establishment is being victimized by the people who were infected; Western medicine is heroic and therefore effective; alternative medicine is not heroic and therefore not effective; Western medicine consists of 'miracles' (not science); the hero is also a miracle worker; the 'dragons' can be slain, but a few by-standers may be killed by the 'dragon's death-throws'; blood transfusion is the elixir which makes the surgical miracles possible; dying from side-effect is destiny ('tragedy'), not the result of human engineering or intervention; scientists have had 'wild dreams' for the

last twenty years; some scientists do not buy rational arguments and facts, but rather myth; the Krever inquiry is expected to produce and reinforce such myths; victims of side-effects should do their duty for the 'cause', even if they have to die; thereby they can also become heroes, in particular if they get the elixir for the survival of science - research funding; having done this, they should die gracefully and gratefully. (Approximately one million men died, 'heroically', in Napoleon Bonaparte's service for nothing, he called them 'cannon-fodder', but he still is a hero). Medical people are larger than life, demi-gods almost, and therefore they can legitimately transcend the conventions and norms of the ordinary people.

The 'heroic motif' seems to emerge whenever a person has violated a societal norm, rightly or wrongly, knowingly or unknowingly, in the conduct of his or her duty - in particular when 'authority' does not accept its share of responsibility. An alternative is the 'victim motif', the 'defeated, powerless hero', when authority is perceived or constructed as overwhelming. A third alternative is the 'obedience motif', when authority is ostensibly at fault and held accountable. (All three motifs appear in the movie "*A Few Good Men*".) I believe that these are profound, archetypal 'survival' adaptations to situations of profound dissonances of the 'guilty mind' (regardless whether the 'guilt' is rational or 'irrational'). The ultimate adaptation (and 'healing'), or maladaptation ('scarring', etc.) may depend on the initial archetypal response. The heroic motif has clearly emerged in the Latimer euthanasia case, the victim motif is extensively being used by the blood establishment ('defeated heroes in face of over-

whelming natural forces'). The 'obedience motif' emerged in various testimonies of medical directors who felt compelled to follow 'policy'. Dr. Hershfield's 'myth construction' is ambivalent, as he finds himself also being 'victimized' by infected patients. This ambivalence aggravates his dissonant experience. His response - that those damaged should just be happy that they are still alive, that they should join and support the heroes, and then die quietly - is abusive: I referred to this kind of 'inner ecology' as 'psychopatho- or sociopathomimesis'.

Note: In writing my own autobiographical account I had to be careful not to become trapped in this sort of 'counter-victimism'. I also had to avoid a tendency to transform a sense of counter-victimism into a pseudo-heroic narrative. I hope I managed to explain that my troubles came mainly from my own inadequacy and ignorance, and from deceptive circumstances which I could not or would not interpret as I should have (see Appendix 3). Apart from the occasional, more or less accidental 'heroic intervention', nothing heroic happened. I was stuck amongst the 'dragons and alligators', and did not even recognize them. However, once the 'helpers' appeared on the scene, I could recognize some of the 'reptiles'. Having lost my own blindness and denial, I was able to continue my journey (the 'helpers' are mentioned in the acknowledgement). Having said that, I have to admit that, at times, while I was working in the Red Cross, I had the idea of doing heroic things, without realizing that I was a fool. I have been labelled as 'court jester' by some of my former colleagues; but I could not read the 'king's messages; see page 200). Consequently, I was a 'fool of a different sort'. (For the interpretation of the 'hero's journey' used here see Campbell 1968).

My own experiences, Dr. Hershfield's letter, and the reading of Joseph Campbell's account of mythology leads me to believe that myth-formation is a fundamental adaptive process which makes individual and collective atrocities against other human beings tolerable and an acceptable element in an individual's or a society's narrative (the collective adaptive myth construction is discussed in Chapter 3). If this is not or only

partially possible (as in the Holocaust, or in Dr. Hershfield's account), any truthful account may be declared to be a 'distorting myth', a kind of nefarious, misleading, exploitive public relations strategy used by victims who are not really victims but enemies or even demons (example: the Holocaust being constructed as a fabrication of Zionism).

As a 'rational account', Dr. Hershfield's letter does not make any sense. As a 'symbolic narrative', it does make sense: it has potential healing powers and reconstitutive powers of homeostasis for those who believe in the myth. Such myths have no healing-power for many of the victims, of course, not so much because of what had happened to them, but because such expressions of the 'guilty mind' (in particular of those in power) add insult to the physical damage. While the myth construction may be partially successful for the events of the early eighties, no suitable myth can be invented for the spread of hepatitis C.

If myth construction is an inevitable 'inner ecological' response - and it appears to be just that - the disclosure of 'truth' should precede the construction of 'reality' (the kind of every-day world people wish to live in after they put the truth behind them), so that the memory of the past truth can be preserved and invoked to serve as a precedent for those who have no memory of the truth.

I would suggest then, that if the 'whole truth of the contamination of the blood supply' is not told, the myths created around it will remain offensive (and it does not matter how many semioticians are put to work): the wound will never heal, or it will get worse, and in any case, humankind will have learned nothing. It is left 'unadapted'. Worse even, it may have learned the wrong lessons, and thus become 'maladapted'. The 'inner

authentic' must be allowed to express itself in the 'publicly accountable' (see Appendix 3; see also Campbell on the 'suppressed gods which become demons', page 166), if necessary, against the instructions of legal counsel. In my deposition to the parliamentary subcommittee in spring 1993, I implied that the best possible truth is more important than the punishment of the guilty (DOC 45); I also suggested that 'Royal Commissions', like the Grange Commission in Toronto, are more apt to conceal the truth than to reveal it; therefore they are a waste of time and public money. Besides, such commissions appear to be 'coolers' for agitated public opinion, and they tend to 'find' or 'discover' what already has been decided, strategically, much earlier.

7 The 'Medical Semiotic Jungle': 'Networks', 'Secrecy', 'Human Kaleidoscopes' 'Spin-Doctoring', 'Consensus' etc.

1) 1987- The year of publications

In 1987, Sandra Panem, then Program Officer at the Alfred P. Sloan Foundation, prepared a report on the way in which the American bureaucracy handled the AIDS crisis: *"The AIDS Bureaucracy; Why society failed to meet the AIDS crisis and how we might improve our response"*. It was published in 1988 by Harvard University Press; the copyright is held by the "President and Fellows of Harvard College". In the same year, 1987, Randy Shilt's book *'And the Band Played on'* was published. Also in 1987, The Centres for Disease Control in Atlanta, in conjunction with the University Department of Medicine, Royal Infirmary, Glasgow published "Blood, Blood Products and AIDS". Randy Shilts reports on the May 1987 AIDS conference in Washington:

"On the conference program was a seminar offered for blood bankers about how to defend themselves in blood transfusion lawsuits. The seminar speaker was an attorney of the San Francisco Irwin Memorial Blood Bank, recently the first blood bank to make an out-of-court settlement with the family of a transfusion victim. The Borchelts had been on the way toward probably winning a huge jury award when Irwin decided to settle. In an odd twist, the Borchelt family lawyers had tried to subpoena Don Francis to testify, having heard of his

frustration with the blood industry. In the end, the U.S Attorney filed a petition on behalf of the Federal Government in Federal Court, blocking Francis's appearance; it simply would have been too embarrassing for the government.

In 1987, before the opening of the conference, Don Francis was approached by the WHO to work in Africa on AIDS. (He had to leave the CDC - Centres for Disease Control in Atlanta.) He had worked in Africa before, but it seems that there was interest at the international level to remove him from circulation. At the conference he was an 'unknown'. In 1986/87 I accused the Red Cross Board of 'unethical decision-making' while I was already under severe pressure to quit. In spring 1987, I was offered the opportunity to work for the Dean of McMaster University. Suspecting some kind of foul-play, I declined later in the year. In 1986/87, the contamination of the blood supply had become a serious litigation issue, and the contingency plans for this circumstance which, I believe, were conceived between 1982 and 1984 were put into action. This included a purge of those people who might have been willing to testify against the system.

Dr. Francis's story is the main strand of Randy Shilts's multi-stranded account. His name is not mentioned in the other two aforementioned publications. When I talked to a person in Toronto who had been working closely and confidentially for Dr. Perrault, former National Director of the Canadian Red Cross Blood Transfusion Service until 1990, about Dr. Francis, the response was "*Who is Don Francis?*". Yet, by then, Don Francis had testified in the Pitman trial in Toronto, he had been on Canadian national television in 1992, and he was the main character depicted in the movie "*And the Band Played on*".

2) Networks: Dr. Donald Francis, Harvard University and the Sloan Foundation

Harvard University played an early role in AIDS, as Dr. Don Francis of the CDC raised the viral hypothesis as early as June 16, 1981 with his former mentor at Harvard, the animal virologist Dr. Myron Essex. In December 1981, Don Francis realized the similarities in the epidemiology between hepatitis B and AIDS. On March 3, 1982, he concluded that the AIDS agent would be transmitted via blood products. On July 13, 1982, Dr. Jim Curran, one of Don Francis's co-workers at the CDC, at a symposium at the Mt. Sinai Hospital in New York, reported that there was evidence that the AIDS agent had entered into the blood supply and that the spread was similar to Hepatitis B. In January 1983, Don Francis tried to convince the American blood-bankers to use hepatitis testing as a surrogate test for excluding blood donors who might have been carriers of the AIDS virus.

On May 12, 1982 Don Francis approached the doctors, who were treating AIDS patients at the Sloan-Kettering Institute to get to work on AIDS, because they had one of the few retrovirus laboratories. (The Sloan Foundation finances cancer research, and through leukemia and related diseases is also greatly interested in hematological research and transfusion therapy.) Dr. Francis never heard from them again. By December 1982, Dr. Gallo of the National Cancer Institute had clear evidence that the putative agent was a retrovirus - and he stopped his research. He only started again after Dr. Montagnier of the Pasteur Institute had made headway with his AIDS research. The Pasteur Institute moved well ahead of Gallo and reported on the isolation of the virus (LAV), for the first time,

in February 1984. Dr. Gallo had been working with the theory that AIDS was caused by a leukemia virus, although all the evidence pointed to the opposite, that the virus was destroying white blood cells, not making them proliferate. Later in the year, when Dr. Gallo began to promote his 'discovery' of the AIDS virus (HTLV III), Don Francis got into serious trouble by telling the American press that the French had discovered the virus, not Dr. Gallo. (Randy Shilts believes that this and other encounters with Dr. Gallo were the deathknells for Don Francis's career.) (Note: this summary is based on a number of entries in Randy Shilts's account and can be tracked by the names and dates provided).

3) 'Scientific rivalry and secrecy'

The central question in Dr. Gallo's story is why he dropped the research when he had evidence of retroviral activity; and when he started again, why, as an experienced researcher and with an opportunity of earning a Nobel Prize, he would direct his research against all common sense. Sandra Panem refers to a chronology of the Montagnier-Gallo controversy which was published in *Nature*, 326, 2 April, 1987: 435-436. This must be seen in the "1987 - litigation context" described above. The publication appeared the same year as Randy Shilts's account. The account was prepared with the help of and advice from Dr. Jonas Salk.

"This statement from Robert Gallo and Luc Montagnier constitutes part of the agreement between the U.S. and French research groups.

This history is by no means exhaustive. It outlines the main contributions of the two central parties and of some other groups to the determination of the causative agent of AIDS (acquired immune deficiency syndrome). This is not to diminish the important contribution made in this field (either independently or in collaboration with us) by other laboratories and clinicians distributed world-wide.

Both sides wish it to be known that from the beginning there has been a spirit of scientific co-operation and a free exchange of ideas, biological material and personnel between Dr. Gallo's and Dr. Montagnier's laboratories. The spirit has never ceased despite the legal problems [!] and will be the basis of a renewed mutual co-operation in the future". [France had not used the American test-kits, because the French test kits were not ready! At the time of this communique, France had accumulated its own mountain of liability problems]. (Panem 1987:153-154; my comments in square brackets).

None of the information which was made available to Randy Shilts by Donald Francis shows up in Panem's account or in this published history. According to the 'official' account, there would have been no scientific rivalry. Sandar Panem summarizes the scientific rivalry issue as follows: ***"The biomedical research establishmentwas criticized for slowness in its response to the crisis and for reliance on a peer review system whose incentives may encourage personal ambition at the expense of the overall scientific effort [not at the expense of the public]".*** In the main text she discusses the institutional history of research in the U.S., but does not comment. However, with respect to the media (without which none of the serious issues would have ever seen the light of day) she becomes explicit: ***"how the media contributed to the politicization of the crisis, thus exacerbating it."*** (Panem, 1988:5)

Panem briefly discusses the secrecy surrounding health research, for

the protection of 'trade-secrets' (Panem 1988:110-117). She stays away from the implication: that the same rationale for secrecy can be easily extended to unethical or even criminal practices. Secrecy for competition's sake is a horrendous risk for the consuming public, since competitive pressure does not just lead to better products. It also leads to short-cuts and compromises on safety.

The French scandals of not using American tests kits shows how closely science and business interests are linked and how deeply competitive 'trade secrecy' reaches into 'scientific rivalry'. David Suzuki is blunt about this when he refers to '*the prostitution of academia*'.

"Across Canada, universities are rushing to become part of the industrial enterprise, as faculty are being encouraged to become entrepreneurs who exploit the discoveries for profit. There have been few objections to or questions raised about this process," and "Let me be specific by considering one of the hottest areas of applied science - biotechnology - genetic engineering or organisms for commercial purposes. Biotech companies have been sprouting up on campuses like mushrooms. In a number of international meetings held at universities to discuss the future of biotechnology, none has seriously considered the potential misuse or hazards of technology. Surely an academic community of scholars who maintain an arm's length relationship with vested interests of society should be expected to raise those questions. Who else will do it". (Suzuki 1991:73-78).

The following two statements (of mine) are central and important to the contamination of the blood supply, although no direct connection can be shown:

Throughout the contamination of the Canadian blood supply and its aftermath, the Canadian scientific community has not raised a single question.

In 1993, Dr. Henry Friesen of the Medical Research Council of Canada and Judy Erola, President of the Canadian Pharmaceutical Manufacturers Association announced that the pharmaceutical industry had pledged one billion dollars for biomedical research in Canada.

How can there ever be any scientist in Canada raising the questions which David Suzuki is referring to? And is there a single reason, why one should trust anything that any biomedical scientist is saying, if one considers the number of scientists (after due deduction of capital and administrative costs) a billion dollars can buy?

Canadians should be wary of the uncritical push to increase the links between university academics and private industry because there are unacceptable "costs". (Suzuki, 1991:78)

'Pushing' means nothing until those who are and have been 'pushing' are identified. A number of individuals who may be or might have been amongst the 'pushers' were close to the events surrounding the contamination of the blood supply. Most of the individuals in the 'medical-political kaleidoscope' have been shifted: the network patterns are different, many of the individuals are the same.

Justice Krever was co-chairing the Royal Society Report and is now heading the Commission of Inquiry; Dr. Gilmore, Chairman of the National Action Committee on AIDS (NACAIDS) is now working at the Institute for Medicine, Ethics and the Law at McGill University; Mary-Anne Lark, former National Director of Nursing of the Canadian Red Cross Society Blood Transfusion Service has been now working for Miles-Canada (verified 1994); M. Begin, who was Federal Minister of Health in 1982 and 1983 is Dean of the Faculty of Health Sciences at Ottawa University; Dr. Denise Leclerc-Chevalier was Executive Director of the Canadian Blood Committee between 1983 and 1988 and is now Dean of Pharmacy at the University of Montreal; Dr. John Bienenstock, who was Chairman of the Scientific Advisory

Committee (renamed later Blood Services Committee) of the Canadian Red Cross Society in the early to mid-eighties, became Vicepresident of the Medical Faculty of McMaster University; Huguette Labelle, President of the Canadian Red Cross Society in 1982, 1983 is Chancellor of the University of Ottawa (she no longer includes her Red Cross engagement in her publicized resume); Dr. Roger Perrault, former National Director of the Canadian Red Cross Society Blood Transfusion Service, is now President of a lobby group of the biotechnology industry (lobbying for what is called 'reasonable regulation'); former Federal Minister Judy Erola is President of the Canadian Pharmaceutical Manufacturers Association; the writer of the Royal Society report, Dr. B. Aye, assisting then Dr. Michel Chretien and Justice Krever, is now National Director of the Canadian Red Cross Society Blood Program; George Weber, National Commissioner and later Secretary General of the Canadian Red Cross Society is now heading the League of Red Cross Societies in Geneva; former Federal Minister of Health B. Bouchard is Ambassador to France (there are major French pharmaceutical interests in Canada; and the French investigation of French ministers and their involvement in the French AIDS scandal may also be of interest; not to mention issues of Quebec sovereignty); former Minister of Health J. Epp ended his political career and did not become Lieutenant Governor of Manitoba - but Manitoba will have one of the largest virus banks on the continent; Doug Lindores, formerly working for the Privy Council on matters of 'privatization', is now Secretary General of the Canadian Red Cross Society; Dr. Boucher, formerly working for the Bureau of Biologics of the Health Protection Branch is now working for the Canadian Red Cross Society; Dr. Gail Rock, formerly Medical Director of the Ottawa Blood Centre

of the Canadian Red Cross Society, is now employed by the Health Protection Branch of Health and Welfare Canada; Dr. Peter Gill, working formerly for the federal Laboratory Centre for Disease Control (LCDC) is now working for the Canadian Red Cross Society. Dr. Roslyn Herst, former Deputy Medical Director of the Toronto Blood Centre and serving on the Medical-Scientific Advisory Committee of the Canadian Hemophilia Society is now Medical Director of the Toronto Blood Centre.

4) "Conspiracy" = "legal strategy" (or in reverse)

Corporations and governments do not 'stumble' into quagmires like the contamination of the blood supply and seek legal advice after the fact. The main investment in legal departments is not for litigation, but to define to what extent litigation can be avoided. I would propose with confidence that, latest in 1982, when the CDC made its announcement as to the possible contamination of the blood supply and infection of hemophiliacs, legal departments, risk managers, publications departments went into high gear. (The industry had learned earlier lessons, such as those from the thalidomide scandal). More specifically, the legal preparation of corporate and government strategy can and will establish what a corporation or government department can get away with. If litigation, as a result of such planned action is predicted to be unavoidable, the litigation cost can be estimated. This puts the 'health consumer' at a tremendous disadvantage, because the corporate case preparation has been done long before the first suit is ever filed, with reasonable prospects of winning. In the case of the contamination of the blood supply, one must at least assume that the legal

preparations aim for understandings between the industry and government. Finally, since the commercial plasma industry consists of transnational enterprises, several governments needed to be engaged in such strategies. International understanding, or at least acquiescence, was of paramount importance. France was in a unique and eventually more risky situation, because the government owned the French blood industry.

The arguments of Judge Lang, in her decision in the Pitman case in Toronto points to such a 'preparation' and the strategic use of the law and precedent decisions (DOC 12). The case was not even argued under the Food and Drug Act but under the Sales of Goods Act. (Counsel of the Pitman family has still to come up with an explanation why the Food and Drug Act was not invoked, and why the complaint did not include the Federal Government.) A tiny hint of Federal Government interference might be that Dr. Gail Rock, former Medical Director of the Ottawa Blood Center, who was fired in 1988 by the Red Cross and was one of the most important witnesses for the Pitman family, was listed by Judge Lang as being retained by the Federal Government to advise on transfusion related drugs. It is not clear however, if she was already manoeuvred into some kind of conflict at the time of the testimony.

The case cannot be analysed in detail here, but a few summary comments regarding precedent setting can be made (the issue of 'hindsight' was discussed in Chapter 5):

- 1) The Federal Government, as 'protector of public safety', was not called into the witness stand;

2) All witnesses for the Red Cross appear to be 'credible witnesses';

3) All witnesses for the victims appear to have 'credibility problems'; (courts only accept 'respected expert opinion');

4) Only established standards of care and practice (i.e. used under routine conditions) seem to be admissible in emergency situations;

5) In matters of scientific complexity an agency needs to act only according to one of two respected bodies of opinion; there is no third concern of risk to the public from such controversy; if there is no consensus, the courts should not concern themselves with such controversy.

6) In Canada, in cases of civil liability, the plaintiff must establish substantial connection between inaction or action and injury (this does not apply to the Food and Drug Act, which was not invoked).

7) It was up to the Red Cross to weigh the risks from infection against risk from having to cut back the blood supply. The Red Cross appears to be protected in this by the 'hindsight ruling'. (Of course, weighing the risks was the job of the Health Protection Branch, not just the Red Cross's).

8) If a practice by an entire industry is injurious, a participating accused agency or company may be excused.

The implications are :

1) All of these considerations, which were used by Judge Lang to exonerate the Red Cross, could have been readily anticipated by the industry and the Justice Department. There was little legal risk, if the conditions for giving rise of such considerations could be created or maintained (such as the condition of lack of consensus, or consensus, or lack of credibility of potential witnesses for the plaintiffs).

2) The line of argument would change in a criminal context.

3) The line of argument would change under inclusion of the Food and Drug Act and the mandates of the Health Protection Branch. Only then can the matter be argued as a matter of 'public health hazard'.

4) Management of public safety by consensus may protect the health managers but not the public: consensus protects them from liability as a result of injurious action; lack of consensus protects from liability as a result of omission of necessary action. In my opinion, this constitutes a double jeopardy for the public.

5) 'Lack of communication'

The following are Randy Shilts's entries regarding Dr. Bove:

December 10, 1982: Dr. Joseph Bove, who headed the FDA's blood advisory committee and served as an officer of the American Association of Blood Banks, went on network television to say flatly that there was still no evidence that transfusion spread AIDS. (The CDC had made public that hemophiliacs and a baby probably had transfusion-related HIV.)

January 4 1983: Dr. Joseph Bove, Director of the blood bank at Yale University Hospitals and chair of the FDA advisory committee on blood safety, joined in those objections. "We are contemplating all these wide-ranging measures because one baby got AIDS after transfusion from a person who later came down with AIDS and there may be a few other cases. (In 1982 6 out of just 100 hemophiliacs in Ohio were dead of AIDS and 3 more were suffering from severe blood problems associated with the syndrome).

August 1, 1983: "Even if - and it is still a big if- a small number of AIDS cases turn out to be transfusion related, I do not believe that this can be interpreted to mean that our blood supply is contaminated", said Bove. (In July the first wife of a hemophiliac in Miami became known to have contracted AIDS from her husband).

January 26, 1984: In a January essay in the New England Journal of Medicine, industry spokesperson Dr. Bove wrote, "Whether the disease is caused by a transfusion-transmitted infectious agent is still unknown and will continue to be until further data are gathered and the agent is isolated...Patients should be assured that blood banks are taking all possible steps to provide for safe blood transfusions." (By then AIDS had become the leading cause of death amongst hemophiliacs in the United States.)

March 1984: Industry spokesman Dr. Joseph Bove told the Wallstreet Journal "that more people are killed by bee-stings than by transfusion AIDS." (The first two adult cases with AIDS having received blood from a donor who was suffering from AIDS had been identified.)

September 1984: Dr. Bove, who had led the opposition to blood screening for surrogate AIDS markers, was so shaken by the unfolding statistics that he was shifting views and was arguing for FDA regulations to require hepatitis B core antibody screening. When the FDA advisory panel on blood products considered the issue again during the summer, however, other blood industry spokes people prevailed and Bove's arguments were rejected. (The first cases of AIDS in both wife and infant child of a hemophiliac had been reported; as many as 69 percent of the most severe hemophiliacs were infected with HTLV-III, later known as HIV).

All along it had been clear that surrogate testing had a good chance of eliminating donors without overt AIDS, and that the long interval period would result in a time-lag before transfusion related cases would show up. The hemophiliacs had been infected much earlier, because of their product being pooled from tens of thousands of donors.

Sandra Panem (1988:23) defends Dr. Bove:

Bove's skepticism toward official pronouncements was the result of a dearth of information. To implement a policy change he needed to be convinced more than what seemed to be isolated instances of blood contamination....At the August 1983 congressional hearings, Bove testified that he had learned only in the morning that the CDC was regularly supplying information to the National Hemophilia Foundation. "But the three major blood collecting organizations have not received that information. Now I have learned that it is available, I will see if I can get it; but why did I have to learn it here this morning in this way?" (page 97/8) At the August 1983 congressional hearings held by Weiss, Joseph Bove, representing the American Association of Blood Banks, registered the preoccupation of his industry. Asked what was needed to quell the public fear, Bove replied: "Information, sir, information..we need an ongoing and open line of information from the CDC".

Bove expressed the frustration of the blood banking community, as well as the apprehension of the general public. But he did not comment on the evident irony of the CDC's changing the free distribution of the MMWR - its main information channel - to subscription sales, in order to comply with budget cuts. This change took place in October 1982.

Sandra Panem does not comment that, why when free distribution of the CDC's communique had been discontinued in October 1982, Dr. Bove did not even notice until August 1983. If he was not aware that it existed before October 1982, he would have been negligence as chief advisor to the

FDA on blood safety, in particular when he availed himself to the national media. Perhaps he was not willing to listen to the CDC, and rather went along with the prevailing intentions of the blood banking industry. After he did get the information from the CDC, it took him another twelve months to be 'convinced'. Sandra Panem's analysis is a poor attempt at 'white-washing'.

The real question, of course, is what were the higher FDA executives doing to protect the public (who would have been subscribers to the CDC publication), since Dr. Bove was only an advisor. Besides, the Hemophilia Scientific Advisory Committee was stacked with interests of the blood industry.

Sandra Panem tries to paint a picture of 'poor communications', 'bureaucratic bungling' and budget cutbacks. In his functions as executive of the American Blood Commission, as chairman of the FDA Advisory Committee, and as Director of the Yale blood bank, Dr. Bove was right at the "cross-roads of information of blood banking information flows". Dr. Bove may have been set up as 'patsy' for the industry. He may have realized it in September 1984. By then the first trial test kits for HIV had been manufactured, and Dr. Joseph Bove's 'usefulness' had come to an abrupt end.

6) A 'failure of society' (?) (a phrase from Panem's book-title)

"In 1986, after more than one million Americans had been exposed to the AIDS virus and more than 10,000 had died of the disease, there was little doubt that AIDS constituted an emergency" (Panem, 1988:147).

Why would there be any doubt, even a 'little'? Why would anybody have any doubt at all, when 5,000 had died and half-a-million Americans were infected? This quote is taken from Panem's '*Proposal for a Novel Health Emergency Plan*' (Panem 1988:146-149). Apparently her own 'internal-ecological' threshold for 'emergency' is extraordinarily high, lacking 'empathy' and 'compassion'. In the same chapter she suggests:

"...But the most attractive (!) body to draft such a plan is an independent national commission. Such a commission might be convened by the Secretary of HHS [Department of Health and Human Services] (with the President's mandate) and represent the interdisciplinary skills needed for effective crisis management of novel health emergencies. The commission would be non-partisan, operate in public view, and be prepared to issue an independent report.

Among the planners should be representatives from Congress and HHS, state and local officials, and health professionals representing the three parts of the health research establishment..."

She is saying that the same, or the same kind of individuals and institutions which made the emergency happen would be the most 'attractive' ones to plan for the future. Not for a moment does it occur to her that the million of infected Americans still alive (which by now may have grown to several millions, if hepatitis C is included) may have something important to say, and may not want to be constrained to 'viewing' the construction of a 'new and improved citadel' of the health establishment.

Apparently, in Panem's 'inner landscape', society is constituted by those 'planners' (including herself). Those infected, dying or dead do not belong; they are a source of revenue or revenue lost:

"Figures abound in the press that estimate the costs of AIDS on 1986 alone to be at least \$10 billion. But what of the cost of productive years lost to the economy by the death of thousands of

young Americans? Improving the national response to an epidemic such as AIDS by means of an emergency health plan is cheap at any price."

We are valued by 'Panem's society' if we are productive. It does not occur to her that the thousands of young Americans dead might have been happy just to live. If society (not in Panem's sense now) 'fails', it is because it can no longer recognize the sociopathic nature of 'Panem's society', which produces and reproduces such pronouncements, as well as the 'Panems' required to make them.

7) From 'concealment' to 'spin-doctoring' to 'total fabrication'

Over the past decades, I watched the assassination of President Kennedy in several movies. I always saw the spray coming out from the back of his head, which means that he was shot from the front (which of course flies in the face of the Warren Commission report). I also recall a prominent coroner indicating that the 'original Kennedy corpse' had the back of the head blown off, to the extent that there was little brain left in the cavity.

Now, on the '20th Century' series shown on the '**Arts and Entertainment**' channel, somebody came up with a filming of the assassination, in color, where the spray comes out in front (there is a small pinkish plume). Also, a drawing of the back of the skull with a neat little bullet-hole in the back is shown. The head of the President is very difficult to

see, because the figures are so small. The whole thing looks simulated, or electronically manipulated. Somebody must have alerted the American Medical Association, which endorses the Warren Commission report, that something needed to be done about the 'spray'. After the spray demonstration, the movie shows a multitude of theories which prompt the narrator to indicate that we may never know what happened. Anybody who did not grow up in the Kennedy era would find it difficult, if not impossible, to evaluate this movie and would be left entirely ambivalent - and suggestible.

The Commission of Inquiry on the Canadian Blood System leaves the public with an incomprehensible mass of conflicting information (so far half a million pages have been produced). And Judge Krever said publicly that we may never know who was responsible.....

Cyberspace, virtual reality and textual manipulation may not so much lead to social psychosis through simulation and atomization. Rather they have the potential to be used for 'virtually' impenetrable, total fraud of global dimensions. The makers of the 'Piltdown skull' were very much ahead of their time. But that was meant to be a 'practical joke'.

8 Accounts of Victims

In this chapter, five accounts of victims and their families are presented. The source material varies from account to account (for an overview, please refer to the chapter on methodology). Each account has been extracted and summarized from the respective source material and includes significant verbatim quotes. Verbatim quotes are presented in italics, my occasional comments are in square parentheses. After the case presentation, salient issues are summarized and discussed in the context of the theory presented in the introductory chapters.

Jerry and Marlene Freise

These data have been extracted from a document submitted by Jerry Freise as Chairman of the HIV-T (Transfused) group (DOC 2). Mr. Freise is not infected himself, but his wife is. The circumstances surrounding the discovery of his wife's infection and the experiences following the discovery led him to become an activist, first as active participant in the Canadian Hemophilia Society and its Chapters, and later, frustrated by the procrastinating attitudes and inaction of the Society, as leader of an independent break-away group as of March 1993.

The summary and quotes are based on a document *'Silent Partners; Canada's Blood System and the failure to notify those who received HIV contaminated blood product: A personal perspective and statement of fact.'* It was prepared for and presented in part at the Krever Inquiry.

Marlene Freise received blood transfusions during treatment of ulcerative colitis in November 1982. She received four units. The third unit was later identified as HIV contaminated. To-date, Jerry Freise has not been able to obtain the hospital charts and to verify the necessity of this transfusion series. [Personal communication from Jerry Freise]. At the time of transfusion, they had one son, Jordan. Marlene gave birth to a daughter, Whitney, in February 1988. In November 1990 they applied for life insurance. On January 7, 1991, the insurance agent called Jerry and told him that his wife had a 'contagious disease' and her application had been refused. Jerry's policy was refused, unless he was willing to move out of the

house and, effectively, break up marital relations. It took several days before the insurance company (Confederation Life) released the information to the family physician of the Freises, who told them that Marlene was HIV-positive, most likely from the blood transfusions she had received in 1982. The following is quoted verbatim:

"Our world fell apart. It did not take long to realize that Whitney, our daughter, almost 3 years old, born in February, 1988, was very likely infected also. It was still possible that I was infected due to the window period of testing [for several months after infection the antibody to HIV may not be detected, although the blood may already be infectious].....The best way for me to describe the feeling is to relate the image that I felt that our whole family was pushed and held under water and we had to find a way to the surface. I now knew that Marlene was infected, Whitney might also be, and I was exposed to the HIV-virus for all those years without knowing it. Suddenly, all our plans for the present and future and all the hard work in the past seemed meaningless as we dealt with this threat to our lives and our family.....Now we were facing a horror that was beyond our comprehension and we had no known way to deal with the overwhelming consequences."

Daughter Whitney was later found to be HIV negative. In May 1991, the Freises heard of a HIV-T support and information service, a function provided by the Canadian Hemophilia Society and funded by the Federal Government. There they met other people who had been infected. Most of them had found out about their infection by accident. Jerry and Marlene chose to bring legal action against the Red Cross. Consequently, Jerry was not able to talk to the Red Cross directly. When he tried to, he was told by his lawyer that he had been instructed to advise Jerry to restrict communication to his and the Red Cross' lawyers.

What followed was a struggle to initiate a public inquiry into

what had happened, an initiative to notify infected people and to obtain some compensation. This process, which involved several letter writing campaigns and media appearances, stretched from mid-1991 to late 1992. By November 1992 Jerry and Marlene finally had an opportunity to testify before a subcommittee of the Standing Committee of Health of the federal legislature. After one year of exchanging letters, Dianne Poole, M.P. of the Ontario legislature, who had been fighting for the cause of the Freises inquiry, still wrote on April 9, 1992: *"...Two senior provincial cabinet ministers have privately and publicly stated that the Government will not give more recognition to those who have tested HIV positive as a result of a contaminated blood supply."*

In trying to get funding for the discovery of infected people, Jerry turned to the Federal Government directly: *"On May 10, 1993, I called Mr. Brian Bell, Director, Health and Welfare Canada, Programs Division, to simply inquire about the possibility of funding for the HIV-T Group. He indicated that "the Federal Government is not, at this time, interested in pursuing trace-back issues".* The government was apparently still buying time, because, as Dr. Hutchinson had indicated in a televised interview (see below) that hospital records were only kept for 10 years or less; time was getting close for all records from the early eighties to expire and to be legitimately destroyed.

These are only two typical occurrences in 35 pages of references describing Jerry's struggle with various bureaucracies at the federal, provincial and municipal levels, but also with the Canadian Hemophilia Society, which did not want to bring the issues before

the public. Given the role of the Canadian Hemophilia Society described in the government document (see Appendix 1), this is not at all surprising. The attitude of the agencies involved in the contamination of the Canadian blood supply is best represented in a response given by Dr. R. Hutchinson, Chairperson of the Canadian Blood Agency, the body which is composed of provincial representatives, and which recommends blood budgets to the provincial ministers of health. Dr. Hutchinson spoke on the Patrick Conlon CBC talk show of November 28, 1993 with Jerry Freise and Mr. Doug Lindores, Secretary General of the Canadian Red Cross Society present:

"I think that the tone of the media's approach towards the blood situation has been pretty sensationalist. I think we should have some compassion for the men and women who tried, in a very difficult situation, with inadequate knowledge, in a very new, almost science fiction type threat, to make the blood system safe in the early 80's. They did their best. We've learned a lot and I think, rather than looking for blame, or vindictiveness, or vengeance, we should be concentrating on what we can learn, how we can make our system better. There are lots of things we can do to make it better. We've got a marvellous system now, that, as I said, has never been, in the history of blood transfusion, safer and, yet, public confidence is gone. Now that's a question that the media has to answer. Where has it gone and why?" [Jerry does not list any comment that would be compassionate vis-a-vis the infected people. There have been very few compassionate remarks regarding the victims throughout the Inquiry on the Blood System in Canada.]

Jerry Freise recorded the attitude of the Canadian Hemophilia Society as per remarks made by the past President of the Society on November 19, 1992:

"While the HIV-T Group had joined with Hemophilia Ontario to call for a public inquiry into the blood scandal, it

was reported in the Toronto Sun of November 19, 1992 that "Health Minister Benoit Bouchard says he'd welcome an inquiry into Canada's HIV-tainted blood scandal - if he thought it would turn up new information. I would not hesitate for a minute if it would help. But what would it give now - the answer is nothing. There's no reason now to have an inquiry". Mr. Bouchard said his department has contacted the "major stake-holders" in the issue and was told by some hemophiliac support group that they don't feel an inquiry is necessary. On the same day I called K. Little - President of CHS regarding the Toronto Sun article and his reasons why they are not supportive of an inquiry. I indicated that while we were out in front calling for an inquiry, CHS [Canadian Hemophilia Society] is giving the Federal Minister of Health cause to refuse. Mr. Little indicated his concerns for CHS backing an inquiry and explained them one by one: 1) concerned about harming existing relationships with the Red Cross and other agencies; 2) is concerned a public inquiry could hurt chances of compensation; 3) apathy among members; 4) CHS were put in a reactive mode by document leaks without fore notice; 5) is concerned re: liability issues on part of CHS; 6) is concerned re: cost to CHS of a public inquiry, i.e. legal and staff time and effort; 7) is concerned re: relationship to the Red Cross in setting up a fractionation plant in Canada. [Mr. Little resigned soon after; personal communication, Jerry Freise].

The Freises received federal compensation (Emergency Assistance Package), but they declined the provincial package which was offered in 1994, because of its inadequacy and because of the waivers of criminal and civil litigation.

Discussion:

External ecology:

Iatrogenic infection

In the summer of 1982 it was known to the Federal Government, the

Canadian Hemophilia Society and to the Red Cross (and we must tacitly assume, to the commercial fractionators who held the biggest stake), that AIDS was a deadly, exponentially progressing epidemic which had spread into Canada, and that there was good reason to suspect that it had entered the blood supply. (Shilts, 1988: 131-132 and *passim*; in June 1982 the CDC held a meeting in New York where the characteristics of the epidemic, its disease markers and the possible spread into the blood supply were discussed; see also Appendix 1.) On July 15, 1982, the Centres for Disease Control had reported 471 cases of GRID (the old name for AIDS) in 24 states, 184 had died. Jim Curran of CDC gave an interview to this effect to the Washington Post on July 18, 1982. As of July 13, the CDC knew of 4 cases of immune-depression in hemophiliacs, one of them suspected in Montreal. (Around the same time more than 100 million dollars were spent to investigate the cyanide-lacing of Tylenol). The first positive connection between blood donations and transfusion AIDS had been made on October 30, 1982 (as had been expected by the CDC).

The sensible response to such a threat would have been, as an interim measure, to put the entire blood supply on emergency supply, to switch to safer therapies (cryoprecipitate was the logical alternative for hemophiliacs), until more was learned about the epidemic. Instead, the industry decided to continue business as usual, until more was learned about the disease. In the U.S., where blood centres depended on revenues from the sale of blood, there was a strong economic disincentive to react (see Ottosen, 1993, *passim*). In Canada, there was no such disincentive (except for the American suppliers of plasma fractionation product). Switching to emergency uses would have saved money. In fact, there was never any restriction on the use of blood throughout the crisis, except for

new cases of hemophilia. At the same time, of course, all transfused patients were already exposed to a known residual risk of being infected with Hepatitis B and a known risk of being infected with hepatitis non-A, non-B (later known as hepatitis C).

Marlene was infected in November 1982. It has not yet been established whether the four units given over three weeks were essential and 'life-saving'. She could have been kept on low hemoglobin levels, as red blood-cells adapt to blood loss metabolically and thereby enhance the ease with which oxygen is released to the body tissues. The public had not been made aware of the exponentially spreading epidemic and the potential dangers from blood therapy.

Iatrogenic infection, that is the propagation of an infection by medical treatment, is not a new phenomenon in Western medical culture. The most notable example were the post-partum infections of women hospitalized for delivery in the 19th century, which eventually led to 'antisepsis'. After World War II, a large number of Viennese women who had been raped by soldiers of the Russian Arm. after the fall of Vienna had contracted syphilis. The widely held belief is that they had been promised to the soldiers as 'spoils of victory'. Some months after treatment of syphilis they came down with hepatitis, which was then shown to be caused by the repeated use of injection needles without sterilization (similar to the 'sharing' of needles amongst intravenous drug users). The link between needle use and hepatitis led to the obligatory heat sterilization of needles and, later, to the use of disposable needles. This example shows that the medical profession, on earlier occasions, had been prepared to take measures, although the infectious agent had not been identified and was not

identified for another 20 years. There was no scientific proof, but the association was deemed strong enough and the threat to the public severe enough to warrant a change in the culture of medical practice. One of the excuses, which is repeated over and over again by people responsible for the contamination of the blood supply is that there was no 'scientific proof at the time'. If one accepts this argument, then it would not have been the AIDS virus but a perverted application of the concept of 'scientific proof' which killed the transfused infected people! This is even more troublesome than economic motivation, because one may be more likely inclined to distrust economics than science.

Despite all that knowledge of transmissibility of viruses via blood, the risk of transmission through blood transfusion had always been discounted, mainly because much of the blood was used in serious, life-threatening situations (hemophilia, leukemia, trauma, intestinal bleedings, etc). Thus blood was used in the 'heroic domain', the 'frontiers' of medicine, where 'desperate measures were taken' to 'save lives'. In the sixties, doctors themselves were part of this culture: I remember one of my professors of pathology bragging that he had infected himself with all three types of hepatitis (A, B, non-A, non-B). A considerable number of my colleagues contracted hepatitis B, one ended up with chronic liver disease, and my own professor of gastroenterology (who had participated in the original syphilis-hepatitis study) died from a subacute form of hepatitis B within twelve months. I infected myself during research into transfusion-related hepatitis B, and I remember feeling quite 'heroic' about the whole affair. With the discovery of the hepatitis B virus around 1970, the 'heroic age' had come to an end. By 1980, this would have been no longer a meaningful explanation and other cultural explanations have to be sought. The

heroism', however, is still ringing through Dr. Hutchnison's argument in the television interview.

Non-notification

Marlene, like many others, was not informed that she was at risk of contracting HIV (or other diseases, for that matter, like hepatitis) when she was transfused, nor was she informed after the transfusion. Unknowingly, she had put her husband, and later her child, at risk. The disclosure of her status and her husband's risk occurred in the most callous way imaginable, eight years after the fact and not through initiatives of any of the responsible agencies. Not so much the shock of discovery, but the subsequent total unwillingness of the responsible agencies to do anything to find infected people and to prevent the spread of infection, prompted Jerry Freise to take the matter to the public. In this context, the issue of the 'health-care system as epidemiological vector' became a matter of public interest.

Suppression of suffering and mediated public display of suffering and 'reverse victimization'

Jerry Freise's case is paradigmatic for the suppression of knowledge, the suppression of suffering, and attempts at suppressing the display of suffering (such as attempts to prevent a public inquiry). Without Jerry's and a few others' campaign little might have happened, all records might

have disappeared and hardly any evidence would have been left. The non-notification can only be reasonably explained as an economic ploy in the overall ecology of the contamination of the blood supply. Since the approximate number of infected people was known, cost of litigation could be estimated as well as ways of avoiding such costs. Cost avoidance could have arisen from the death of transfused people from causes other than HIV and from death from HIV itself. Whether 'intended' or not, with every passing year during which the extent of the damage could remain hidden, money was to be saved. Even the length of the current Inquiry, which is to last for more than two years, contributes to cost-avoidance, as remaining court cases have been effectively stalled.

Jerry Freise's account points to the Federal Government (at the Cabinet level), the Red Cross, manufacturers and the Canadian Hemophilia Society as the main sources of suppression of an inquiry and public exposure of the events and consequences of the contamination of the blood supply. By the fall of 1992, the media had taken up the issue and began to display victims and their plight. The reaction of authorities and the medical profession has since been one of 'counter-victimism' (see letter from Dr. Hershfield - Chapter 6 - and Dr. Hutchinson's response to Jerry Freise). This form of 'victimism' is routinely used by politicians, whenever a damaged segment of the public attempts to display their suffering in public. This creates a significant ambiguity in the public mind, resulting in suggestibility permitting the insertion of simple and misleading explanations. (See also the 'cycle of meaning', Chapter 1).

Note: this phenomenon of 'counter-victimism' was an important critical consideration in the matter of the allegations of sexual harrassment. (See Appendix 3). I had to go through a careful analysis of all of the events. I needed confirmation from other sources.

I could not rely strictly on my own recollection to reach the conclusion that I had been targeted. I also had to face up to and account for my own contributions and indiscretions. Thus I had make sure not to trap myself in 'counter-victimism', before I could let the scales tip in favor of outright deception by the other party.

The creation of ambiguity was also accomplished by the Red Cross' repeated insistence on 'balanced reporting' by the media, under the pretext of 'protecting the blood supply'. From time to time positive reports on the Red Cross appear, however the Red Cross has never responded specifically to any specific allegations of the victims. The most powerful strategy of creating ambiguity has been the claim of ambiguity surrounding the early phases of the AIDS epidemic itself. Another strategy of ambiguity is the Red Cross' claim, after having failed to suppress an inquiry through the Federal Minister of Health, that it 'welcomes this inquiry' (after having been one of the 'stake-holders' not interested in an inquiry, as per Benoit Bouchard; this is my own recollection of Benoit Bouchard's televised response to the request of a public inquiry).

Up to this point, the media have avoided analysis of the contamination of the blood supply and have restricted their writing to event reporting and rather superficial editorials. However, there have been hundreds of victim accounts published over the last two years. In conjunction with the testimonies given to the inquiry, it can be assumed that the victims have had a significant impact on the public perception of the blood scandal. The degree of the impact has been recently disclosed by the Red Cross: a quarter of Canadians surveyed would rather not have a transfusion, and another forty percent or so have doubts. In the summer of 1994 the Federal Minister of Health spoke in the legislature to the matter of protecting the blood supply, when U.S. inspectors of the FDA

(Food and Drug Administration) cited violations in Canadian blood centres according to their inspection standards. The inspections were continued during the writing of this thesis.

Inner ecology

'Blind faith in the system' and rupture in the cognized life-world

Jerry Freise's description of his life prior to the discovery of his wife's HIV status is one of security, balance, homeostasis, and some transformational plans regarding their future, a good match between the expected and the actual, or at least the absence of dissonances severe enough to induce any degree of reorientation. At the time of Marlene's transfusion, there had been no signs noticeable to the Freises that this security might be at risk. In the absence of notification by the Red Cross and lack of media-reporting on transfusion-related issues there was no 'external stimulus' which might have resulted in questioning their state of security.

The discovery constituted the first profound rupture of the life-world of the Freises. The rupture was widened by the fact that those who would have the role of the shaman in our society appeared to be hostile instead of supportive. In a sense, the shamans had become 'sorcerers' and there were no other humans to turn to for remedy. At this point the ordeal became a symbolic process, enacted in the process of seeking a public inquiry. The Freise's became their own symbol and their own shamans at the same time. (Jerry described it as an extremely distressing process.) His attempts to receive some 'symbolic injection' and interpretation from the

CHS failed, as that group, from an apparent guilt induced by real or perceived collusion in the contamination and in the cover-up, had lost its 'healing power'.

It seems, however, that it is not sufficient or not feasible to be one's own ritual, symbol and shamanic interpretation. I would suggest that the cycle of meaning was filled with new content: court proceedings and the Inquiry as ritual, a community participation through the media, symbolic injections (guilty verdicts, or scape-goating, as in the case of Dr. Bain in the Pitman case). The main problem is that the 'appointed' shaman, Justice Krever, is part of the 'sorcery'. Worst of all, he reports to the 'chief' as per Order in Council. The ritual does not permit emotional expression (lawyers are not allowed to plead). The sought-after symbolic act may not occur (prevented by a wall of lawyers and public relations specialists; the explanations are constructed by the same people who caused the damage).

The 'guilty mind'

On the other side of the issue are people who are confronted with a situation which threatens to deligitimize their authority. One can thus expect that they will attempt to reconstruct their own cycle of meaning. There is a severe dissonance between the shamanic 'ought to be' and the damages which were inflicted. The first attempt to silence the dissonance was a 'cover-up' and, later, the offer of compensation. The waivers put most of the 'neglected gods', at least temporarily, in chains, but not all of them (see reference from Campbell, page 166). The inquiry is now the only ritual available to the victims to let those 'gods rise as demons'. Since the Commissioner appears to be a 'friendly shaman' (who may on occasion shake

the hands of the doctors, but never the hands of the victims), there is some comfort to be had from him, and some expectation that he will let these demons rise with vengeance. Unfortunately, this is not in his terms of reference: the 'shaman' may not be a shaman at all.

Some symbols have been injected, such as 'heroic medicine'; fighting the forces of darkness of unpredictable nature (see Hutchinson, page 257). The interpretation and healing arises from new technologies and new legal contexts, which will eliminate all future 'demons' (i.e. side-effects of medical treatment).

The Inquiry is a corrupted ritual for the victims, as it really serves to 'heal' the guilty minds of the violators, not the victims. The Inquiry seeks to strengthen the status quo of power relations, whereas the victims are seeking a transformation of power-relations. A ritual cannot serve two contradictory purposes.

It would appear that the proposition of the cycle of meaning being a neurocognitive universal (not its content) is supported by the experiences of the Freises. It further supports the notion that the sign-ordered rational systems of civilization are inhibitive of the processes to unfold. The more they are used to solve the problems which they have created in the first place, the more problems are created and the worse the dissonances become. There may come a point when the elites of this civilization will resort to their ultimate rational intervention: crude force. (In response to the revelations on the Hepatitis C study by the Canadian Hemophilia Society, Krever has already threatened that he may shut down standing of a group before the Commission. He has effectively established that the Commission is not established to help the victims, but that victims' counsels are there to help him, forgetting that it was the victims

who brought the Commission into existence in the first place. See editorial of the Globe and Mail, October 18, 1994.)

The first most significant neurognostic process in situations of severe suffering is the emergence of the 'cycle of meaning' towards a kind of new homeostasis. When suffering was inflicted, the second most significant phenomenon is the emergence of ambiguities induced by the 'guilty mind', which preserve ongoing suggestibility. The third significant phenomenon is 'hyper-rationalization', as exemplified in Mr. Little's arguments as to why there should not be an inquiry. The construction of very complicated rational arguments seems to be an adaptive process which occurs when the rational order has run into serious contradictions with the 'ecological order' and damages cannot be concealed. This adaptive response is not oriented towards avoiding future damages, but towards avoidin future incrimination. Currently, there are lawyers, bureaucrats, public relations people, ethicists working on the construction of new systems of rational arguments which would make future incriminations virtually impossible.

There is some indication that these efforts are becoming more and more confused, or serve to confuse. The Toronto Red Cross had stored samples of donations from 1984 and 1985 and was forced by Gerry Freise's group, with the help from Dr. Powell, to test them. The advice of the ethicists was that the positive results should not be reported to the donors, because the donors had not consented to the test, and that notification would constitute a human rights violation. This was intercepted by Dr. Shabbas of the Provincial Ministry of Health, who insisted on notification. (Jerry Freise and Dr. Powell, personal communications). The Canadian AIDS Society (CAS), unseccessfully, sought a court injunction to prevent

notification. The CAS is appealing. The Canadian AIDS Society is thus, knowingly or inadvertently, protecting Justice Krever, the Federal Government, and the Red Cross, who were engaged in the suppression or avoidance of notification of transfused-infected individuals. From a public health point of view, there cannot be one rule for infected blood donors and another rule for infected patients. The CAS is thus contributing significantly to a process which confuses the issues for the public, and provides a smoke-screen and argument of defence (legal-political difficulties, with respect to human rights) for the responsible agencies. The general public good becomes undefinable. I suggest that this kind of confusion puts the public at further risk.

The question of empathy

In personal discussions Jerry Freise told me that the worst stress is not being able to understand what had happened, or why it happened. It was not until he was pointed to the various commercial interests in the blood business and other circumstances, that things began to make sense and he began to feel some relief. Key to any successful healing ritual is 'empathy' in the sense of 'understanding'. If empathy as the fundamental 'organizing principle' in the alleviation of human suffering is compromised, the healing process may be corrupted and lead to further 'pathology'. Since the empathy of the commission seems to be misdirected, i.e. towards the protection of the 'guilty minds', the chances for the Inquiry to be a successful healing ritual are virtually nil.

The Ottosen-Swain family

Note: This account is based on the book by Joleen Swain Ottosen *"The Blood Conspiracy"* (see Ottosen 1993). She may have had some problems with the title, as 'conspiracy' is a much maligned term. On the North-American continent this is mainly due to the traumatic experience of McCarthyism, and later, to discredited attempts by journalists to make some sense of the Kennedy assassination while the records of the Warren Commission are kept under lock for 75 years. The 'antidote-term' to 'conspiracy' is 'witch-hunting'. Judge Kever said at the opening of the inquiry that '*there will be no witch-hunting*'; the same term was used by Justice Grange in the 'Grange-Commission'; see DOC 26. I myself have used the term 'cover-up' in public, which does not address what is being covered-up, but which does imply an understanding or agreement to keep incriminating evidence from public awareness. The term used in the French trials is 'collusion'. It does imply some decision made by individuals in power which had been harmful to the public and were subsequently covered up.

'Conspiracy theories' are played down, not because conspiracies do not happen (after all, intelligence services are there to 'uncover' conspiracies); but they are not supposed to happen in government, other institutions and amongst people in power (which is the most likely place where conspiracies are happening). This falls into the rubric of belief systems which are maintained by elites to stay in power. 'Conspiracy', in the generic sense of the word, that is secretive action planning, can, like anything else, be used and abused (as 'business strategy' in a good sense

or as criminal conspiracy in a bad sense); it can be used in reference to the uncovering of harmful strategy, or it can be abused in reference to witch-hunting or scape-goating a vulnerable and innocent group. It is self-evident from the amount of information which is emerging from the Krever Inquiry that some of the events of the early eighties were indeed covered up during the late eighties.

Many important decisions are not made in formal meetings but in what is known as an 'informal decision making and consensus-alliance building processes'. Formal meetings generally ratify what has already been decided or agreed upon. Very rarely are such informal decisions overturned or yield a split vote. The informal decision-making process leaves no paper trail or voice trail. I myself have been frequently involved in 'secret', informal decision-making processes. There need not be criminal intent or outcome from secretive understandings to render them harmful.

This brief excursion into 'conspiracy theory' was necessary to protect the credibility of Joleen Ottosen's work, which has to be understood in the 'conspiracy' context as outlined. Her book was endorsed by Donald Francis, the CDC physician (Centres of Disease Control in Atlanta) who took a stand against the establishment and eventually had to leave the agency (see Chapter 7).

Joleen's father, Orville Swain underwent cardiac by-pass surgery on January 3, 1985, during which blood from 18 donors was used. Neither he nor his family were informed of the transfusion risks. It appears that, by the end of February, he fell ill with Hepatitis B, which remained undiagnosed at first. He never felt well again

thereafter. In June 1985, Jonathan, the two year old grandson of Orville's brother, was diagnosed with AIDS. He had received five transfusions in March 1983, in the wake of a premature birth and streptococcal infection. By Christmas 1985 Orville's wife Ora (Joleen's mother) came down with 'flue-like' symptoms and never felt well again. The family doctor looked for everything except AIDS. In January 1987, Orville was finally diagnosed with chronic hepatitis B and cytomegaly virus (CMV) infection which had begun to affect his eyesight. The doctors of the University Medical Centre in Salt Lake City did test him for AIDS but did not reveal the results. In May of 1987, it was finally revealed that Orville was suffering from AIDS. The responsible blood centre claimed that he had acquired AIDS by some means other than transfusion (implying sexually). In June 1987, Joleen's mother was diagnosed with AIDS, apparently transmitted sexually by her husband. Joleen's mother died in August 1987. Her father died in 1988. Jonathan was still alive at the time of writing of Joleen's book. His story has appeared in book which educates children about AIDS: Sharon Shilling 1990: *My Name is Jonathan (And I Have AIDS)*; Prickly Pear Press, Denver, Colorado).

Joleen addresses the most salient issues:

Jonathan's father wanted to make a 'directed donation' for his son and was refused (Note: there are some contra-indications for directed donations, but arguments against it are mostly administrative. It is claimed by the blood establishment that blood from relatives would not be any safer than random donations. At the time of the early AIDS crisis, this was not true in many areas of North-America.

4

PM-1 3½"x4" PHOTOGRAPHIC MICROCOPY TARGET
NBS 1010a ANSI/ISO #2 EQUIVALENT

PRECISIONSM RESOLUTION TARGETS

Orville: In 1985, there was no doubt whatsoever about the role of AIDS in transfusion, and Orville should have been informed. There is no excuse. Donor selection and screening for hepatitis B core-antibody and elevation of liver enzymes would have reduced the probability of transmission considerably. Directed donation or autologous methods (which utilize the patient's own blood) were not offered as an option.

Ora, Orville's wife: The blood bank knew in June 1985 that one of the donors for Orville had HIV. Orville had not been informed of a possible HIV infection although in April of 1986 the American blood banking organizations (AABB, CCBC and The American Red Cross) recommended that all recipients of blood from known positive donors be notified. The Swain family was notified a year later.

Dr. Madsen, the family's physician, played a key role in covering the tracks between the first test and the disclosure that Orville had AIDS from transfusion. He delayed his treatments, including Orville's move from the local hospital to the University hospital in Salt Lake City. For a while he prevented Orville from receiving pentamidine treatment which would have been beneficial for his respiratory infections.

Joleen eventually took up the issue and began to investigate the infections of her parents. The result is probably the most comprehensive compilation of documents, policies, news casts and reports on this matter available. (It is very difficult, for instance, to follow the 'transfusion trail' in Randy Shilts account). She is campaigning to persuade individuals to make their own informed transfusion choices. There are some features in her account which should be highlighted. They are quoted verbatim:

"Madsen paused and studied the family with a look that was troubled and still. " You must realize that at the time of Orville's transfusion there was no blood test available for AIDS," he said.

It was then Orvin started yelling. Because of our ties to Jonathan's AIDS case he knew there had been surrogate tests available that would have weeded out much of the AIDS contaminated blood. "There were other tests that could have been used," Orvin shouted. "High risks groups should have been deferred. It was 1985, for God's sake. What about the Hepatitis B he got? There were tests for it."

Madsen stepped out of the room - a wise thing to do when Orvin gets riled.

Orvin turned his anger on LaRee "I've tried to tell you for months that the doctors were lying to us. And you said I was paranoid. Are you still going to defend those bastards?"

Something in LaRee snapped. With all her strength she hauled off and kicked Orvin square in the butt. Then she ran from the room.

Dr. Madsen scurried down the hospital corridor after La Ree and her husband. "Now you do understand why you can't sue," he huffed, "The blood bank would drag your father's sex life through the mud."

His statement carried the threat of a shark's tooth. This was a manipulative ploy that some blood banks used to fend off lawsuits. They threatened their victims with exposure of past sexual indiscretions. It was often very effective.

In Dad's case, however, it wouldn't fly. This conservative old man had been married for 54 years and had never sex with anyone but his wife. His children would not fall for the blood bank's sick tactics. We did not fear exposure of Dad's sex life. He had lived the high moral code taught by the Mormon Church and the Mormon named blood bank could never make us believe otherwise.

Nevertheless, the LDS blood bank continued its efforts to discredit my father. Three days after the AIDS disclosure I called the lab that had run the HIV test on Dad's blood that Madsen had drawn. The lab was at Utah Valley Hospital, a large IHC facility in Provo Utah. I asked to talk to Dr. L.L. Anderson whose name appeared on the test results.

"About two months ago you tested my father's blood for AIDS and it was positive," I said. "He got it from transfused blood supplied by the LDS blood bank. I'm wondering if you can answer a couple of questions for me."

"Oh I cannot discuss any AIDS test at all. There are laws against it".

I noticed that he had a speech impediment - slight stutter. "Not even about the test's accuracy?"

"I don't think so. The confidentiality laws are very strict. But leave your number and I'll check it out."

I gave him my phone number, sure that I would never hear from him. Already I was learning that the confidentiality

laws passed to protect the privacy of AIDS patients or carriers provided excellent shields for blood bank to hide behind. They made it impossible for recipients of AIDS tainted blood transfusion to obtain information.

However, to my surprise Dr. Anderson called me back a few hours later. By now his stutter had dramatically worsened, which was unfortunate because he was most anxious to discuss my father's AIDS. Apparently the confidentiality law had been repealed for a few minutes. Dr. Anderson had a message for me from the blood bank and he struggled like a good soldier to get it out [Joleen's notation of the stuttering is omitted here]:

"I called the blood bank" he said, "the doctors said to tell you that your father did not get AIDS from blood transfusion. He could not have symptoms this early. It takes five years for them to come."

His disjointed words reflected off my eardrum with the punch of a machine gun.

I protested, "The incubation period can last for many years or can be very short".

"No, the doctors said that your father got AIDS from his lifestyle. He got it in some other way."

I was stunned and wondered how many other hapless doctors the blood bank would use to do this dirty work. Did the LDS blood bank and IHC control every medical professional and institution in Utah?....

[Joleen then turned to a San Francisco hospital]

"How long does it take for AIDS symptoms to appear after someone is transfused with contaminated blood?"

"It can be within weeks, although most people will go for years. The time it takes for symptoms to show varies widely between patients; we don't understand why. But the blood bank was trying to intimidate you for obvious reasons." (Ottosen 1993:72-74).

[And further down:]

"During 1987 five of my parents' grandchildren were teenagers. They had been taught by their parents and the Mormon Church that living a clean life prevented becoming infected with sexually transmitted diseases. It was heart breaking and confusing for those teenagers to watch their grandparents die of AIDS. Obviously chastity and refusing drugs were not adequate preventive measures.

The grandchildren's belief system toppled. They were upset over the behaviour of the blood bank in its efforts to conceal their grandfather's AIDS infection. At school and church rumors were passed around about their grandparents'

lifestyle. Some classmates were cutting wisecracks. Others were afraid to come near them, thinking they would get AIDS.

It was a year of disillusionment. The LDS Blood Bank and the IHC decision makers were respected doctors and executives. They were not street criminals. They, like most of the nation's blood bankers, merely desired to preserve their safe-blood image and revenues.

Perhaps, for tens of thousands of transfusion recipients who were nationally infected with AIDS, this is the most disheartening aspect of their tragedy. Their past and future deaths are by the hands of such good people.

Dad's eye reflected the betrayal he felt. He knew that most of the blood bank and IHC executives were active Mormons. "What's all this religion good for?" he asked me.

On July 13 I called Dr. Craig Nichols at the Utah Department of Health and asked him if he knew how the donor trace we had requested was progressing.

"I am not able to discuss that with you", he said.

"Are you aware that my mother has tested HIV positive, and my father's condition worsens with each passing week?"

"I cannot discuss the situation," he said.

"You are saying that the LDS blood bank can give my father AIDS and a collection of other viruses and the Health Department can't discuss it?"

"I am not allowed to" he said.

"Can you tell me how many transfusion cases Utah has, or is that classified information?"

"We have only three transfusion AIDS cases. There have been no new cases in 1987."

A few days later I called the Uintah County Public Health Service and talked to Joseph Shaffer. We had a problem with a clogged bathroom drain in my parents' home and plumbers were afraid to work on these lines or clean out the septic tank.

"Could you talk to the plumber about any AIDS risk that they would have in cleaning the drain lines?" I asked.

"That is the stupidest thing I've ever heard," Shaffer snorted. "You cannot get AIDS that way. There isn't a single AIDS case in Uintah County, just fear because of your family."

This attitude of health departments was as sure to move me to anger as an onion does to tears. I knew that Dad and Mother were not considered full-blown AIDS cases, but that they were certainly HIV-positive and seriously ill with AIDS-related conditions and the lack of CDC reporting would not alter that fact. It was obvious that public health officials did not want to become involved with our problems and would have preferred that we kept our situation secret so they did not have to deal with public concern or "panic".

"The health officials main interests is in making their jobs easier", Orvin stormed. "I'd like to see them care for our parents for one week". (Ottosen 1993:84-86)

Note: I am not a supporter of 'directed donations' myself as the pro's and con's in both directions may cancel out - on average. However, the right of the patient to receive directed donations and be informed of the differences in risks should not be curtailed.

Discussion

External ecology

The infection.

The story of Orville and Ora is quite different from that of the Freises. Orville's infection occurred almost two-and-a-half years after the first time possible disease markers had been discussed at the Mount Sinai Hospital in New York. The blood banking industry was still resisting surrogate testing and was waiting for the direct HIV test to be licensed and marketed. Orville was hit by three different viruses simultaneously, and there is a good chance that proper donor screening and a test for hepa-titis B might have eliminated the infectious blood unit. It seems that at this point the entire blood banking industry was locked into a fixed pattern, regardless of what had been learned about the disease from a widespread infection of hemophiliacs.

This persistent, pervasive solidarity in the industry is perhaps the most disturbing aspect of the contamination of the blood supply. It relates best to Dr. Perrault's comment '*that the war was lost after Stalingrad*' - but then it still continued for another two-and-a-half years, claiming more victims in its end-phase than during all the years before.

The inability of 'strategic adaptation' of a population, perhaps combined with an irrational hope that things will somehow, miraculously, take a turn for the better, was combined with 'rational' corporate elites seeing and understanding the 'writing on the wall', and planning for their own future. This should be of utmost concern in late modernity.

The concealment of the infection.

The account describes a blatant concealment and then outright intimidation of the victims. There was little effort to hide the economic-legal reasons for this concealment. The disastrous consequences of our legal remedies for damages from malpractices are self-evident. Just as the economic, authoritative mindset of the health establishment led to the infection, the legal mindset of avoidance of litigation at any cost to the victim became irreversible. In the case of the family doctor, the concealment may have been transformed, ever so subtly, into passive euthanasia.

The public display of suffering.

Joleen's response to the loss of her parents was similar to that of the Freise family. However, given the more extreme 'free enterprise' culture in the U.S., her choice of means was different. Just as Jerry Freise's, her first concern was to 'make sense of all the things which did not make sense', and she began her own, private investigation. The report of the 'House Subcommittee Hearing on Blood Supply and Safety of 1991' was of some

assistance. However, nothing equalling the Krever Commission was ever accomplished in the U.S. On the other hand, the media attention in Canada is not comparable to that of the U.S.. Reports on events in Germany, Switzerland and France, where criminal charges have been laid against blood bankers, are more likely and more completely reported in American papers, such as the New York Times. Following the publication on Jonathan's story, Joleen's approach was a publication. She did not find much support in the publishing industry. She took an additional step by detailing why the blood supply is still not safe, despite continuing assurances of health authorities to the contrary. *'Conspiracy' debunks the safe-blood myth and motivates health consumers to ensure their own transfusion safety.* (John de Grafenried, Director, American Foundation for Safe Blood and Health Care, on the cover of Joleen's book). (Note: a routine application of 'genetic finger-printing' may eliminate most of the risks of viral infection by blood transfusion. However, this is still very expensive. It is currently used by Immuno AG, the Austrian fractionator, on batches of finished product, not on donor plasma).

Inner ecology

The distancing effect of 'authority'

Joleen's account (as for instance noticeable in the heightened stuttering of Dr. Anderson) reveals some of the fear that may have stricken the medical establishment, once it was realized to what extent the trusting public had been damaged. More likely, perhaps, the lawyers had intercepted or had been advising the blood-industry much earlier. In the U.S.,

court awards of compensation for damages of any kind, and for medical malpractice can be very high and might have been potentially ruinous for a number of blood banking establishments.

An important participatory aspect of consciousness is evident in Dr. Armstrong's response: his inability to speak and act according to his own conscience. It does not appear that he really agreed with the message of the blood bank, as he offered no personal opinion and he seemed very distressed by delivering the message.

The same phenomenon is tangible with Dr. Madsen's strange behaviour, in particular his omission to make pentamidin treatment available. This riddle is solved on page 95. Dr. Madsen had refused to prescribe pentamidin, claiming that it required bronchoscopy to confirm the diagnosis of *peumocystis carinii pneumoniae* (a typical AIDS related, 'opportunistic infection') which, he claimed, could not be done in the local hospital. It turned out that bronchoscopy was required by the CDC as a stringent criterion for the diagnosis of AIDS but not for the prescription of pentamidin. On the other hand, orders of pentamidin had been a signal for an AIDS case for a long time (see Shilts 1988, *passim*). Apparently, Dr. Madsen had been instructed by the blood bank, directly or through mediators, to avoid this procedure so that the case could not be registered with the CDC. He had already concealed Orville's HIV status for six months (which he actually reported on Orville's chart).

This phenomenon of doctors not following their conscience is observable throughout the HIV crisis, to this day, as almost the entire medical establishment has fallen in line during the crisis and afterwards, during the cover-up. During the Canadian inquiry, with some deviations, blood centre doctors claimed that they were essentially following national policy

direction (Dr. Huntsman in St. John's Newfoundland, or Dr. McKay in New Brunswick, in their testimonies before the Krever Inquiry), in part as issued by the Red Cross directly, or indirectly as per guidelines recommended by the Canadian Hemophilia Society. All of them claim that everything was done for the larger good of the public or the hemophiliacs, like maintaining their treatment programme and avoiding shrinkage of the supply of donors. Finding infected people was not deemed to be 'cost-effective', 'or would not have been in the patient's interest, because there was no effective treatment available'.

The defence arguments used by the medical profession have moved dangerously close to patterns of defence used by Nazi doctors who participated in the euthanasia of mental patients or conducted medical experiments for vaccines, sulfa drugs and environmental exposure. The Nazi doctors claimed that they were following orders, and that they were doing it for some 'higher good' (in Germany, to save the lives of the German soldiers; see Hoedeman, 1991); also they were doing it 'only' with people who were criminals and thus condemned anyway (some of the decisions made in the HIV crisis are indicative that since 1982 hemophiliacs were thought to be infected and thus 'condemned' to die). This makes the case of the Swains more frightening than that of the Freise's: the subtle or not so subtle tendency of 'passive euthanasia' which had the potential effect of expediting the natural progression of the disease, or 'euthanasia by omission', rationalizing other, rather sinister motivations.

"The pharmacist handed him Dad's medicine and said: "Some things work out for the best. Your father has been ill and depressed for so long over his family problems. With AIDS he won't have to live much longer."

Not only did this licensed health professional fail to connect Dad's prior poor health and depression to the AIDS virus, but he thought that AIDS brought on an easy, story

book death. His comment was one the family would often remember during the remaining 14 months before Dad died. (page 76-77).

Given such 'vulnerabilities' of rational decision-making, any attempts to legalize euthanasia should be approached with the utmost caution. The potential abuse, in particular as 'passive' euthanasia or 'euthanasia by omission', may far outweigh the benefits. We may not be mature enough for such a policy. (This is one example of what I would refer to as the 'ecological limitations of the relational construction of rights codes').

The concealment of the truth inflicted far more damage than the infection itself, and a fundamental loss of trust in the 'high priests of medicine'. For the Swain family the dissonance was particularly severe, because their trusted healers were also members of their own church. (Joleen reports that, eventually, her father was more compassionately treated by a catholic female doctor). Joleen's reaction is similar to that of Jerry Freise, and like him, as an uninfected member of a family, became an activist. She also fulfilled a request made by her dying father.

The cycle of meaning

Joleen's starting conditions were similar to those of Jerry Freise, more severe perhaps, in that both of her parents have died. However, there was no ritual offered to her (no matter how limited). Her approach was therefore 'rationally' strategic, attempting to deconstruct the 'transfusion myths', which had been constructed by the industry (like the 1-in-a-million risk), and to replace it with individual rational choice for the use of

blood transfusion. In this sense, she may be playing into the hands of the medical establishment, which indeed seeks to shift all responsibility to the patients, by supposedly 'enabling' them to make rational choices.

The more significant aspect, however, may be that she has, effectively, established herself as a 'shaman', a person who is deeply empathetic, has gone through a major personal ordeal, who can present the story of her family as a symbol and equivalent to myth, who 'understands' the world of blood replacement therapy, who understands what people in similar situations are going through, and who is available to interpret this kind of world to others. She used, quite deliberately, I believe, a symbol, 'conspiracy'. The term is in disrepute, but as a symbol it can transform 'blind' trust into alertness and vigilance. ('Paranoia' only sets in when such vigilance concerns the 'self' exclusively, and when alternative explanations are rejected out-of-hand. Accusation of 'paranoia' is an 'antidote-strategy' used against 'whistle-blowers').

The pattern of trying to make sense of a situation in which 'too many things do not make sense', is a pattern which I myself have experienced. It is perhaps one of our most adaptive neurocognitive faculties. A brain confronted with too many contradictions, if it can overcome 'denial', may be compelled to find the 'explanantia' and, as is often the case, the single 'chaotogenic explanans' which make sense of it all. In my own experience, a strategy which is in contradiction to some essential homeostatic balances will produce a mountain of numerous contradictions and paradoxical arguments. Again, in my own experience, this kind of confusion is usually 'pathognomonic' of a single 'pathogenic strategy'. On the other hand, it is in the interest of the 'strategy producing agency' to

prevent the discovery of the explanans. The production of a book like Joleen's, representing 'a brain in orientation', is certainly not desired by such agencies.

The Decarie Family

The following summary was prepared from two documents. One was written by Johanne Decarie, the primarily infected individual in the Decarie family. It is entitled '*Living with HIV*'. Johanne uses this document when she gives talks on AIDS in schools. (She gave this talk at Carleton University during a lecture in Medical Anthropology in the fall of 1993. Her infected husband and her infected daughter Billy-Jo were present at that lecture as well). The other document was prepared by Bill Decarie, Johanne's husband, and presented to Don Boudria, member of the federal legislature, on November 24, 1993. Both Johanne and Bill testified before the Krever Commission.

Johanne's first husband had left when she was six months pregnant with twins. On August 6, 1985, she was admitted with complications, delivered twin daughters on August 8, and suffered a stroke on August 10, 1985. She went into a coma for seven days and was left paralysed on the left side when she came out. She recovered partially from the stroke 3 weeks later. She appears fully recovered now. The intracerebral hemorrhage, a diagnosis of liver failure and subsequent hemotherapy point to a classic case of eclampsia, a still mysterious condition which occasionally complicates pregnancies and childbirth. Johanne received several blood transfusions (presumably to compensate for hemolysis), I suspect she received platelet transfusions (as platelet counts tend to be reduced in eclampsia) and coagulation factor treatment. Johanne was told, initially, that it was Factor VIII. This has been corrected recently

by the hospital to have been Factor IX. To this date, Johanne has not been told the diagnosis nor has the hospital chart been released.

In April 1986, she was informed that one of the blood units had been infected with HIV. Johanne was subsequently diagnosed to be HIV-positive. Two months earlier she had met her second husband Bill. After the news the couple practiced protected sex by using condoms. However they had not been given any specific instructions, merely that they should use 'protection'. Bill had three children from his previous marriage. In 1988, Johanne became pregnant despite protected sex. She delivered her daughter Billy-Jo who turned out to be HIV infected. Billy-Jo had her first pneumocystis infection (which is almost a pathognomonic AIDS-related, opportunistic infection) at the age of 6 months.

Bill and Johanne married on February 14, 1992. In August Bill was tested for HIV and turned out to be positive. The Decaries had kept their infections secret, but after Billy-Jo's birth they gradually began to disclose their condition to close family. In September 1992, they began to join other infected couples in meetings and retreats. Bill informed his employer of his condition. Confidentiality was broken and he eventually lost his job. Johanne had been an employee of Bell Canada. She kept it a secret there, until she went public. She was able to continue to work. Gradually, the Decaries went public through national and local media and also embarked on educational activities. To-date, Bill and Billy-Jo have not received any compensation from the Federal Government or the provincial governments.

The following verbatim passage addresses two issues: social discrimination against an infected child and the intransigence of government officials with respect to the limitations of the provincial compensation package (such as no compensation for infected spouses and infected children).

I am not saying that everything we've done has been with no problems. The majority of people that know our situation do offer support. Unfortunately there is some because of ignorance and prejudice that do not understand the disease. This situation occurred when Billie Jo started school. Billy Jo's best friend was removed from the class because the parents were afraid. I felt very sad for my daughter.

I sat down with her and read her the book "viens t'asseoir avec moi", which talks about a little boy who has AIDS. I then explained to her that her best friend would no longer be in her class because her parents were afraid that she would get the same bad blood Billie Jo has. Billie Jo answered:

"Mommy, but why am I going to die Mom, I don't want to die". Again an enormous amount of strength was required to deal with this situation.

Following this incident I wrote the parent of that little girl a letter explaining how hurt I was. I haven't heard from them. Explaining the situation to the children also required a lot of strength. Krystle and Ashley, my twin daughters, being only 9 years old, understand that Billie Jo has bad blood but listening to little friends of theirs tell them that Billie Jo was going to die affected them immensely. We attempted to reassure them.

Following these last incidents in our lives, we attended a meeting in Toronto. Mr. Phil Dresh from the Canadian Blood Agency, Mr. Michael Ennis, Deputy Health Minister attended. What we experienced was two officials standing fast and insisting that the only thing they could say was: This is it and you have a lot of tough decisions to make and that there was nothing that they could do while they heard about deficiencies throughout the package such as exclusion of indirectly infected children, no drug benefits, no funeral expenses, no legal costs and a waiver required for 'potentially connected agencies'. Such benefits were afforded to the Province of Nova Scotia only. [See below the discussion of the Connors family in Nova Scotia.]

These deficiencies were voiced by infected, inflicted, affected persecuted, sick and tired, wasted and, YES, dying fathers, mothers, sons, daughters and relatives. They were cold, and uncaring, in the face of crying, trembling, and afraid victims.

Living with HIV is amongst one of the greatest tasks. No security; dwindled incomes; expenses rising and debts growing; health declining, energy lowered, frustration, anger, fear and discrimination become a way of life. As victims of a system that failed, that we deal with day in and day out is unbelievable and unbearable, but we try to make everybody's lives as normal as can be. Justice and knowledge take time and TIME is what this Canadian System took away.

We are relying on this public inquiry to answer the many questions more than twelve hundred Canadians have been waiting for AND to come away with renewed patriotism and answers for the INFECTED, INFLICTED and AFFECTED.

And Bill Decarie adds:

Now that Justice Krever will extend the inquiry to Dec. 95 from September 94, not to be unfair, should the provincial ministers extend the deadline and stand firm on the waiver and deficiencies designed to aggravate and inflame victims in a time of needs. The result would be legal fees tripling for those wishing advice as to the outcome of the inquiry; HIV/AIDS has become big business beyond our ability.

According to Ontario Justice Montgomery victims infected by the blood system do not have a common issue, justifying denial of funded class action. Justice is not for the common victims, they would end up losing it all and making monthly payments to the lawyers.

I do not feel well, infections, tumors, experimental drugs, plenty of fatigue, insomnia, diarrhea, fever, stress, anger; my daughter has AIDS, I learned of HIV hours after Johanne was given her guidelines and challenged HIV with support for my wife, attempted anonymity, protected sex with condoms and petroleum lubricant causing pregnancy and probably constant reinfection; personal denial until 92. This is 1994, we now have to tie up loose ends and as this inquiry examines the past to decide the future; Johanne and I will have to explain the present to a 4-year old. And I still don't get it! Why this happened? I, we, were expendable, some of us still are!

Discussion

External ecology

The preventable infection

Johanne was infected with (confirmed) HIV positive blood unit (or some other product, we cannot be sure). The Canadian Red Cross was not testing, the American Red Cross had started six months earlier. The excuse used by the Red Cross, that the provinces were slow in setting up 'alternative test-sites', and that earlier testing might have flooded the blood clinics with HIV positive donors, is spurious. The Red Cross could have publicized very clearly that, until further notice, the tests would be done for product safety only, and would not be linked to the donor.

The Red Cross, in my opinion, had even enough assets to bridge-finance alternative test-sites until the governments were 'ready' to act. This would have been perfectly consistent with the general mission and Principles of the Red Cross and the specific moral and legal responsibilities for the safety of the products it distributed. The Red Cross also had the capacity to fundraise for this effort, if the government proved too tardy. Ultimately, the Red Cross could have taken the political route and turned to the public to exert pressure on government. Thus there was a wide range of options available to the Red Cross. One more time, the worst option, to do nothing and wait, was chosen. (An offer from Abbott to use a trial test kit in the preceding year, 1984, was rejected by the Red Cross - Dr. Gail Rock, personal communication). I did raise the issue of not having paid for

testing with the Programme Review Committee of the Red Cross in late 1986 or early 1987. Shortly, before I was fired, I asked the President (volunteer) of the Canadian Red Cross Society, Allan Watson, whether the Red Cross could share the blame for blood transmitted HIV infection with the Canadian Blood Committee (CBC), the agency which recommended blood program budgets to the provincial ministers of health. He clearly indicated to me that the Red Cross should have paid.

It appears that Johanne's treatment with blood products was clinically indicated. However, the hesitation of the hospital in releasing the chart should raise some flags. (She was also given conflicting information in that first she was informed that she had received Factor VIII, then she was informed that it was Factor IX. Factor product should not have transmitted HIV, unless it was from un-heat-treated, infected stock, which had not been recalled). The information is not in as yet. The fact that Johanne was not given the likely diagnosis also raises questions.

As soon as testing in the Red Cross started, all transfused patients should have been tested for HIV. This, of course, could have started almost a year before Johanne was informed, if the Canadian Red Cross had followed at least the pattern of the American Red Cross. Thus Bill's infection might have been avoided. Johanne's HIV education regarding protected sex was utterly inadequate. Petroleum jelly is an inappropriate lubricant and damaging to the latex condom. Therefore Bill might have been reinfected over and over again. It also led to an unwanted pregnancy, a matter in which Bill and Johanne, as Catholics, believed they had no choice. Again I must stress, that the 'hindsight' argument would be pure deception.

Additional issues arise from Billie Jo's social discrimination, and from

discrimination at work against Bill. Bill also points out that the legal control system of society in such circumstances not only becomes a matter of confrontation, which produces its own risks, but also a matter of revenue for lawyers, on both sides of the issue. The Decaries also believe that the duration of the commission works for the elite, not for the victims. (given the compromised position of Judge Krever, this may be so).

The 'steadfast' attitude of bureaucrats is graphically recorded by Johanne. Politicians and bureaucrats seem to take pride in remaining 'unflappable' and 'strong' in the face of the damages which their institutions and colleagues have inflicted. The waiving of litigation, which the victims had to agree to in order to receive their 'compassionate payments' from the Provinces and the Federal Government, is at least some indication of guilt on part of the parties requiring the waiver. The most obtuse condition attached to the provincial compensation package was the requirement that the victims had to sign the package deal, including the waiver, before any significant evidence had become public through the Krever Commission. The deadline coincided with the ruling of the Pitman-case (DOC 12) which ignored any responsibility of the Federal Government, the Red Cross, or any other agency in the infection of patients with HIV. Neither Judge Lang nor counsel for Mrs. Pitman invoked the Food and Drug Act, which was clearly applicable.

In all of these government manoeuvres, there is a tacit rationalization with respect to the 'national deficit' (although it is rarely spelt out). The implicit cynicism is that victims are just out of luck, they were damaged during the recession in the early eighties, they were left uninformed during the boom years, and had to wait for the bust years to ask for compensation.

This account differs from the previous two, as specific test systems were available and their implementation was delayed for reasons which I consider to be rationalizations of the overall agenda of the industry and the Federal Government. If the contaminated product had been a coagulation product, it should have long been removed from the shelves (but the Federal Government never ordered a recall or verified recall). In this case the issue of implementation dates of preventive policies between the U.S and Canada becomes highly significant. Roger Y. Dodd of the American Red Cross claims that HIV-testing was uniformly applied in the U.S as of July 1985 (the American Red Cross started earlier than that, and the test had been licensed in March). This is also in agreement with the calendar of events included as Appendix 1). Johanne's infection was preventable with near certainty. In 1985, transfusion-related AIDS had moved beyond 'guessing' and decisions on the basis of 'likely association'. While commercial and other economic interests must be suspected in 1982-1983, they appear to have become more tangible and less easy to conceal in 1985.

Inner Ecology

The distancing effect of authority.

As in the case of the Freise family and their confrontation with the insurance industry, the Decaries and many other affected families were confronted with the 'iron men and women' of the health bureaucracy. The notion of the 'greater good' together with an order and the agents' own power produce the phenomena which have been observed in concentration

camps, when internees were sorted in groups to be retained for work or terminated. In addition, there seems to be a certain pride in being 'tough', which is most disturbing, as it would reinforce the overall attitude of the individuals involved ('a job well done'; or in the case of a senior bureaucrat - a 'land-mine avoided'). This is not fundamentally different from the 'job well done' by a soldier who has only the vaguest notion why he is doing what he is doing: which is generally carrying out the orders to commit atrocities.

The 'job-mentality' in the commission of atrocities (and I find the pronouncements of the bureaucrats atrocious), is the closest real-life example of Milgram's experiments in obedience.

Social discrimination.

There have been many reports of people with HIV infections experiencing discrimination in their communities and at work. This field needs extensive anthropological and sociological exploration, since epidemics will stay with us for some time to come. 'Irrational fear' or denial by the people and the "not to panic" reassurances of governments, are both inadequate and maladaptive modes of handling epidemics. Lifestyle accusations, witch-hunting, shunning, should be seen as what they are, coping mechanism of fear of the unknown (which would otherwise be classified as anxiety), and the suppression or false rationalization of the nature of an epidemic would be ill advised.

This is where the 'cycle of meaning' could be implemented most bene-

ficially: by structuring the spontaneous sense of uncertainty and ambiguity by communications events, preferably at the community level; also through the media, by inserting key symbolic messages and then provide interpretations as extensively as possible. There is nothing in science that could not be explained, with some patience and effort, to a reasonable person. Thus the professionals and the population would be in a linked adaptational (learning) process, undue influences or exploitation can be minimized, and paranoid situations can be minimized as well. This kind of 'crisis management' permits a gradual adaptation (albeit over a fairly short time period). The means and personnel to do this are available. Since more than one epidemic may occur at the same time, it might be best to find ways of ritualizing this adaptational process, from a very young age on. (At present, an AIDS epidemic, a hepatitis C epidemic, a hepatitis B epidemic, a narcotics abuse epidemic and a suicide epidemic are going on in the same age group - juveniles; I do not believe that any of them have been officially declared as 'epidemics'.) This ritualized social solution could be the beginning of a wider engagement of the general population in broader social, medical and technological issues (but not according to 'consumption philosophies' of conservative, liberal and new-democratic governments. I am remaining adamant that 'health-care' and healing must not be commodified and opened up to corporate and bureaucratic strategy; the Ontario Government, in preparation for elections, is reorganizing the health-care system. 'Consumption' oriented 'social professionsals' may have a major say in this undertaking - Jerry Freise, personal communication: he is serving on one of the 'community groups' who are supposed to make sense out of this new 'health-consumption' strategy of the socialist government. There is no place to hide from this materialist, corporatist 'semiological frenzy'.

In a letter to the Ottawa Carleton Health Department I suggested that, under conditions of new social codes, conventions and practices, ecological changes (including global migration), epidemiological changes are inevitable, and that a new situation needs new approaches (DOC 20). This is a case where 'irrational fear and suffering' could be channelled into adaptive social practices. (Note: the only response to this global spread of epidemics has been a scientific one, in the form of new virus laboratories in Ontario and Manitoba: on the assumption that, if technology fails, one merely needs more and better technology. Science and technology did not fail in the AIDS and hepatitis epidemics, the humans controlling the available science and technology failed!).

Internal ecology

Law, economics, hierarchy and science converged on the Decarie family and produced the particular severe affliction of an entire family. In addition, some irrational constructions of sexuality on the part of health professionals increased the risk. Constructions of disease in the public mind led to serious economic and, social hardship. The issue of compensation, as discussed, brought forward the problem of obedience to authority, and the 'de-empathization' of the 'official'. The issue of 'efficiency' (and other health-economic constructions) are latent in the handling of the compensation issue. In addition, as a matter of job performance, such 'efficiencies' are reinforced through the construction of 'performance on the job'.

Once confronted with the reality that the health system had betrayed them, the Decaries also become strong activists and made their suffering public. It is difficult not to be affected by 'experiencing' Billie-Jo. Johanne's, Bill's and also Marlene's speaking engagements had a positive effect and may have helped to provide meaning for their condition. While it helps to cope, however, it may also detract from another mode of making sense, that is trying to find out who is to blame. Authorities may thus have a dual purpose in promoting such educational tours (the protection of the public and their own). This is not intended as cynical remark: it is painfully obvious in the example of Arthur Ashe as referred to in Dr. Hershfields letter (Chapter 6).

Multiple 'fractures'

With their trust in the health-care system, the government, the validity of church teachings, the legal profession (the Decaries fired their lawyer because of bad advice), in the community and in the Commission fractured, the Decaries face a particularly difficult situation to find and engage in a suitable cycle of meaning. They did accept the federal and provincial compensation packages and signed the waiver. This excludes Johanne from litigation, but leaves the door open for Bill, for himself and on behalf of his daughter. (This opening applies only to the federal waiver, as he had to sign the provincial waiver for Johanne). Johanne is following the pattern of Marlene Freise and went on a public speaking tour. The si-

tuation is more difficult for Bill, in particular since he also lost his job because of his illness.

This is severe suffering from multiple, barely mitigated sources of grief. Survivors of concentration camps had the opportunity to gradually fill their lives with new content and meaning and to connect with their pre-imprisonment experience. The death of a family member or friend is a final event, which can be left behind after an appropriate period of grieving. There are no such circumstance present with respect to HIV infections. The suffering progresses while the victims have to live 'in community' with those who have inflicted the suffering. In other words, the multiple dissonances cannot be silenced. In my personal opinion the only ritual process which could bring relief would be (fair) court proceedings.

The inner ecology of bureaucrats

The inner ecology of bureaucratism, as described by Johanne, raises serious concern about health bureaucracies, and the kind of backgrounds and 'entrainment' such bureaucrats bring to the performance of their job. For the unaffected person, the pervasiveness of 'business-like' handling of things and, ultimately, the faith in 'rational choice', may make such presentations of the bureaucracy look 'normal'. After all, they are protecting the overall economy, and thus, implicitly, the 'public good' and the well-being of the unaffected. Therefore, only if the contamination of the blood-supply can be demonstrated to the public to be a more general problem, rather than a specific problem of a specific industry segment, can the public be expected to react. Part of this realization is, however, an awareness that the

general population itself is part of the problem, by having uncritically accepted and internalized the very conditions and cognitive processes which made the specific problem possible. The same conditions and processes which also contribute to their economic well-being.

The inner ecology of the 'general public'

From an anthropological viewpoint, it appears that human societies have been able to accept readily the sacrifice of their own members in return for their perceived homeostasis in material security, by war, human sacrifice or mass execution, whether the outcome of such measures were successes or not. The Germans were all-too-easily convinced that the Jews were robbing them of their livelihood.

This, perhaps, is the most troublesome, inner-ecological aspect of the contamination of the blood supply. To-date, despite massive and persistent media reporting, there has been no significant public outrage over what has happened. In other words, the conditions of civilization, without any deliberate intervention by the elites, are sufficient to prevent a society-wide empathetic response, apart from politically mobilized protest. From an elite point of view, it suffices to maintain enough ambiguity so that readily accepted rationalizations for an unempathetic attitude can be inserted.

The example of the Decarie account teaches that, while magnificent victories over nature are being celebrated, civilized humans still represent a tremendous danger to each other. This danger increases, the more the use on rational instruments of social and psychological control proliferates.

The construction of sexuality by physicians

The ecological effects of physicians' constructions of sexuality with respect to procreation and transmission of diseases should be matter of great concern, but it is such a broad topic that it must remain unexplored here. Johanne, upon information of her HIV-status was only informed to use 'protection' but was given no specific advice. This led to her choice of condoms but the wrong lubricant. This instruction could also have led to the use of potentially irritation causing sponges, foams or diaphragms, none of which would have provided protection. On the contrary, irritation might have promoted transmission. Apart from the delay of between transfusion and disclosure of Johanne's HIV status (without prior warnings of potential risks from transfusion therapy), this was the most significant factor in the spread of the infection in the family.

The hesitation of medical personnel to give extensive and detailed information of protective measures (this was 1986!) is a phenomenon which stands outside the issues directly related to infections from transfusions, but must be explored in terms of societal attitudes towards sex, contraception, protective devices and so forth. (In Johanne's and Bill's case it was complicated by their catholic background. This issue belongs into the larger issue of the handling of the epidemic and the cultural resistances to promote effective protective measures).

This attitudinal question extends into the medical profession. What goes on the minds of medical professionals in this respect remains unexplored, but one would suspect that medical professional attitudes towards their own sexual practices have a big role to play here. For instance: my own family doctor is a 'Born-Again-Christian' (who even tried to recruit

me). Upon a visit regarding minor a infection he might have asked appropriately whether there had been 'extramarital sex'. Instead he asked if my wife and I had been 'fooling around': a clearly prejudicial, judgemental, moralizing question, not a clinical question.

Individual rights

A parallel attitudinal issue in any sexually propagated epidemic is the construction of a conflict between the need of notification of public health authorities of infected individuals and the protection of individual human rights. There appears to be a willingness to sacrifice human life for the protection of individual rights. This issue has been influencing the spread of the AIDS epidemic from the beginning, and, in my opinion, has been exploited by the commercial blood industry.

The willingness to sacrifice human life for individual freedoms is as troublesome as public endorsement of euthanasia (see Chapter 5). It should suffice here to state that there is no such thing as 'safe sex'; there is only 'safer sex'; and the use of a condom does not relieve an individual who has been at risk of contracting a venereal disease from informing the partner of this possibility. (Hepatitis B, for instance can be passed on by saliva). From this an obligation to know one's status of infection may arise. Since it is well-researched and understood from the self-exclusion programme used in blood donations that 'voluntary disclosure and abstention' does not work (Dodd in Madhok et al.(eds.) 1987:146/7), public health has an obligation to intervene in sexually transmitted infections in an attempt to contain its spread. One must assume that the 'sexual motivation' is far

too powerful that 'rational transactions between sexual partners' can be relied on.

Note: I just found out that my son is being taught in junior high-school (Catholic School Board) that Body, Mind and Spirit are three separate entities. This is being reinforced by letting the children write poems in the context of each of the three entities (in which the entire schools is involved in this writing). The title-page of the book shows what looks like a Buddhist monastery. I have been called a utopian "*it was nice to get to know you as a person, but....*") by a professor of sociology (not from Carleton University). In the face of this kind of organized mass-confusion (and this is not an oxymoron), I have to admit that this may be true.

Body: Celebration of our physical nature, physical challenges/activity (at least 25 sports); body as machine(!), what we 'do' (driving, swimming, dancing, hiking').

Mind: Understanding ourselves (relationships in society or the world), maths, sciences, intellect and philosophy, comments on books, T.V., music and computers).

Spirit: Nature, soul or inner self; creativity and creative spirit, religions of the world, or striving for balance, prayers.

My son (grade 7) fortunately ignored the three 'categories' and selected his own: 'Romance'. (I do not know his source).

*When I look into your burning eyes,
I get the feeling that I'm hypnotized.
When I watch you gracefully walk,
sooner or later I can barely talk.
When you smile right at me,
My heart fills with nothing but glee.
When you talk to me with your beautiful voice,
You leave me only one choice.
but to ask you to be mine.
If your answer were yes I would have to confess
I've loved you for many years
but my heart was locked with fears.*

His 'Self' still seems to be whole and unflappable. His 'suffering' is meaningful. The Decarie family experienced the full and ultimate effect of the fragmentation and the devastation of the our inner ecology which is outlined in the instructions given by the school. If it were not for their six children, their suffering would be meaningless. The most dangerous development of our inner ecology in the late-modern stage of civilization is sequestration of the human body from the 'Self', a sort of misoperationalized oriental philosophy: the 'instrumentalization' and 'resource and utility' designation of the human body, which is euphemized as 'celebration'. Competitive sports essentially selects and rewards genetically determined physical/functional 'machine'-characteristics. Of course, machines do not have emotional experience and behaviour, passion or compassion.

Dr. Alan Powell

This account is built from my notes taken during an interview which Dr. Alan Powell gave to a reporter of CBC Morning News on October, 1994 (Thanksgiving), at his home in Toronto.

Allan underwent coronary bypass surgery in 1986. He felt gratitude towards modern medicine for having restored him to life. In 1990 he was diagnosed with chronic hepatitis non-A non-B (a major portion of which became later known as hepatitis C), most likely acquired from the blood which he had received in the course of his operation. Initially, he regarded this as a (bad) 'luck of the draw'. His illness began with severe, unexplainable fatigue. His doctor did not suspect hepatitis and told him that "*it was all in the head*". Unfortunately the disease was not reportable in Canada. It is now reportable in four provinces. He became aware that the disease can lead to cirrhosis of liver, varicosities in the oesophagus, which can rupture. Blood returning from the intestines towards the heart has to pass through the liver. If the liver is cirrlosed, it has difficulties passing through the irregularly regenerating and scarring liver. It then finds 'bypasses', which lead through the vessels of the lower oesophagus. Bleeding from rupture of such varicosities is a life-threatening condition. Such bypasses also bring organic substances, which would normally be metabolized by the liver, directly to the brain. Eventually, a liver transplant may be the only remaining life-saving intervention.

As the media reports began to expose the issues related to

HIV, he also began to learn that the Canadian Red Cross Society could have done something to substantially reduce the risk of hepatitis C transmission. He watched the Red Cross consistently denying that it had done anything wrong and refusing to apologize. He became very angry. Today he believes that the inaction of the Red Cross constituted criminal negligence (at the time of his infection, there were two 'surrogate' test systems available to the Red Cross: an antibody test for hepatitis B and a non-specific liver enzyme test (ALT-test)).

Note: The tests had been introduced in the United States in 1985/6. As a reminder, viruses causing hepatitis B, C, CM (cytomegaly), mononucleosis (the 'EB - virus, Epstein-Barr virus) tend to travel together or follow each other in transmission by sexual intercourse, blood transfusion and sharing of needles by intravenous drug users; also in feto-maternal transmission). The vast majority of cases of chronic active hepatitis are the result of viral infections, and the vast majority have elevated liver enzymes in the blood stream, as they are shed by disintegrating liver cells). Between 2-10% of blood donors, depending on location and 'cut-off level' for liver enzymes would have become ineligible for donation by such screening tests. This was considered an unacceptable 'loss' (and cost') by the Canadian Red Cross Society, and by the services in the U.S. in the early eighties (American Red Cross, Council of Community Blood Centres (CCBC), which included the Greater New York Blood Program (GNYBP), the American Association of Blood Banks (AABB)). Enzyme screening tests had been available since the sixties, and the Hepatitis B antibody test had been available in 1976. Anti-core testing had been recommended by the CDC, and also by representatives of the American gay community as a surrogate test for AIDS at the meeting in Atlanta in January 1983. See Appendix 1).

Dr. Powell found that there was no support system available for his condition, the hospital could not help him and he felt afraid. In 1994 he underwent a 6-month treatment series with interferon, a biological antiviral substance. He did experience severe side-effects

from the treatment. He felt like 'going crazy' at times, and there was fever. (Other patients cannot endure the side-effects and stop the treatment after two months or so).

In 1994 Dr. Powell began to organize a self-help- and advocacy group. The group is now a national organization with 19 chapters in the major Canadian urban centres, with a fast growing membership. There are now approximately 400 members. So far only the Sick Children's Hospital has been trying to find hepatitis C infected patients (Dr. Susan King had previously initiated a search for HIV-transfused infected children who had been patients at the hospital in the early eighties). The Ontario Hospital Association did not include a hepatitis C alert when it advertised that transfused people should have their HIV status checked. Meanwhile, it has become known that there may be sexual transmission of hepatitis C, also transmission from mother to child, circumstances which had been previously denied.

Dr. Powell is worried that interferon is an expensive treatment, it is not covered by health-insurance, and the poor may not be able to afford it. Interferon works only in 20% of the cases. [With respect to socio-economic discrimination see also DOC 20]. Dr. Powell's group was the last group to be granted standing before the Krever Commission. It is not receiving funding, which is essential to have representation by legal council before the Commission. Mr. P. Levine, counsel representing some Hepatitis C patients before the Inquiry is not representing a formal national organization. However, he did open the issue on hepatitis C at the start of the Commission hearings in November 1993.

Dr. Powell has strong views regarding the future configuration

of the Blood System in Canada. He believes that the monopoly of the Red Cross must be broken, that the blood transfusion service should be integrated with hospital-care services, and that an autologous blood transfusion program should be mandated. There should be no paid blood donations. He pointed out that now the Red Cross is picking up donors with chronic hepatitis C infections (by a specific hepatitis C-antibody test implemented in 1991). Donors thus identified receive a rather callous letter, asking them to refrain from donating and to get themselves tested. Donors may be feeling ill and guilty (as they may have donated blood on previous occasions and infected other people).

[Dr. Powell's group is preparing a class-action suit]. Dr. Powell reported that some people do not need the [compensation] money yet. Older people are told that they do not need to worry, because they would die anyway before the hepatitis would become an issue for them [which is nonsense, of course, because the course of the disease is not really predictable].

The Ontario Government has been unsympathetic so far, and the Federal Minister of Health, Dianne Marleau, has been extremely unsympathetic. In June 1994 she made it clear in the House that she would not consider a compensation package for Hepatitis C victims. [Meanwhile, class-action suits have been filed or are being prepared in London, England and in Australia.]

Discussion

External ecology

The possibility of transmitting hepatitis other than of type B has been known for a long time (Krassnitzky et al. 1970), for hemophiliacs as well as for general transfusion recipients. However, the virus was not identified until 1989 (Kuo G. et al. 1989). Thus, together with hepatitis B, it had been in the blood supply for a long time. The hepatitis B problem was solved, in part, by the introduction of an antigen test (hepatitis B surface antigen), but not entirely, as it mainly picked up cases with chronic hepatitis or asymptomatic carriers. Hepatitis B became a renewed problem in the late seventies, when hemophiliacs were given the new Factor VIII concentrate which was produced from pools of tens of thousands of blood or plasma donors, many of them paid donors. In the late seventies, acute hepatitis B was spreading amongst some donor groups by sexual transmission. (A similar hepatitis B epidemic exists now in Canada's high-schools, but the measures to prevent transmission by blood transfusion by the Canadian Red Cross Society have not changed. The Red Cross has been recently cited by FDA inspectors for not using surrogate testing). Not all of the acute cases were picked up by the antigen-test. An antibody-test for hepatitis B, which is the most encompassing and reliable test for any kind of hepatitis B infection, might have picked up additional cases (about 10 % of all; see Ottosen 1993). The test was not introduced by the industry in the late seventies. It was used later by the plasma industry, after the AIDS epidemic settled into the blood supply as a surrogate test for AIDS.

(See Appendix 1). Together with AIDS, hepatitis C moved into the blood supply. Since liver function tests were generally not used by the industry, the majority of hemophiliacs were infected, as well as a large number of transfused patients. Surrogate tests were used in almost all Western industrialized countries, but not in Canada (Blajchman 1994).

Instead of introducing the test, the Canadian Red Cross decided to 'study the problem'. On various meeting occasions, I heard or overheard Dr. Perrault, National Director of the Canadian Red Cross Blood Transfusion Service, indicating that '*Canada is the only country where a prospective study can still be done*'. The study was developed in conjunction with McMaster Medical School. On one occasion I indicated that there was already enough evidence in the literature that aminotranferases are indicative of infectious liver disease, and that a prospective study would not be necessary. My comment was met with total silence and then ignored. I have since analyzed two important studies (Feinman et al 1988; Blajchman et al. 1994). Today I find the studies unethical, because more than a million Canadians were exposed to a known risk in order to find 'scientific proof' and the precise 'efficacy' and cost-effectiveness of a test. Today it is clear that the test would have prevented most cases of hepatitis C transmission (Blajchman et al. 1994).

The study was in part funded by Health and Welfare Canada. This, in addition to not having regulated the hepatitis C threat, implicates the Federal Government in all the circumstances of the study.

I would suggest that this approach was not only unethical, but that the possibility of criminality exists (if not by existing codes, but at least in terms of the intent of codes referring to crimes against humanity). Surrogate testing was 'state of the art' at the time and, while not scientifically

proven, it had a high likelihood of being at least partially effective. A 'prospective study', even if consent was obtained from a captive population, would rank with concentration camp experiments and with hepatitis inoculations which were performed on children, who were inmates of an orphanage at Willowbrook, Texas, by Dr. Krugman and Dr. Giles during the sixties. (Krugman et al., 1962). Since the degree of efficacy of the surrogate test was not accepted by the Red Cross, patients were not given the available truth that there was at least a chance that surrogate-tested blood would be less risky than untested blood, and that there was a significant probability of chronicity. (However, a watered-down version of such information was provided to the participants in the prospective study).

The Canadian study was performed between 1988 and 1992. In 1984 to 1985, the Toronto Blood Centre (as a transfusion hepatitis related project, initiated by Dr. Damiana Wrobel, Medical Director of the Centre between 1968 and 1985) had retained aliquots of some 150 000 donations. According to the Feinman study (1988), these specimens were collected for the purpose of this study - and then they were not tested. This could have been a reasonable, prospective, exploratory study. In all likelihood, it would have yielded enough evidence to consider or discard the idea of the 1988-1992 prospective study. The specimens could also have been tested for HIV. The specimens were discovered by a lawyer for Jerry Freise's group, because the Red Cross had used such specimens for its own defence in court in at least one hepatitis related law-suit. (Jerry, Freise, personal communication). I suspect that the Toronto Blood Centre Medical Director and Dr. Feinman received instructions not to test, so that the excuse of not having enough evidence to screen donors with surrogate tests could be upheld for years to come. Dr. Feinman acknowledges Dr.

Perrault, National Director of the Canadian Red Cross Blood Transfusion Service, Dr. Martin Davey, Assistant National Director, Dr. Nusbacher, Medical Director of the Toronto Blood Centre in 1987, Dr. R. Herst, Deputy Medical Director of the Toronto Blood Centre under Dr. Nusbacher, for 'advice and encouragement' (!). Dr. Damiana Wrobel, Medical Director at the time of the study, and Dr. Andrew Kaegi, Deputy Medical Director at the time of the study, are not mentioned at all. (Dr. Wrobel was forcefully retired in 1985, Dr. Kaegi was not granted directorship, but it was given to Dr. Nusbacher. Dr. Kaegi left in 1985 'because of issues'. It seems that Dr. Feinman has done a fine job of implicating some of those who might have had a say in not testing the samples and, by exclusion, to recognize those who might have had their arms twisted and who were eventually forced out of the system. It is very difficult not to moralize on the hepatitis C issue. The uncertainty theory ('we could not be sure the surrogate test would be effective') does not hold up at all in the case of hepatitis C. Regardless what the motivations may have been, the issue was kept concealed longer than the HIV issue, and it was only brought to the Commission of Inquiry by a single patient and his counsel. It still took almost a full year to enter into public awareness to the same degree as HIV.

The commercial motive is most likely the same as for the distribution of HIV contaminated product: the American government had implemented surrogate tests to prevent the spread of hepatitis C and stock untested with the prescribed procedures could no longer be sold in the U.S. In the absence of corresponding regulations in Canada, the product could still be sold in Canada. In addition, Canadian governments may have been locked into cost-rationalized strategies of their own.

Chapter 9 contains a summary discussion of the ecology of transfusion-related infections. It will be pointed out that there has been a blindspot amongst blood bankers for such infections (in fact, many blood bankers hardly ever see a clinical case). The blood banking profession was focused on blood group serology and later on component production. This changed with the hepatitis B testing around 1970. Thereafter, the knowledge and volume of publications on transfusion related hepatitis was growing rapidly and it was no longer possible to claim ignorance. Dr. Wrobel of the Toronto Blood Centre and Dr. Feinman of the Mount Sinai Hospital in Toronto began to investigate transfusion related hepatitis non-A, non-B as early as 1972.

The hepatitis story has a long-standing pattern of transgressions of the boundary between 'healing practice' and 'inflicting damages'. The Krugman/Giles study at Willowbrook was a criminal undertaking. Dr. Krugman still travelled with results from testing of stored samples in Europe in the early seventies. By the standards of the Nuremberg tribunals, his study was a 'crime against humanity'. (This is what my colleagues and I thought in Vienna at the time).

With respect to notification, counselling, transmission, prevention and compensation, a hepatitis C transfused infected patient population was handled exactly the same way as HIV infected people and no detailed comment is required here. There is one difference so far, in that it had no particular association with any identified high-risk behaviour group, and thus patients did not incur the social stigma which was attached to HIV. There is another difference: HIV leads to death in the majority of infections, whereas Hepatitis C shows chronicity only in a percentage, of which only a portion will progress to incurable and eventually deadly liver di-

sease. The timelag between infection and chronic illness may be decades and is thus, on average much longer than for HIV.

Inner ecology

The conditions of inner ecology of the hepatitis C victims is not fundamentally different from that of the transfused HIV victims. However, the possible prevention is much more readily evidenced for hepatitis C than for HIV, in particular during in the mid-eighties. All the circumstances of neglect, lack of consultation, lack of disclosure at the time of transfusion, lack of counselling, lack of financial support, unsympathetic responsible government agencies are phenomena which have been observed by HIV victims before. The original blind faith in the system and medical professional authority, the initial denial, disbelief and, eventually, a gradual learning that the most trusted institutions had betrayed the patients is a familiar pattern.

Alan is a sociologist by training and profession, he is also an experienced social activist. He may deal with the intransigence of institutions in a more detached, strategic manner than other citizens who had not previous experience with the 'system'. As late-comer to the process, he still has considerable faith in the Krever Commission, although recent events may be changing that: such as the threat to ban the Canadian Hemophilia Society from the Inquiry, requested by counsel of the Red Cross and supported by Judge Krever on the grounds of 'untimely publicity of the hepatitis C study'. Alan has commented on the undue secrecy used by the Commissioner and Commission counsel. The same has occurred with respect to the 'safety panel report' of the Commission. Judge Krever retracted his

attempts of deferring or preventing publicity.

The victims of HIV infections had to deal with a great amount of complexity. Comparitively, the complexity of heptitis infections can be overwhelming. For instance, Alan was infected with hepatitis C through a blood transfusion. It is not easy to construct a model of all the bridges between the circumstances of his infection, between hepatitis B, HIV, the plasma industry, the Federal Government, the other victim groups, hospitals, the Red Cross, provincial public health services, funding mechanisms, individual players and so forth. (This has been difficult enough for me with considerable knowledge of the system; it is dreadfully difficult for an outsider. The realization of the total power which this 'system' represents can be very distressing).

Alan, as an experienced activist, and despite serious money problems, is totally focused on the management of his victim group. The activism provides a 'rational preoccupation' which may be attenuating his suffering. Relevant meaning has been an important factor for victims in their coping strategies. If an infection is just a matter of 'overwhelming nature', people may be able to find meaning in that fact itself or in whatever spiritual processes they have access to. If the suffering is inflicted by other human beings, if it is the result of social processes, the search for meaning is far more difficult, and also far more engaging. It involves an extensive re-orientation in a taken-for-granted social world and in concepts of justice which appear to be corrupted. Most importantly, it results in breakdown of the faith in authorities and their rational and symbolic influences in maintaining prevailing belief systems - under conditions of democracy.

Of all threats, this is the most significant threat to the medical professions, to the pharmaceutical business, the Red Cross and the Federal

Government. A recent upsurge in television programs on the medical profession may not be accidental, but a concerted public relations effort in 'damage-control', to head off the worst consequences for severely tarnished professions and institutions. The pharmaceutical industry has even managed to co-opt a socialist government in Ontario (Premier Bob Rae) as part of the damage control.

Randy and Janet Connors

Randy Connors was a severe hemophiliac, residing in Halifax. He died of AIDS-related complications, a few months after he gave his testimony before the Krever Commission in February 1994 in Toronto. He would not have lived long enough to testify when the Commission came to hold its hearings in Halifax (in September 1994). He had been very eager to testify in Toronto. His wife Janet had been infected by him. Both of them were amongst the most engaged HIV victim activists. Janet is continuing the work after his death. At the time of the testimony, Randy was quite ill from AIDS related respiratory infections and had great difficulty speaking. Janet has had manifestations of AIDS (not just an HIV infection) for quite some time. It has not diminished her resolve to bring the truth of the contamination of the blood supply into the open. I spoke to her in October 1994, and she indicated to me that at times she is quite afraid of some retaliatory response from the industry, because of her and her husband's activism. I myself experienced similar feelings during 1993, in particular before I testified before the parliamentary subcommittee. This feeling became particularly acute, when I was approached that I should withdraw my application for testimony on grounds of 'mental distress'. I also received 'hints' that the community would turn against me as it did in the case of a Winnipeg man who had fought for bilingual traffic tickets, all the way to the Supreme Court. (He won, but suffered a heart attack and lost everything.) This fear is typical of whistle-blowers as described by Glazer and Glazer (1989). I assured Janet that she has become a Canadian icon and, therefore, she should not be worried about her personal and her son's safety. (Another undisclosed activist, whose identity I must protect,

expressed similar feelings of fear of recriminations and threats to personal and family safety and had a new alarm system installed in the home. Fear is perhaps the least disclosed emotional experience in this whole matter. The ruthlessness with which people were infected (and effectively killed) makes this fear at least understandable and, to some extent, justifiable. The following is a summary of Randy's and Janet's testimonies, given under questioning from Commission counsel M. Edwardh. To make this summary manageable, the questions and Janet's and Randy's responses are flowing together at times. Like for all the testimonies, transcripts can be obtained from the Commission office.

At the beginning of his testimony, Randy indicated that he has some increasing memory problem, in particular in remembering sequences of events. Both Janet and he had gone public in November 1991. [Janet explained to me that this had been the best strategy to overcome fear, but also to ensure personal safety]. Randy described the importance of the Inquiry in terms of compensation for infected people, to find out what happened, who was responsible, and why it happened. Thousands of infected people had not been told that the blood was infected and had their lives destroyed. What had happened was devastating to Canadians across the country. Measures need to be put in place so that it will never happen again. Randy believed that it was criminal. He was afraid for his son if he ever should need a blood transfusion. In the beginning Randy thought it was just bad luck. Later he found out that it was known that Factor VIII was infected and it was given anyway. He became furious. He did not know who to blame, he did not know what to tell his son. Janet echoed the devastation of their lives, and the need to know

what had happend, why it had happened.

Randy had lived in Montreal until the age of 13, then moved to Moncton with his parents and, finally, to Halifax. Educated as a teacher, he became a computer programmer with the Federal Government in 1985, until disability set in. Janet is and has been a member of numerous voluntary organizations and projects, either hemophilia-related or AIDS-related. Both had many speaking engagements at provincial, national and international meetings, they spoke to students of social work, pharmacy and journalism, and they gave more than 100 interviews to reporters. They supported other people with infections, including hepatitis C infected people, across Canada.

Randy had received whole blood and plasma as an infant, bleeds were severe and frequent. He spent, in total, many months in the hospital. In the early seventies he went on cryoprecipitate. This was much better, as he did not have to be hospitalized for the treatment of his bleeds. He was treated as an out-patient. However, he often had to wait up to four hours for an intern to inject the cryoprecipitate. He was eventually put on a preventive maintenance trial, to prevent bleeding episodes rather than treat them. This was the beginning of the 'prophylactic treatment'. This significantly reduced the bleedings and he went for his treatments four times a week. Cryoprecipitate gave some freedom.

In the late seventies, he was switched to Factor VIII concentrate and, in 1980, to 'self'- or 'home'-treatment. In 1981 he moved to Halifax. At that point Randy was advocating for home care. He would get two weeks supplies upon prescription from his attending hematologists. The prescribing hematologist recommended a knee-joint fu-

sion for his damaged knee, but Randy did not take his advice. Randy did not see a doctor for the next few years, he just picked up the Factor VIII from the Halifax Infirmary. He never had any problems and there was never an emergency; product was never withheld. The quality of life was dramatically changed with the concentrate, there were no spontaneous and few other kinds of bleeds. With factor VIII concentrate, Randy became a 'productive member of society', he was able to go camping, he hitch-hiked across Canada, he travelled across Europe. He was not dependent on other people such as his parents.

Bleeds had become very rare. Immediate injection would stop the bleeding. He kept Factor VIII at the desk at work, at his parents' house and at his own home. Bleeds were never severe, and recovery was always instant. Various manufacturers, Miles-Cutter, Hyland, Armor and Alpha had all been suppliers of Randy's Factor VIII concentrate. In December 1985 he learned through 20/20, an American show, that Hyland products had exposed American hemophiliacs to HIV. He removed Hyland product from his stock and felt that he should get tested as well. In the years preceding this discovery, the hospital had his address and phone number, but he was never contacted by any agency or doctor who had anything to do with these products. Nobody had advised him that AIDS might be transmitted via the product, that there was an increased risk of AIDS from the use of concentrate, or that 9 hemophiliacs had contracted AIDS in 1982, or that hemophiliacs showed abnormalities in the immune system very similar to abnormalities detected in patients with AIDS. He stayed at the same number and address till 1990.

If someone had told him in 1982 that AIDS could be transmitted by Factor VIII, that it may cause an immune deficiency, that the mortality of AIDS was high, it would have made a difference: given the opportunity to make a personal choice, he would not have used the product and he would have switched back to cryoprecipitate. All along, he lived only two blocks from the hospital and only a mile from the Red Cross Blood Centre, until 1990. [Thus to get the cryo injected at the Infirmary would not have been a serious aggravation]. When the Canadian Hemophilia Society Medical Advisory Committee recommended criteria for the distribution of non-heat-treated [presumed infectious] factor VIII, no permission was sought from the patients. Randy perceived the need to be tested for HIV from the American television show, not from anyone in the Canadian blood system.

He went to Janet's doctor and asked for an anonymous test. There was no pretest-counselling. When the result came back positive, the doctor commented that this was to be expected, as at that point most hemophiliacs were infected. Janet was tested at the same time. Her results were negative. Randy received the result by phone. He was not too upset at the time, the doctor at the infectious diseases clinic told him that there was only (!) a 50/50 chance that full-blown AIDS would develop. Randy thought he had a chance, and did not worry about it at the time. It did not seem real. He did not know much about AIDS. He had heard that it was a 'gay plague'.

He booked an appointment after a year. After that the intervals shortened. He received 'safe sex advice' but was told that hemophiliacs do not seem to pass the virus to their spouses, and

that safe sex would be his personal choice. The couple did use condoms thereafter, but they were not advised on the use of lubricants. Public Health later pressured the doctor to release the name, to the point of threatening him with loss of license to practice. Janet called Public Health. The doctor wanted to do a look-back or trace-back, but once he realized that Randy was a hemophiliac, and that Randy had been infected many times over from a large donor pool, he did not pursue the matter any further. The Connors' had been concerned about confidentiality of Randy's test result because of the experience of an elementary teacher in rural Nova Scotia. The doctor's secretary leaked his positive test result to the school-board, and the teacher fired and virtually run out of town.

Janet confirmed that after they had learned about their HIV status (Randy positive, Janet negative) at the Infectious Disease Clinic at the Infirmary, she planned to be tested every three month, then stretched it to six months. The assurances that spouses would not get infected were strong enough not to pay much attention to the number of condoms which were breaking. The family doctor recommended brand names of condoms, advised to keep using them, but gave no information on lubricants. There was no contact from any other health officials in Nova Scotia.

In 1989 Janet had not been feeling well, she had flue-like symptoms and discovered lumps in her armpits, near the collar bone, the back of the head, groins, on inside of her thighs. She was tested for mononucleosis (EBV). The the doctor thought it might be breast cancer and wanted to refer her to a specialist. Janet insisted on an HIV-test instead. She got the result from the doctor's secre-

tary during a lunch break. She asked Janet to see the doctor and told her that the specialist appointment had been cancelled. At that point Janet knew that she had AIDS. She remembers every detail of this day, it was such a nice day, and it was the last day of freedom and the end of the life that she had had.

Randy and Janet could not tell Janet's parents, as their son was fighting cancer and was hospitalized. For years they kept the information to themselves. After a while they could not remember whom they had told what. Festive occasions and family gathering also did not provide the circumstance in which the truth could have been revealed. It was never a good time to tell Janet's parents.

Janet was officially told in the doctor's office the next day. Randy could not believe it. It was not supposed to happen, they had been told that hemophiliacs were not passing it on. Randy did not know what to do and what to think. As a hemophiliac child he had been used to being sick, and for him, at the time, being HIV positive was 'just one more thing'. Janet had never been sick in her life. Randy had to deal with the thought of having inflicted it on her. Their son was 9 years old at the time. The doctor had told Janet that her 'AIDS' test was positive, Randy had been told that his 'HIV' test was positive. The doctor did not know the difference in meaning.

Janet suddenly had the feeling that she was dirty. When she went to the Infectious Diseases Clinic, all the nurses were coming in, one by one, as they were curious to see a 'women with AIDS'. (Janet was one of the first women with AIDS in Nova Scotia; some others had died from it earlier; but she was the first women presenting in

an emergency department). Janet felt like a freak, complained about it to hospital administration, and was told that there was nothing that could be done about it.

Randy also tested positive for hepatitis C. He had been tested 20 months before this testimony, but was told of the result only two months before the testimony. It was announced by the hemophilia clinic as not being 'a big deal'. If Randy had not requested the result, he would not have known. He could have infected Janet again as well as their son. There had been reports of young children infected by their parents.

When he told Janet, she had a screaming fit. He should have been informed when the result had become available. Janet and their son tested negative later. Janet had been told six months before this inquiry not to worry about Randy's hepatitis test. The argument was, that if Randy had tested positive, he would have been informed. The excuse given for not informing him was that the lab-report had been put into the chart before the doctor had a chance to see it.

The matter had to be discussed with their son before he got tested, which was very difficult. He became scared, his parents had always assured him that nothing could be passed on to him. He wanted to know if he might die from it, he did not understand, he had a sense of some amorphous danger. This evoked an enormous amount of guilt in Janet. The faith that their son would be spared had always been the source of some comfort. She had read about hepatitis C and that in some cases it would result in terminal disease. She did not hold back this information from her thirteen year old son. The doctor again turned out to be ill-informed and could not tell if Janet

and her son were at risk. At that point, for the first time, Janet had suicidal ideation. Although Janet and her son tested negative, the son let his parents know that now he cannot feel joy anymore, which is very distressing for Janet.

Other information had been withheld from the Connors family as well, such as their T-cell count in the late eighties. As a result Randy did not get AZT (a chemical used in AIDS treatment) when he should have. Randy heard about it when the hematologist called him to establish eligibility for the federal compensation package (1989). His T-cell count was below 200 - indicative of clinical AIDS. At that point Randy became very emotional, he realized that his condition had become very precarious, and that he would not be amongst the 50 % which would not get full-blown AIDS. He realized that the withholding of the information might have cost him years of his life. Many other supportive treatments, which could have been made available to Randy were missed during those years as well.

Janet talked to the hemotologists about this a few days after she found out that she was positive. She told the doctor that she wanted Randy removed from her care, and early on she should have been encouraging Randy to attend the Infectious Diseases Clinic. She told her that she had shortended Randy's life considerably, and that the test information did not belong to her but to Randy.

Randy never liked the hemophilia clinics, he did not like to have his life controlled, he found it to be an oppressive, unsympathetic regime [see early recommendation knee joint fusion above, which Randy fortunately never followed]. He felt that the whole cli-

nic was a waste. When Randy was to be switched to a safer, bioengineered (monoclonal) product, he experienced the worst of oppression. He was told that if he would not provide all the documentation that was requested of him, he would be cut off from the product and be taken off homecare. In addition, to be eligible for monoclonal Factor VIII, he was required to participate in a clinical trial during which he was to stay without Factor VIII for five days. [Randy's hemophilia was severe enough to result in spontaneous bleeds if went on without product for 5 days. In addition his mobility was reduced, and an accident or fall could have been catastrophic]. Janet found out that such studies had already been done in the U.S. and that there was no need to repeat them in Canada. Janet was told, that they [?] just wanted to repeat the study, so that they [?] would have Canadian statistics.

Janet added later that the removal of homecare would have been particularly severe under Randy's conditions, because of large disruptions in their lives, and long waiting times in emergency departments. Without prophylactic treatment he would have incurred further joint damage. Life would have revolved around the hospital. Janet indicated that the attending hematologist was responsible for these policies and threats and the decision, whether Randy would stay on homecare or not. No other hemophiliac in the province had experienced similar threats, although some fears were expressed by one other hemophiliac.

Note: It appears that Randy was singled out. This mixture of extreme callousness and combined with 'care-giving' have characterized the institutional handling of the aftermath of the contamination of the blood supply. It appears to be the

expression of two parallel strategies: to placate victims (with compensation and new product), and to intimidate them at the same time: either way, it might have reduced their resolve to seek civil or criminal redress. The authorities seem to forget, however, the degree of contradiction, 'double-binding' and 'dissonance' this creates. As activists in a province where a fractionation plant is to be built, the Connors' represent a particular threat to industry and government. Thus they may have found themselves more harrassed than others, and at the same time more generously compensated than others.

In his closing remarks Randy expressed hope that this Inquiry would bring to light what had happened, and why. He thought it was a real tragedy, he could not believe that he was given product that would destroy his and his family's life. To some extent he was still in denial that someone made a conscious decision to give out product that was infected. Something needs to be put in place that it can never happen again. It should have never happened. He was still angry. He felt that part of the tragedy was the long distance between the time of infection and the appearance of symptoms. People sit back and if it does not affect them now, they believe they can forget about it. He did not want his family exposed. The system still cannot be trusted, and even one person infected is one person too many, in particular if you are that person.....He did not know who to point the finger at. People responsible should say that they are sorry, and ask what they could do to help. Compensation could have been granted many years ago, if they had taken the blame, that would have been great, but that has not happened.

When Janet was found infected in 1989 at the Infectious Diseases Clinic, she was told that the average life-expectancy for a women discovered to be HIV-positive was six months. She actually believed

that she had only six months to live. When she asked about quitting smoking, she was told that she would be long dead of AIDS before respiratory problems from smoking would become a problem. The whole thing was handled in a rather 'cavalier' manner.

Janet was Randy's care-giver. She was the only driver in the family, she had to change the surgical dressing for a permanent intravenous cannula with a sterile procedure, which she had been taught to do. The line had to be flushed with saline regularly and a blood thinner had to be administered. Randy was not strong enough to get in and out of the bath tub and could not go up and down the stairs. Janet had to inject factor VIII because Randy could not reach the site for injection himself. She also had to administer i.v. drips for medication for his nausea. Randy needed a wheel-chair, assistance with change of clothing, and many personal services. Janet provided essentially round-the-clock care.

Her T4 count is now close to 200 and thus approaching AIDS. She had bacterial pneumonia in 1993, oesophageal thrush, an early symptom in women, which men tend to get in the mouth; skin problems, seborrhea, bright red rash, very itchy; chronic fatigue, while she is limited to care for herself. Randy was very concerned that he would not be around when Janet would need Randy's help and for his son, Robert Angus Donald Connors.

Janet also became an activist for women with AIDS. Hemophiliacs had been ignored before, women were still having a problem to convince family physicians to test them for HIV, prostitutes may get it and they may use drugs, but 'nice women' (mothers and wives) have nothing to worry about. Men were asked to protect themselves

when they have intercourse with a prostitute, but not to protect the women they have intercourse with. There are sex-related differences for the development of AIDS, one of them may be a higher risk of cervical cancer, oesophageal or vaginal thrush may be the first opportunistic infection and may go untreated for a long time. The Nova Scotia AIDS coalition has done a project on women and AIDS such as a province-wide needs assessment, women as care-givers, educational needs for uninfected women; the establishment of a maritime multi-provincial support network for positive women. There is still a lot of ignorance, fear and misinformation. It is difficult for women to find support and a doctor who will test. Mothers are not considered to be 'sexually active', or even 'sexual beings' (the meaning of promiscuity is being confused by the term 'sexually active'), and the risk involved in having sexual (including extramarital) relations is thus camouflaged.

In 1993, when the Sick Children's hospital in Toronto started the search for infected children, people in Nova Scotia were told by the Health Department that Nova Scotians did not have to worry, and that such a search was not worth the time and money it would cost. This was publicized in series of newspaper articles. Janet wrote to the editor:

Imagine one child was infected, imagine that that one child is now 19 or twenty years old, imagine that that one child, now a young adult, has had four sex partners, imagine that those four partners had four partners, imagine that those sixteen partners had four partners, imagine that those 64 partners had...you get my point.

Imagine that the nineteen or twenty year old is your child. Imagine it is you. Nova Scotians who received blood or

blood products are not different from anybody else, they have sex, some of them get married, some of them have children, they can all pass on the virus.

Janet then asked that all transfused Nova Scotians be tested for HIV. As a result of the letter the public was advised to get tested. The announcement was carried on the inside-pages of two newspapers, not on the front pages. The announcement referred to blood, not to any other blood product. The announcement was not repeated.

Randy and Janet Connors were confronted with a unique issue, the construction of plasma fractionation plant by Cutter-Miles-Bayer [the key supplier of fractionation products, including factor VIII, to Canada, and preferred subcontractor of the Canadian Red Cross Society] as a joint project with the Canadian Red Cross Society in Nova Scotia, before the Inquiry had arrived at its conclusions and recommendations. The proposal for the plant had been previously denied by the Canadian Blood Agency. Janet was afraid that jobs would be traded for health. As President of provincial hemophilia chapter she expressed concern regarding the planned dependency of Canadian hemophiliacs on this plant. If in the future production difficulties should arise, Canadian hemophiliacs could be forced to use the products of this plant to preserve the jobs, even if such products would no longer be acceptable off-shore. The plant is not intended to produce monoclonal or recombinant Factor VIII and hemophiliacs may be forced to stay with the traditional blood technology. Similar decisions had been made with respect to Connaught Laboratories in Toronto in the mid-eighties, with disastrous results.

Note: In order to run efficiently, that plant is planned to be twice the capacity of what would be needed for Canadian self-sufficiency in plasma products. To utilize the extra capacity, plasma would have to be imported from off-shore, from anywhere in the world, and would thus come from paid donors. The product would then be exported, with a Canadian export stamp and the Red Cross emblem on the label, conveying a potentially deceptive image of safety and humanitarianism.

Janet commented on the role of the Health Protection Branch of Health and Welfare Canada by making reference to the 'tuna scandal' a few years ago, which resulted in the resignation of a responsible minister. [The tuna was found unfit for human consumption, but not to be a risk to human health. I had one of those cans myself at the time. The tuna tasted awful, I ate it anyway and did not get sick]. The Bureau of Biologics should have taken charge and notified users of products. But everyone else who had something to do with it should have been involved in the notification effort.

When Janet had written to the papers to alert Nova Scotians to get tested, the Red Cross started an ad-campaign with large posters "*The Red Cross doesn't need blood, people do.*" Shortly before that Janet had referred to the fractionation plant proposal as 'obscene'. While it cannot be proven, Janet felt that this ad campaign was in direct response to her interventions. The ad-campaign should have dealt with getting the people who received transfusions to be tested instead.

Note: It has been a consistent pattern of the public relations campaign of the Red Cross to counter every bit of bad news about its performance in the contamination of the blood supply with positive advertising, positive stories and so forth. This effort is financed with a 1 million dollar public relations

contract, presumably from public funds. While this may be a valid strategy from the Red Cross' point of view, it is designed to maintain a high degree of ambiguity regarding the image of the Red Cross, and the resulting confusion and suggestibility of the public can be exploited in favor of the Red Cross. Victims simply do not have the kind of funding necessary to keep pace with this.

Janet's comments with respect to the blood system are as follows: the blood system should be responsible to react as soon as a hazard is suspected. It is not good enough to claim avoidance of public panic or not enough scientific knowledge. When suspicion arises it is time to act, anybody who suspects has the responsibility to act.

The Canadian Hemophilia Society, and in particular the Medical-Scientific Advisory Committee must consider that not all of the hemophiliacs belong to it. It did have a responsibility to notify hemophiliacs. There is one concern that professional people are members of the Society: this may lead to conflict of interest. The Hemophilia Society may be better served with independent experts.

With respect to compensation Janet advocated for no-fault insurance program for blood-borne illnesses so that people do not have to lose their homes as a result of job loss and rising expenses. All the provinces decided not to act independently. The Nova Scotia Minister of Health (conservative) broke ranks with the other provinces [prior to this testimony]. The Minister acknowledged that the Connors had a reasonable request and understood. Randy wanted to see this as a compassionate humanitarian gesture.

Note: the plasma plant flies in the face of such claims, and makes the settlement look rather like a placating strategy to minimize bad publicity in the Province which could turn the population against the plant. By the same token, Nova Scotia may have been the only province which did not get product from the more highly infected American paid-donor plasma. Thus the plans for building a plant in Nova Scotia may date back to the early eighties, under a liberal federal government, now implemented under liberal federal government and a liberal provincial government. The ceremonial sod-turning has taken place. Janet attended as a protester but was ignored by the officials present. Premier Savage had a chuckle, because he thought there were no protesters at the ceremony. He had not noticed Janet's presence].

In the future, victims should not have to rely on the kind of process they had to go through to get compensation for damages from the contamination of the blood supply. [Randy and Janet Connors did not have to sign the waivers to get the compensation package from the Province of Nova Scotia]. Janet urged for recommendations for mandatory notifications, of infection of sexual partners. In the future there should be proaction rather than reaction, authorities should not wait until thousands of people are infected, before any action is taken. AIDS care needs funding. Criminal justice is required. Once evidence can be narrowed down on individuals they should be prosecuted with the full force of the law and sent to jail. People should not be allowed to get away with it.

Discussion

General comments

It seems that all processes leading to the contamination of the Cana-

dian blood supply have converged on Randy and Janet Connors, with the one exception that their child has been spared any direct effect. However, the matter of hepatitis C did have a major impact on their son. Their account is paradigmatic for many other hemophiliacs and their families, hundreds of which can no longer testify because they have died. I should add that I did not listen to the broadcast when it was taped because I was out of the house, and I reviewed the video tape only after virtually everything else in the thesis had already been written. As result of the review, some additional changes in the thesis paper have taken place, in particular in the discussion, but nothing that profoundly changed earlier interpretations which are offered. I am viewing this testimony as a very special verifications of the theories advanced in the thesis. I have found no cause to make substantial adjustments.

A feature which had not surfaced previously was the element of fear of retaliation to activism, which is colored by the kind of institutions from where the retaliation may come: the Federal Government and the corporate sector. This will be the most significant element to be added in the discussion, in particular on the aspect of the use of suffering and the fear of suffering as a coercive social control instrument. The problem with this aspect is that it is rarely overt, and can be easily construed as 'activist or whistle-blowing paranoia'. The other aspect which emerges in Randy's case is the abusive form of medical investigation and research, which was imposed on Randy under threat of withdrawal of care. Since it appears that he was singled out, this feature is also linked with the use of fear in controlling social behaviour. It is disturbing, of course, that this is done in the context of 'health-care', 'humanitarianism' and under the Red Cross emblem. Jerry Freise had experienced intimidation and bullying, but not

the instilling of fear. In Joleen's case, blackmail had been quite overt. In a private conversation, Allan Powell told me that he had been bullied by one of the lawyers representing before the commission. The Decarie family experienced the bullying tactics of bureaucrats. All in all, the use of suffering and fear as social control instrument may have hardened the resolve of the people presented in this thesis, which would be typical of activists and whistle-blowers.

The data available for this thesis are not enough to prove that institutionally legitimated psychological coercion (as a form of infliction of suffering and violence) is a widespread problem in our society. However, the variety of people who participate in this particular manifestation of coercion, doctors, lawyers, news managers, public relations people, politicians, humanitarians, institutions, bureaucrats, regardless of gender, age, and ethnic background, should give rise to a concern that this may be a far more systemic phenomenon than is acknowledged. However, the careful legal construction and associated spin-doctoring will make it very difficult to investigate. Overt violence, which is much talked about, may ultimately be the result of a kind of silent oppression and psychological violence which is not talked about much. In other words, violence may now be a generalized problem in our society.

Instead of a discussion, a list of the internal and external ecological processes which engaged Randy's and Janet's situation is given.

External ecology

- o The intrusion of viruses (HIV and Hepatitis C) into human technology
- o The further sexual propagation of this technology-induced epidemic
- o The dependency of the human organism on technology
- o The benefit of technology of achieving 'productive participation in society'
- o The social norms which lead to the neglect of Janets risks of infection
- o The relative incompetencies of specialists
- o The system of suppression of display of suffering by concealment, compensation and intimidation
- o The break-through effect through public display of suffering
- o The counter-victimism response
- o Long-term corporate strategy of survival
- o The inaction of federal responsibility vis-a-vis corporate interests
- o The absense of formal spiritual authority (as in many other forms of suffering)
- o The economics of the victims
- o The economics of the provincial government (employment)
- o Non-use of scientific knowledge for ulterior economic motives

Internal ecology

Victims

- o Denial of severity of affliction (to feel comfortable with a 50/50

chance is denial)

- o Faith in rational authority
- o The achievement of a state of being a 'productive member of society'
- o Janets 'freak-experience' (instead of compassion being an object of curiosity of nurses: a severe state of dissonance)
- o The threat to ego once the security of the son was threatened; suicidal ideation; retreat in to the aggression/depression cycle
- o The demolition of rational authoritative control (through the Canadian Hemophilia Society there is some of this control still left; the Society receives significant funding from the Federal Government and from Miles-Canada, the company which is building the fractionation plant)
- o The emergence of personal quest: activism
- o Entry into the 'material cycle': focus of problematics and product and services solutions (more regulation, law and order)
- o An extensive alienation from society
- o The rebuilding of society through self-help group formation (resulting in the self-help cycle, in particular for Janet)

Economistic-rational strategy:

- o The unempathetic healthcare system (rational authoritative distortion)
- o An unsympathetic engineering intervention (suggestions of knee-joint fusion)
- o Non-disclosure of risk
- o Non-disclosure of infection (twice, hepatitis C and HIV)

(some passive euthanasia ideation might have been at work there)

- o Non-disclosure of severity of illness (Janet and Randy) (again euthanasia looms large)
- o Lack of counselling (in 1989!)
- o Breaking the news on the street (indiscretion)
- o Forcing a trial under threat of withholding safer product
- o Forcing paper compliance with threats of withdrawal of autonomy and of imposing severe restrictions on an already highly compromised life (this might have been retaliatory to Randy's activism)
- o Non-information of the public
- o Delay in compensation

Myth creation (symbolic authoritative distortion)

- o Wives and mothers are asexual beings
- o Nice women do not get AIDS (but they get breast cancer and mononucleosis)
- o AIDS was a tragedy (Randy was still vacillating in his testimony)
- o Biotechnology is the future of the maritime industry
- o Damage from medical intervention is 'luck of the draw'
- o The 'compassionate government' (suggests a suppressive tactic to ensure acceptance response to plant by Nova Scotians)
- o The Commission will bring about change for the better (it also

delays or may even prevent court action).

o Blood is an essential for Nova Scotians

The most disturbing aspect of this array is that many items occurred around 1990, not at the beginning of the eighties. Thus, instead of the system becoming more compassionate, it has hardened and become more ruthless than ever, but also more 'clever'. 'Rational-distortive authority has moved just a bit closer to functional psychopatho-mimesis, with health professionals, administrators and politicians obediently co-operating.

9 Discussion

The discussion consists of the following elements:

- 1) A discussion of difficulties encountered in representing and analysing 'complex processes'.
- 2) A brief recapitulation of human-ecological concepts developed and used in this thesis;
- 3) A discussion of how the documentary accounts and the accounts of victims can serve to inform the model of 'human internal and external ecology' and vice-versa;
- 4) A discussion how my own involvement and motivation may have helped or distorted the theory-construction and interpretation of data;
- 5) An evaluation of how well the data confirm or disconfirm the specific hypotheses as stated (on page 1).
- 6) A discussion of the utility of this kind of analysis for anthropological inquiry.
- 7) Some conclusions and recommendations.

1) The representation and analysis of complex human-ecological processes

The theory constructed for this exploration is an adapted composite of different anthropological subdisciplines. It does not contain any new elements. It was shown that ecological anthropology today remains a field of inquiry without a widely agreed-upon system of classification to deal with complex ecological processes with optimal inclusion of contingent processes. The ecological map generated for this thesis attempts to overcome this void. It may be far from what it ought to be, but it helped to select and organize what one may call 'messy data' from diverse frames of reference, with some degree of comprehensibility - I hope.

I know from personal experience in management that such organizing processes require many iterations before 'messy data' become comprehensible. For the purpose of this thesis only two iterations were carried out. There remains a lot of 'bridging', explanatory text and narrative, which tends to clutter the 'packaged relational content' to be communicated. However, we do not have, at this point, good methodologies to represent and communicate multiple, mutually contingent processes. The production of text is an inherently inadequate tool for such purposes.

Randy Shilts's account is a typical example: he presents a large number of processes (e.g. those which took place in the blood industry, the gay community, various health institutions, the White House, in the Pasteur Institute in France etc.), by chopping them up into 'events'. He then packages the individual events, synchronically, into 'dates'. Finally, his book became a temporally ordered string of such packages. This makes it difficult to read, but it provides a sense of synchronous relations

between events. However, it is very difficult to retain sequence of events for each individual process in one's memory. (I had to 'extract' sequences when needed, see for instance the account of Dr. Bove).

In late modernity, simple network analysis is no longer sufficient. The example of the analysis of the contamination of the blood-supply shows that it is necessary to identify relational, cybernetic and transformational patterns. The relational patterns themselves need to be developed on the basis of three kinds of networks and their interrelations, in which 'events' are embedded.

- 1) The networks of individuals and 'informal communications' (the basis for 'hear-say' accounts; used, in part, by Randy Shilts, 1988);
- 2) The networks of institutional infrastructures and environmental conditions (the basis for 'circumstantial' accounts; see Sandra Panem, written 1987, published 1988);
- 3) The networks of material ('objects') and coded information (the basis for 'hard evidence'; see for instance Madhok et al., ed., 1987.)

The concept of such networks is used, intuitively perhaps, in historical accounts, but usually with emphasis on one, or at the most, two kinds of networks (archeological accounts are, for instance, limited to networks of the second and third kind). These are, of course, only 'external ecological networks'. If one wants to include 'agency' in this kind of analysis, the 'internal networks' (the 'inner ecologies') of individuals need to be added as fourth kind of network.

Note: Courts do not consider the ecological frame (the law is a relational construct) and primarily rely on 'hard evidence', circumstantial evidence as second choice, and not at all on hear-say. Paradoxically, however, they tend to rely heavily on the 'softest' information of all, which is of the 'fourth kind' and 'inner-ecological': motivation, character, and the likes. (On the confoundedness of motivation see Appendix 2).

The mutual contingencies represented by the Royal Society Report, the Pitman trial and the Krever Commission is an example how such an extended network analysis can be utilized. The Pitman trial could not be a 'fair trial' until all the evidence had surfaced in the Krever Commission. Yet the judgement was needed to let the victims know that they have no chance in court. The precedents brought to bear in the Pitman judgement are mismatched with the actual processes which produced Mrs. Pitman's infection (e.g. by omission of the regulatory process). The Pitman trial has now become an 'deviation amplifying precedent' for the Krever inquiry. The 'hindsight hypothesis' is read, over and over again, by implicated officials, into the record of the Commission. Thus a miscarriage of justice has become 'reputable evidence' for the Commission. No wonder Justice Krever feels secure to say, in public, that *'we may never know who was responsible'*.

This suits him fine, since he himself may be partially responsible for the infection of some Canadians by his participation in the report of the Royal Society. Without such extended, 'ecological' network analysis of individuals, text and institutions, the credibility of the Commission of Inquiry on the Canadian Blood System could not be challenged.

The implication of such complexities is that its potential incomprehensibilities can be used and abused by authority with enough resources to manipulate the representations of what happened almost at will. In other

words, the creation of incomprehensibility has become a requisite instrument of power. This can be achieved, quite deliberately, by forming committees, councils, advisory boards with multi-institutional representations, consensus conferences, which tie various networks together, until, seemingly, there is no longer a discernible 'locus of control'. In business, similar networks can be established through various joint ventures, cross-appointments to boards, and multiple ownerships of companies, conglomerates and multinational locations of operations. At the same time potential countervailing networks can be disrupted by 'musical chair appointments', 'kaleidoscopic shifts', temporary and contract employment, the 'home-based' work, co-optation of leaderships of marginalized groups, the 'information highway', electronic supervisors, applied semiotics, 'event reporting', 'balanced reporting'. Thus incomprehensibility becomes almost total, and collective comprehension leading to collective resistance almost impossible. 'Big Brother' of 1984 needed surveillance and coercion. 'Big Brother' of 1994 only needs 'incomprehensibility'. "2 plus 2" is not what the state tells you it is, but whatever opinion you prefer.

Such an 'incomprehensibility jungle' has been fairly successfully created and used by the authorities involved in the contamination of the blood supply. The incomprehensibility of the contamination of the blood-supply is now 'cultivated' by the mass of data and information (not 'knowledge') generated by the Krever Inquiry.

However, this is not a complete jungle, but there are fairly small 'primary' networks (individuals, institutions and information) which have relatively more controlling influence (in terms of 'steady-state' as well as 'trans-formation') than others. I have referred to them as the 'loci of control'. They can still be summarized as the 'ruling elite' and its instru-

ments of power: elite strategies and interventions are cloaked by the incomprehensibility generated by the secondary, tertiary, etc. levels of networks.

However, since things have to get done sooner or later, some trails of elite strategy are still apparent, if one can make the correct assumptions on who, what and where the primary loci of control are. Financial processes (legitimate and not so legitimate) still provide the best clues. (See, for instance, the magazine *'Common Cause; People, Power and Politics in Washington'*, the publication of an American citizen's lobby.) Financial information invariably leads to individual networks, which lead to institutional networks, which lead to strategies of elites in power. I think there is some urgency to invert the Marxist structuralist metaphor, and to declare economics to be the superstructure and institutions to be the base - if for no other reason than to encourage 'lateral sociological thinking'. This 'network', 'critical path' and perhaps 'critical myth' exploration was used in this thesis to question the validity of the 'hindsight, helplessness theory' for the contamination of the blood supply, and to replace it with a 'foresight, strategic, adaptational, survival theory'. As important as the theory itself, which may, in good time, be deconstructed, discredited and politically trashed, are the actual 'adaptational processes' described in this thesis. They are in wide in use and can be observed.

Power can now insulate itself from the suffering it inflicts, without the ostensible use of coercion, suppression and oppression, simply by the 'incomprehensibility management', manipulating the networks mentioned above. Thus the most fundamental adaptive human processes, suffering and empathetic-compassionate response can be rendered ineffective. Ecologically, one would predict that if too much damage is accumulating, the

power system will eventually collapse from the weight of the side-effects of its actions. But like the Marxist prediction, that capitalism would become absurd and self-defeating, such predictions are not likely to come true. Under a threat of collapse, elites in power can and will adapt. But the suffering along the way could be more than horrendous: it could be or become generalized (see also my comments on 'generalized' psychological violence and in the 'footnote to the title page'). Corporatism and post-modernism have arrived at a mutually satisfying 'symbiosis'.

2) Recapitulation and summary of the basic human ecological concepts used in this thesis.

a) Processes of adaptedness ('steady-state') and adaptation ('transformation') occur simultaneously and are mutually confounded in all life-processes and in the cognition thereof. The 'corporation' is suggested to be the most viable form of human organization in late modernity. It can control processes of adaptation and adaptedness competitively and strategically - by extension of its systems of control into the boundary conditions of its operations.

b) Representational and predictive errors and distortions may arise from exclusively relational analysis which does not account for steady-state processes and transformational processes and their mutually confounded networks. An ecological framework of analysis is suggested to ameliorate such distortions.

c) Additional representational errors and distortions arise from narrow definitions of a problem without considering all relevant contingencies. (Note: it was not discussed in this thesis, but 'thesis' and 'antithesis' do not necessarily represent sufficient contingencies for each other).

d) Cognitive dissonances are not only confounded but also easily manipulated by authority.

e) Human consciousness, and with it, pain-related experiences and actions, participate in homeostatic and transformational human ecological processes. Accounting of this participation must include phenomena of action, behaviour and production observable in Others and Self, but also of conscious experience, which cannot be directly observed by others, and non-conscious processes.

f) The meaning, interpretation and ecological participation of pain-related phenomena are closely related to processes of social organization and their constraints (homeostatically and transformationally), and to changes in such processes.

g) The same distortions of representation which apply to consciousness in general thus apply for pain-related phenomena in particular.

h) Some of these social processes can be represented and examined with the model of the 'cycle of meaning'. (Laughlin et al, 1990). Modernity is characterized by a loss of cosmology, ritual expression, and holistic shamanic intervention, but specific substitutions have occurred. The 'cycle of meaning' developed by Laughlin and the concept of double-hermeneutic can be used for analysing substitutions in the cycle of meaning, cross-culturally and historically. It can also be used to explore the human-ecological position of suffering.

i) Excessive suffering (inflicted by humans) may have arisen in premodern civilization from the constraints of a badly ('non-ecolo-

gically') constructed cosmology. In contrast, late modernity may experience a rise in suffering from the constraint of 'lack of cosmological wholeness. 'Rights' and other protective codes are not ecologically constructed (they are relationally, not processually constructed) and represent late-modern, non-ecological constraint. Therefore they are potentially 'pathogenic' in an ecological sense. In the absence of cosmology, however, such 'simple rules' may be our only protection from a purely 'corporate cosmology' or other predatory or parasitic belief systems.

j) Starting with Forde's conception of the 'middle-term' between the environment and human activity, a model of 'human ecology' was developed, which equates 'culture' with 'human ecology' (and its adaptive and maladaptive manifestations), and accounts for neuro-cognitive and emotional processes as participants in human ecology. The currently preferred practice of 'economistic' ecological modelling is used to show the shortcomings of limited ecological frameworks.

k) The structural cognitive modalities of relation, cybernetics and transformation (including their application to pain-related phenomena) invoke the significance of preferential modes of cognition and emotional expression, feeding forward into 'external ecological processes' which, in turn, shape the modalities of cognition and emotional experience.

l) Pain-related phenomena are currently explained with a wide

diversity paradigms. The ecological framework is used to ameliorate the fragmentation in the understanding of pain-related phenomena.

m) Some known neurocognitive phenomena can be correlated with the ecological construction of pain-related phenomena.

n) The above concepts were tested in a comparison of preliterate and late-modern constructions of pain-related phenomena.

Pain-related phenomena are a particularly instructive field for the understanding of human ecological phenomena, as they comprise highly recognizable sets of signs and symptoms of adaptive and maladaptive processes of human individual, social and environmental organization. This has been demonstrated with the accounts presented in this thesis. In application to 'medical anthropology' it would shift the focus from natural sources of suffering and respective healing practices to human-inflicted, socio-cultural sources of suffering, and thus from the 'bright side' of culture-specific accomplishments in human well-being to the darker side of infliction of suffering by omission, commission and 'social compromise'. This includes issues of 'thanatology', horrendous death, and what I have referred to as 'generalized suffering'. The contamination of the blood supply resulted in horrendous death, and if we account for the consequences of downplaying the risks in the early eighties, death was more horrendous than has been admitted.

As dark as this subject may appear, in accordance with the opening quotes by Joseph Campbell, it has the potential of becoming also the 'bright light of prevention', a meaning sought after by those who are

dying from the 'social compromises' chosen at the time. 'One death' from such compromises is 'one death too many' was Randy Connors' conclusion. This society is far too wealthy to be able to seriously justify even one death from calculated omission and 'rational choice'. Besides, if we legitimize one, we will have effectively justified a thousand in advance. Such is the nature of the 'rational authorized action' dimension of our internal ecology. We have gained this insight with respect to capital punishment. We are nowhere near this insight in healthcare. As a corollary, the more willing we become to accept errors in judgement in capital punishment (and have a 'built-in' excuse of 'limited facts available at the time'), the more ready we may become to accept errors in judgement in other areas (with the same 'built-in' excuse of 'the limited knowledge available at the time'). In both cases, experts would determine what constitutes fact and knowledge, and in a case of misjudgement, the same experts would have the power to determine the limitations of facts and knowledge 'at the time'. This is one of the many 'cul-de-sacs' of pure 'rational choice'.

3) The question how the data informed the model of human ecology and pain-related phenomena and how the model informed the data.

Discussion of the external ecology of the contamination of the Canadian blood supply.

The ecology of blood-transfusion as vector of viral infections

The practice of transfusion (and the more generalized field, transplantation) introduced an ecological transformational process, to which humans were biologically not adapted (blood group incompatibilities were an earlier sign of this kind; see references Race and Sanger 1975; Mollison, 1972). Subsequently, the technology engaged in this transformational process was adapted ('blood typing'), but only partially. As the utility transfusion practice (initially as life-saving intervention for war casualties in World War II) became more widely established in medical and, in particular, in surgical practice, we became more and more dependent on this technology. While the dependency rose, the transmission of infectious agents became the ecologically most prominent problem. The transmissions of malaria and syphilis were amongst the earliest recognized, hepatitis became the most widespread. However, little attention was paid to the transmission of those diseases. In 1972, Mollison devoted a mere 11 pages out of 700 in his standard reference text on clinical transfusion medicine. Today, a substantial number of pathogens are recognized as transmissible by transfusion (See Ken Shumak, testifying before the Krever Commission.)

Transfusion (and for that matter plasma protein therapy of hemophiliacs) was not thought of as an ecological transformational process, but as a 'functional, relational solution' to a 'functional defect or loss'. The therapy is also referred to as 'replacement therapy'. The incursion of the HIV epidemic (in itself a human-induced ecological disaster) into the blood supply represented a massive and calamitous transformation in the transfusion ecology, to which the suppliers to the homeostatically designed 'blood system' could not adapt quickly enough. If other systems (such as the 'health protection system') had adapted, a portion of the suppliers would have been shut down. Instead, the industry had the requisite 'viability' not to be destroyed. The adaptive response to this threat was to prevent the 'health protection system' long enough from 'adapting', so that (economic) homeostasis in the supply system could be maintained, until various screening and process technologies of product sterilization could be introduced. In the corporate sector, a costly transformation of technology from plasma to recombinant technology (between the early eighties and the early nineties) also became feasible in the course of this 'homeostasis maintenance'. Survival and adaptation of the industry was achieved at the expense of the 'homeostasis' of recipients of blood. They represented a boundary condition to the 'system' which was effectively (and feasibly), controlled, neglected and even exploited (by the sale of infected product), until the supply system had completed its adaptations.

The ecologically most significant aspect of this homeostasis maintenance was the ability of various corporate entities to be, ecologically, the 'locus of control', which extended to all participants in the blood system, including the regulatory authorities and the medical profession (the rational/legal-scientific-economic-regulatory complex). The example of the

blood industry demonstrates that the corporate organizational design (in the widest sense) and the control of boundary conditions may not yet have the capacity of total simultaneity of homeostasis and transformation. But it has the capacity to generate sufficient overlap to survive major, sudden changes in boundary conditions. It appears that this adaptability extended into an entire transnational 'industry' by temporary suspension of competition, as those companies who might have provided safer product did not push very hard to 'corner the market'. In other words, in a major ecological crisis, an entire industry, rather than the individual corporation may be the 'viable entity'. Democratic governments (one might be tempted to say, 'obediently') submit to the imperatives of industry and corporate survival. The influence of the corporate locus of control extends into the Inquiry. Although this is a 'judicial inquiry' (as per format), the presiding judge nevertheless reports to the Cabinet and the Prime Minister. It is thus under political direction, it is not directed by the legislature. It is not at all independent. This is very significant since the political party which was in power in 1982/83, the critical years when the worst could have been prevented, is in power now, and the same corporate giant (the Germany based Cutter - Miles Canada - Bayer) is pushing for the building of a fractionation plant in Nova Scotia.

The ecological consequences of the collision between inevitable infliction of suffering and the deligitimation of the infliction of suffering.

This degree of viability of an organized entity cannot occur without significant losses to other, less adaptable entities, such as government, institutions, communities, individuals (and the natural environment) - all

the boundary conditions of corporate entities. The public was not only damaged by the various contaminating viruses, but is also paying the lion-share for compensation and awards of damages through federal and provincial taxes.

Modernity differs from premodern civilizations, in that enterprises and corporations do not require territorial acquisitions and military force to maintain or enhance their viability against countervailing boundary conditions. (Premodern civilizations used religious controls for homeostatic maintenance and military force for transformational, expansive purposes). The corporate organization uses rules, policies, procedures and manuals, rewards and threats of 'sanctions' (i.e. abstract rules and very simple operant conditioning methods), threats of 'closing down and taking the business elsewhere', as well as some rudimentary symbolism for the maintenance of homeostasis. It uses marketing, public relations, lobbying, technological development, and some plain predatory, acquisitive methods for transformation and expansion. In such systems the human being is 'instrumental' as investor, worker and consumer, and the corporate 'adaptation' to human emotion, including suffering, unfolds accordingly. There is nothing in the corporate design which even remotely resembles 'empathy'. Charitable donations are usually under the jurisdiction of marketing, public relations and development, i.e. transformational and expansionary corporate functions.

In particular under conditions of survival, empathy would diminish viability. There is very little difference between corporate and military designs; there is also very little difference between corporatism and Mo Tzu's concepts of social organization (his was a militarist philosophy). Human suffering (and emotions) may represent some utility for corporate operations and transformations: they can be exploited in marketing; they

may be utilized as fear. They may also be irrelevant (if a powerless group is affected).

At the same time, in late modernity, the infliction of pain is delegitimized by various protective codes. This is a condition which represents a serious but not insurmountable constraint on 'unempathetic corporate operations and transformations'. I suggested that this resulted in the suppression of suffering and its public display on one hand, and in mediated, enhanced public displays as 'ecological response' of the affected groups (also referred to as 'victimism'), and generally, as cultural patterns of 'organizing emotional experiences' typical of late modernity.

Considering the degree of viability (i.e. adaptability) of corporate entities, this is not a level playing field, and corporatism is likely to prevail, unless corporate viability itself can be effectively constrained (i.e. by sanctions and force, which is currently not the case). Scientific, legal and governmental institutions are increasingly 'corporatized' through economic dependency and by the introduction of corporate principles and ideologies of management. They no longer represent effective mitigating constraints. Since individual lives, families and non-profit-organization are progressively organized in a business-like manner as well, corporatism is on its way of becoming a pervasive ideology and the 'natural order of things'. Damages from 'business-like operations' will also become accepted as 'normal'.

Late modernity is thus characterized by a convergence of corporate, unempathetic modes of operation; the continuing transcendental and unpredictable of the natural operating environment (as demonstrable with the AIDS epidemic); the inevitability of the infliction of suffering in

combination with a deligitimation of the infliction of suffering; and by corporate entities being on top of the 'survival chain'. In this ecological 'brew', 'rational choice' is emerging as the dominant strategem for corporate adaptation:

- The deregulation of industry;
- Methods of 'pseudo-empowerment', by letting the patient take the initiative and making choices of medical intervention, by making the individual responsible for his or her suffering (without the benefit of a professional education and associated background understanding). As the examples in the contamination of the blood supply have shown, information made accessible may also be misleadingly selective. The most critical information has been and remains secret.
- Establishing trade-offs between suffering eliminated and suffering (side-effects) inflicted;
- 'Rationalizing and operationalizing the transcendental environment' ('nothing is 100% safe');
- Expenditures for 'care' are displaced by technical service and products;
- A transformation of 'health-care' into 'health-consumption' (see Pitman case; commodification of healthcare, health-products are becoming 'normal' consumer products).

- A 'pseudo-compassionate' preoccupation with euthanasia; many suffering people may be 'pure cost' and 'burden' to society, euthanasia has the potential of becoming the ultimate 'sequestration of suffering' and the pretense of mercy; a consequence of 'compassion' without empathy' transforming into passion and legitimization of non-compassionate (economistic) and self-serving goals.

The consequence of these strategies would not only be a reduction of the liability risk, but also a growing willingness of the 'consumer' to accept damage and of the 'care-giver' to inflict damage. Similar, but differently constructed 'rational choice' tendencies in ideologizing processes can be identified in military operations, in human sacrifice, and other atrocities which humans have inflicted on each other. They have been critical contributors, as described by Bauman, in the processes which led to the Holocaust. I disagree with Bauman in that such phenomena of 'horrendous suffering' are restricted to the rationality of modernity. They have been characteristic of civilization throughout its spread and evolution.

There is one aspect of the blood transfusion ecology which has not been dealt with in this thesis. For the sake of completeness it should be mentioned here: the phenomenon, as altruistic behaviour and as paid service. This aspect has been described by Titmuss. The commercial aspect of paid plasma donation for the production of Factor VIII was the primary ecological 'epicentre' of the contamination of the blood supply.

The preservation of older forms of legitimation of pain-related experiences

The diachronic chart in Chapter 1 suggests that, while in each stage in the evolution of human civilization the legitimation of infliction and experience of suffering takes on its epoch-specific form, older forms of experience, interpretation and legitimation are preserved (just as phylogenetically, older forms of cognition are preserved). The chart also suggests that, in the future, scientific ecological constructions of emotions and pain-related phenomena in large societies (including a global concept of society) may lead to their organization which increasingly resemble preliterate, symbolic organization in small societies - modified to suit large populations (with three question marks and without any degree of certainty, however).

The significance of the symbolic order.

Suffering as part of the symbolically constructed (but not universally shared) order is expressed in Dr. Hershfield's letter, by invoking a 'natural order', the 'heroism' of the medical profession, and picturing Arthur Ashe almost as mystical, magical figure with the capacity to render all the misery and attacks irrelevant. The 'natural disaster' or tragedy is relatively easy to construct, as much of the suffering inflicted was the consequence of omission, not commission and, therefore, not the demonstrable result of 'human action'.

Such myths however, are not legitimized by any spiritual authority.

Besides, in civilization, symbolic/spiritual authorities have never played an important 'empathizing' role in human-made disasters. On the contrary, they have started some of their own. The Church played no mitigating role during the Holocaust. It intervened in the German euthanasia program when it was almost completed. The performance of evangelical churches in the U.S., personified in Jerry Falwell, was utterly unempathetic (bordering on passive euthanasia or worse) during the first years of the AIDS epidemic (see Shilts 1988), while the other churches stayed silent. The non-role of spiritual authority surfaces in Joleen Ottosen's account, as she confronts all those 'good people' who belonged to the Mormon Church and took a hostile attitude towards the devastated Swain family. In the case of the Decarie family, religious considerations led to an infected child. More ostensibly, Johanne's belief in patriotism (or 'Canadian Society'), which I would consider as a spiritual equivalent, was shaken by the events affecting herself and her family. There are no sorcerers and evil spirits to be blamed. There are many blundering, conniving, acquiescing, strategizing, intimidated, or obediently ignorant human beings who were engaged in the infliction of suffering-related to the contamination of the blood supply. (I am not including 'greed' here, because 'economic survival' was the most significant condition, of which 'greed' would be a distorting and superficial interpretation and oversimplification. There still remains the 'trade-off' between human lives and economic survival). The persistence of this perception by victims, which does not acknowledge any 'force majeure' or 'natural tragedy', but insists on causal relations, is manifest in the criminal charges which were laid in France, Germany and Switzerland. A feebly and hastily constructed symbolic order will not have any bearing on how the victims perceive the contamination of the blood supply by the victims.

The use of suffering as social control.

Explicitly, this is not possible in late modern society, except in cases of established criminal and civil liability. However, eleven medical personnel, most of whom had taken a critical stance towards the Red Cross, were terminated or 'left'. One has resigned recently. The threat of existential catastrophe, including existential threats to whole families, remains an effective social control tool, in particular if the span of control is institutionally monopolized (which is still the case with the blood program in Canada). This circumstance may not have caused the virtually total solidarity amongst professionals which is apparent in the Krever Inquiry. It may have helped to make it possible. (One former colleague of mine, whose identity I must protect, effectively admitted that he considered himself economically black-mailed and therefore could not help me in my quest).

The use of the 'fear of suffering' was used as an effective social control instrument with hemophiliacs, who were dependent on an elite which was comprised of the Red Cross, medical professionals, the Federal Government, the plasma industry and the Canadian Blood Committee, as well as national and international organizations for hemophilia. One of the most powerful controls which could be used with hemophiliacs was the notion that Factor VIII would make them 'full persons', freed of the limitations on social status incurred from a severe chronic condition; able to do anything any other individual could do. (Factor VIII concentrate was not superior to cryoprecipitate in clinical efficacy). Once provided with this 'gift', the threat of losing full personhood and social status was a powerful incentive for using the product, although early on it resulted in wide-spread

hepatitis B infections. There is little evidence that hemophiliacs were advised that the probability of chronic liver-disease may be as high as ten percent, and what chronic liver disease really means. Dr. Kaegi, Medical Director of the Calgary Red Cross Blood Centre, was an exception. In the late seventies he advised against the use of concentrate because of the hepatitis B risk. He resigned from the Red Cross 'on issues' in 1985 (his role was discussed during Dr. Bowen's testimony at the Krever Commission in Calgary). Indirectly, he may have protected some hemophiliacs not only from hepatitis B, but also from HIV, cytomegaly virus (CMV), and Epstein-Barr Virus (EBV), hepatitis C. (These viruses tend to be 'travel-companions', or 'travellers using the same trail' in the spread through sexual contact, in pregnancy from mother to child, through transfusion and needle-sharing in intravenous drug use).

The same pattern was repeated with Hepatitis C (which has a chronicity rate of at least 25%) and HIV, which was known to be lethal. The argument of the 'wonder-drug', Factor VIII, is still being used by medical authorities trying to justify their inaction. Mothers of individuals with hemophilia A (who are the carriers of the defective gene and pass it on to their male off-spring with a 50% probability) would also have been an easy target for promises of a 'normal life' for their sons. The implied threat of losing normal life and social status could have easily wiped out concerns for hepatitis infections (B and C). (With a relatively small investment of a freezer with an alarm and recoding system for power-out, cryoprecipitate could have been converted to home treatment as well. The only 'serious' restriction would have been on long-distance travel). Yet the early types of suffering from joint and other bleeds, frequent hospitalization, correc-

tive joint surgery and the restricted radius of action and participation in normal life activities were powerful imprints and remain powerful to this day. Clearly, the hemophilia community was not positioned to 'rationally' weigh the pros and cons of Factor VIII concentrate treatment and was totally dependent on 'rational choices' by the blood-establishment.

I should stress that there were other empathetic individuals besides Dr. Kaegi, but most of them did not extend their empathy publicly to the patient population. The treating physicians (such as those who worked in comprehensive care centres) were not really part of the decision elite themselves. To break through the conditioning of hemophiliacs would have required rather powerful legitimation from the elites, in particular the national elites, such as the advisory board to the Canadian Hemophilia Society, the Federal Government and the Red Cross. This was not forthcoming. The treaters still have to answer why, as a group of professionals, they were not speaking out at any point during the crisis and during the aftermath.

The most telling account of intimidation and fear are Mr. Little's arguments against a public inquiry (see Jerry Freise's account). Two individuals from the hemophilia community with whom I spoke expressed outright fear, not only in terms of loss of service but also of recrimination. It is irrelevant whether this fear can be 'substantiated' or not: it has been instilled into the minds of many. Joleen Ottosen is reporting a more direct incidence of intimidation (the threat of exposing her father to questions of sexual practice, if the family had considered litigation). Randy Connors' story adds to this pattern (threat of removing home-care and prophylactic treatment).

Suffering as the price of progress.

The notion of 'price of progress' was implicit in the silence surrounding the hepatitis epidemic in hemophiliacs. There were some places where the 'price of progress' was deemed too high. The treatment centre in Bonn and the Children's Hospital in Vienna switched new cases to heat-treated product in 1980, as soon as a heat-treated product became available. They and others may have been instrumental in getting the German Behring Werke to explore heat-treatment as a decontaminating measure. It is worth noting that Behring Werke used a 'wet-heat treatment', which remains the most effective method. But it results in higher activity losses (and thus higher revenue losses) than 'dry-heat treatment'. The American industry started out with 'dry heat-treatment' (See Appendix 1).

'Price-of-progress' is an especially insidious form of legitimation, because it is in wide-spread use, not just in science and the economy (see for instance the ravages of capitalism in Russia), but also in well-meaning social movements which choose not to pay attention to 'collateral damages'.

The 'suppression of suffering', victimism and counter victimism

This has been demonstrated in just about every case reported in this thesis. The suppression of suffering took on the following forms:

1) Downplaying the risk of infection

2) Delay in notification of possible infection, or no notification at all

- 3) Minimal safe-sex alert for infected individuals**
- 4) Psychological interventions, funding of self-help groups**
- 5) Compensation packages**
- 6) Attempts to prevent a public inquiry**

The suppression of public display of suffering was manifest as follows:

- 1) Claims of 'a fair inquiry' (Justice Krever's opening remarks)**
- 2) Insistence on 'balanced' and 'fair' reporting in the media**
- 3) Delays in public education, which left the population uninformed, prejudiced and scared for their own safety; under such circumstances a public empathetic response to public is impossible (see discrimination in the work place, in the community; the Decarie family)**
- 4) Intimidation of victims**
- 5) Compensation packages and signing of waivers**
- 6) Denial of class-action suits**
- 7) In the case of the Swain family, outright blackmail**

Victimism took on the following forms (victimism is not used here in its pejorative sense, as by Sykes):

- 1) Pressure for public inquiry
- 2) Case reporting in the media
- 3) Court cases
- 4) Attempts of class-action suits
- 5) Pressure on politicians (see the Freise account)
- 6) Book-writing (e.g. Joleen Ottosen)
- 7) Lecture tours (e.g. the Decarie family, Marlene Freise)
- 8) Networking (several networks exist)
- 9) Decline of compensation package, litigation kept in reserve
- 10) In Europe, in particular in Paris, public demonstrations.

'Counter-victimism' took on the following forms:

- 1) Interventions by the Red Cross lawyer against other lawyers' 'inflammatory statements' (M. Cherniak criticising Dawna Ring, Randy and Janet Connor's lawyer, in Halifax).
- 2) Interventions by the Canadian Red Cross Society with the Ombudsman of the Canadian Broadcasting Corporation to complain against 'unfair reporting' (at issue was an interview I had given to two CBC radio reporters).
- 3) Complaints about the media 'pummelling the Red Cross' (See for instance Lindores speaking at the 'media scrum' on the contamination of the blood supply)
- 4) Claims of insufficient funding to meet FDA standards.
- 5) Public reactions to the FDA reports referred to as 'hysteria'.
- 6) Blaming the media for reduced attendance at donor clinics.
- 7) A 1 million dollar contract given to a lobby group to protect the public image of the Red Cross and, possibly, of the Federal Government.
- 8) Dr. Hershfield's letter

The most significant method of suppressing public displays of suf-

fering was the compensation package and the associated waivers. The masking as 'compassionate intervention' and the of unempathetic delivery method are discussed in the account of Decarie family.

The role of science

'Material authority' is a complex network of legal, scientific, economic and regulatory processes. Lately, some philosophers have been welcomed into this complex (promoting '*rational choice with the knowledge available at the time*'). They may have been happy to oblige. These philosophers have no apparent awareness that corporatism does not work with the knowledge available at the time, but with the requisite privileged knowledge to invent its future with a ten year horizon (more or less). Such philosophers are useful to explain, naively, the damages inflicted on the way to the future to a confused public. They are beginning to blend into the corporate design in a way which has never occurred before. This is one of the most significant developments in late-modern human ecology: the 'four processes are merging into a paradigmatically unified process, which is essentially becoming economic/scientific. Victims have to confront expressions of these paradigms over and over again. The operating systems of corporate entities can be pointed at as the 'locus of control' for this transformation.

Science always had influence, but it never had and still does not have a power-base of its own. Aztec, Chinese and Egyptian science served the emperors, medieval science served the church, early modern science served the state, and late modern science serves the corporations and

those interests which are willing and eager to serve corporations (for them science and technology is crucial for competitive survival: hence the economic-scientific complex. Medicine is no exception. Inevitably, law is shifting in the same direction (it is becoming both scientific and economic).

'Post-modernists' are left to play with issues of no immediate interest to this massive paradigmatic complex. The more 'deconstruction' and atomization goes on in the 'left-over fields', the less likely will any organized resistance to the dominant paradigm arise.

The internal ecology of the contamination of the Canadian blood supply

An unempathetic, dispassionate health-care system.

This is perhaps the most significant manifestation of the conditions which led to the contamination of the blood supply and its aftermath. A mythical excursion appears to be appropriate here. While 'strategic ruthlessness' sprang from Zeus' prefrontal lobes in the 'Gestalt' of Pallas Athene, the wisdom of Metis remained in his stomach (whom he had swallowed - women had already become the chattel of men). In good time, Athene acquired the head of 'earthy' Medusa, Athene's 'alter ego', which had not been passed on by mother Metis who resided in Zeus' stomach at the time of Athene's birth. Athene, representing strategic rationality, protected and guided the male enterprise of acquisitive war of any kind: empathy took on a dangerous, blinding, man-killing 'Gestalt' and was shown off by rational Athene, on her shield, as a wild-eyed, 'pathogenic', ugly monster. Dissociated from the 'snake-goddess' (depicted with two snakes, see also the Caduceus in Appendix 2), representing empathy entwined with reason, empathy (and empathetic compassion) may be ridiculed, or be characterized as infantile expression, not worthy of rational adult (masculine) superiority. A few decades ago, it would have been denigrated as feminine 'emotionalism'. The Cretan snake goddess had been split in classical Greece, leaving 'pure reason' to triumph. The Caduceus of the medical profession may be transformed in a similar process and one of the two snakes (together a symbol of infinity, communication and wholeness similar to Yin and Yang), may already have been dropped

(the 'Yang snake'), leaving behind the Yin-snake, 'ruth-less', meaning 'void of compassion' (perhaps Yin and Yang are really two stylized snakes).

Defenders of rational choice invoke 'value-systems' as substitutes for emotional responses. They do not appear to have an awareness that most of the values which they invoke emanate from the very systems of rational choice from which they are being promoted. The foremost value for a legal person is the 'rule by law'. The foremost value for a scientist is 'scientific proof'. The foremost value for a doctor is the kind of medicine he practices. Most importantly, the foremost value for 'rational choicers' is rational choice.

I wrote the following letter to Dr. Paula Stewart, Associate Medical Officer of Health for the Ottawa Carleton Region, in response to her comments in the Ottawa Citizen on the Hepatitis B immunization program for grade 7 school children:

"I do not know whether I should consider your comments to the Ottawa Citizen of October 4, 1994 callous, cynical or as a reflection of government at all levels which has lost its essential marbles. On October 3, 1994 the Citizen reports that Hepatitis B can cause liver damage and death, and that there is no cure. The next day the Citizen reports that "only" 5 to 1 percent will die (if Ontario data can be extrapolated to Canada, this could reach several hundreds cumulatively - if not thousands). You state that if parents can afford it for their older children, 'its a good idea', meaning if you are poor you may have run out of luck. The pattern is consistent with earlier discriminatory strategies shown by health authorities and professionals towards groups with limited power, such as hemophiliacs and gay men with respect to Hepatitis B, C and HIV. This time young adults from low income families appear to constitute the group targeted for 'strategic neglect'. This is revolting, and apparently the revolting has become the normal."

(Hepatitis B is now an epidemic in schools, transmitted sexually amongst teenagers; 300 cases are reported annually in Ontario, an unknown number remains unreported. The children most vulnerable to being infected

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PM-1 3½"x4" PHOTOGRAPHIC MICROCOPY TARGET
NBS 1010a ANSI/ISO #2 EQUIVALENT

PRECISIONSM RESOLUTION TARGETS

with hepatitis B, are sexually active senior high-school students, who will not be immunized).

The examples of victim's accounts leave no doubt about the lack of empathy in the medical profession. Dr. Stewart's letter somehow resonates with the logic in Marie Antoinette's alleged comment, that "*if the poor do not have enough bread they should eat cake*". These are severe 'distortions of the professional mind'. As I am writing this section, I am told an anecdote by Dr. Brill Edwards, who had attended the medical rounds in cardiology at the Ottawa Civic Hospital on this day of writing, where one of the senior physicians complained about the performance of unnecessary diagnostic procedures on a patient, not because they were an unnecessary burden for the patient, but because '*as a taxpayer he would not be willing to support this waste*'. (Another one who lost his Yang snake).

Considerations of external ecology alone cannot explain this phenomenon, which I am inclined to term 'functional psychopathy' or 'psychopatho-mimetic behaviour, which shares with 'true psychopathy' the hallmark of 'lack of empathy'. From an 'external ecological point of view, one may propose that the 'rationalization' of medicine is the product of corporatism and free enterprise. But this argument alone could not explain the apparent total lack of resistance to such tendencies. The following may add explanation.

The inner ecology of the clinical health-care professional.

I have indicated in the introduction that apart from painful or pleasurable experiences, our inner ecology is formed, transformed and constrained

ned by what we are actually doing. This is strikingly obvious when we compare the shamanic healer and the Western physician. It starts with the selection of an individual to become a shaman (although some may become shamans from their own experiences), which presumes certain capacities of the initiate to endure the induction process. Without a capacity for empathy, an individual is not likely go through the ordeal in order to do some good for the others. Thus the initiatory transformation is the most important aspect of the shaman, not the acquisition of the specific practical remedies. The object of the shamanic intervention is not disease, but the suffering individual, and the disturbance the individual may cause in the community or even in the larger environment. (The shamanic initiatory experience is similar to the Hermetic process, in which the transformation of the alchemist is the primary intent, not the material transmutations of matter. See Berman on Jung, 1986:57-105.)

The medical student reads a lot of books and publications, performs biophysical-chemical experiments and works on dead bodies and body parts. Thus the main 'penetrating content' is a mass of more or less connected texts, diagrams, numbers, models - and dead bodies. The body of requisite knowledge in medicine is discernable as a gigantic classification system. McMaster University has been trying to improve this by exposing the student to actors who play patients, to develop a more human approach and 'empathetic' communication with the patient, before he or she is actually confronted with real patients. At the same time, McMaster has heightend the initiating 'ordeal' by letting the student doing more independent research and discussion in study groups. (However, since this 'ordeal' is embedded in textual study, I believe it will only heighten the receptivity to the sign order and classification system to be learned). The

long-term benefits of this kind of education are not unequivocal. As I have suggested, empathy is a matter of early childhood socialization, and not something that can be 'injected' at a later age, in particular when other motivations like economics, power and their systems of rewards and punishment are already competing for attention.

For a 'general' practitioner the 'practical training' is fairly short (only a couple of years, compared with eight years of undergraduate and graduate school) and, paradoxically, the specialist may spend three times that much in training. Practical training occurs at a time when the inner ecology has already taken on a certain shape and looks for 'application'. In a clinical research environment, which is the case with many specialty training programs, the 'objectification' and 'rationalization' of the 'patient' (literally: the 'sufferer') move to yet another level.

The hospital physician acts very much as technical specialist or 'consultant', whereas the actual empathetic component, the 'care-work', is done by nurses. No wonder that nurses would perceive themselves more like 'healers'. At the same time, they are restricted from the acquisition of the requisite knowledge and authority of the 'consultant'. They are also constrained by an ever increasing body of rules of administrative procedure and efficiencies. Thus the patient is confronted with a healer who knows relatively little and is not allowed to care, and a knower who cares relatively little to begin with: not just one of each, but multitudes. Thus modern medicine produces 'repair-people' and 'repair-consultants', organized in 'efficient', complex administrative and technological machineries. The division of labor into knowledge and (rudimentary) 'caring' professions makes the individual development towards 'empathetic knowing' impossible. When I started my training in internal medicine at a university hospital in

Vienna, one of the first rules of thumb I was given was that those who really look after the patients never make it into an academic career: they never get the proper research orientation, or if they try to do research anyway, they burn out from overwork and conflict of interest. I did research, I did not burn out, and, admittedly, some of my action were unempathetic. One of my former colleagues mentioned to me at one time that he regards the patients only to be a source of various bodily fluids to be tapped for various research purposes. Fortunately, he became a pathologist.

As a coherent classification system, medicine was easily transformed into a data-system. It is wide open to unlimited varieties of data manipulation (insurance, legal, administrative, economic, political, strategic), which would be a typical adaptive occurrence in civilization). However, it slowly reaches the point, as more and more knowledge and data are amassed, that humans will not be able to carry with them the 'requisite data' and computerized expert systems will take over (at which point other expert systems can intervene faster than human experts ever could). At this point (and probably before that) the treating physician will be cued by the 'system', not by his own 'inner ecology' and the experiences of the patient. To put it crudely, the health-care professionals will become 'system-dopes'. Given the nature of their entrainment and their working environment, they cannot be anything else.

In addition there are reinforcing processes which make this phenomenon inevitable. The main legitimation of a shaman comes from his or her community. The legitimation in the medical profession comes from medical authorities and from peers. Practice reviews of physicians are checks of adherence to rules, not a measure of success or satisfaction of patients.

Despite all the rethoric on 'health consumption', 'customer satisfaction' does not appear to be at issue. At no point in the HIV crisis were the people given an informed choice. As medical authorities (at the policy level) are even more removed from any communal or individual empathetic relationship than the treating physician, their inner ecology (and their perceptual and action constraints) will be entirely shaped by data and rules by which the data are manipulated. Given their authority, they can also induce a high degree of obedience in conjunction with peer pressure and threatening loss of career and employment: the effectiveness with which empathy was suppressed in the health-care system with respect to the contamination of the blood supply should not be entirely surprising.

Given the massiveness of entrainment of the health-care professional, it may be impossible for the vast majority of them to go through any major transformation (the entrainment may be 'non-disintegrateable'). There have been exceptions, and there have been some individual ruptures (which I did not report on in order to protect individuals). The defences used in impending rupture have been discussed in the example of Dr. Hershfield's letter.

The inner ecology of victims.

There are three parts to the inner ecology of the victims as they relate to their affliction:

- 1) The illness**
- 2) Dealing with the 'system' as the 'vector' of the illness**
- 3) Dealing with the systems efforts to conceal its role as vector**

No healing system can avoid the infliction of suffering entirely. It remains associated with the limited knowledge of an ultimately unknowable 'operational environment'. However, this must not be interpreted as a 'blanket excuse' for all suffering inflicted in the course of interventions. There are instances of suffering which can be avoided. The circumstances of commission or omission which produce avoidable infliction of suffering range from incompetence and quackery, to greed (unnecessary procedures), to misguided scientific zeal, to abusive application of medical knowledge as in the German euthanasia program (or not to tell patients that they are infected with HIV, 'because there was no cure available'), to bogus economic arguments and administrative goals, which are organized primarily by legal, professional and commercial enterprising strategies. The circumstances of the contamination of the blood supply, which were omissions motivated by an economic gamble, are new only in terms of the specific gamble.

From a victim's point of view, it is not the contaminated product that mattered, but the vector, which in the final instance were the prescribing physicians. As time progressed, the submerged portions of the total vector, the blood industry and its affiliated governmental and scientific institutions become visible. As time progresses further, there is gradual realization that the 'vector' of the contamination of the blood supply may have the capacity of being a more general vector for an unknown variety of afflictions. The most devastating realization is that the vector of afflictions presents itself as the supposed healer of affliction; the caretaker as potential killer is a most awesome contradiction and source of devastating dissonance for the victims, not the infection itself. Not surprisingly, the incumbents of the healing system will try to conceal, diffuse, and suppress

this association, they will try to create ambiguities in the representation of what happened, and they will try to generate confusion, ambivalence and thus suggestibility in the victims and the observing public: by control of meanings, information-overload, lies and, if necessary, coercion.

The suffering process, interpreted as 'grieving process', is essentially an 'adaptive process' (learning process), which may involve considerable reconstructions of the 'taken for granted'. An acceptance of the illness as 'a natural tragedy' would be the easiest adaptational option. Victims who are confronted with their infections could deal with it like any other circumstance of future death or chronic illness. We do not know how many victims have settled for this interpretation. But many of those who accepted the compensation package and thus forfeited litigation as option for a healing process may have settled for it. A number of the victims had to take this option, as their remaining life-expectancy would have been too short to see convictions or financial settlement in court. Since class-action was denied (in London, Toronto and Montreal), the legal costs were prohibitive for most. The settlement allowed them to deal with the illness in material terms, and 'rational choice' prevailed. A class action by hepatitis C victims is still pending.

Those who do not accept this interpretation have to adapt to the 'vector' and have to go through a far more profound and lengthy adaptational (learning) process. They find it indeed very difficult to adapt to the notion that their democratically elected system and its institutions, which they thought would protect them, did not. They may resort to more limited explanations, such as blaming the Red Cross, which is still a very jarring explanation, as the Red Cross still presents itself as the world's foremost humanitarian organization.

Those who are not directly affected by the disease (and are thus not weakened by the effects of the illness itself and the efforts to cope with it), but had to witness the agony and suffering of their close family members are most likely to accept the idea of the 'larger vector' (Joleen Ottosen, Jerry Freise). However, individuals like the Decaries, who pushed the issues to the highest political level, (and were pushed back), or Janet Connors, may continue to try to deal with the issue of the 'larger vector'.

As discussed in the context of the Freise family, the Inquiry provided, at least superficially, for an opportunity of ritually enacting their grieving. It also provided the opportunity to take the suffering to the public. However, although the inquiry is public, the sessions are no longer broadcast live (they were at the beginning, in Toronto), but often weeks later. This greatly diminishes the significance and effect of the public display. Media are highly selective in what they report on newscasts. The display of suffering in front of a room full of lawyers, some of them defending the 'system', is hardly a substitute. (Similar tactics were used in the Grange Commission to protect the doctors, and to expose the nurses to the gaze of the public: DOC 26). Judging from the general attitude of the victims testifying, there is still some credibility vested in the healing power of the 'ritual' which the Commission tries to simulate. For those who have an awareness of Judge Krever's role in the Royal Society study, the credibility is lost and the ritual is meaningless. (This does not apply to hemophiliacs, who were looked after by the Royal Society report). For them, the damage inflicted, the cover-up of the damage and a phony ritual add to the loss and anger already incurred. The Connors family incurred a fourth insult by those who they consider the destroyers of their existence, and who were given the permission, by the provincial and federal governments

to build a fractionation plant in the home-province of the afflicted family.

There is a level of suffering, which has not surfaced to the full extent; shattered marriages, alienation, alcoholism, disorientation, depression, and I suspect, violence. In face of an overpowering system, some individuals have been able to reconstruct their life-world by engaging in public education campaigns on AIDS.

4) Effects of my own involvement on this study

I have described my status as 'observing participant', rather than 'participant observer'. While this circumstance provided me with extensive background understanding, it is also a drawback: my capacity to analyse 'from beyond the system' may be limited. However, with respect to HIV and other infections I was not a participant. I was able to avoid the kind of participation bias which would apply, for instance, to medical directors of blood centres, or to individuals who served on various committees during the crisis. Given this circumstance, the benefits of my various experiences and my educational background may have outweighed the draw-backs of not being an 'in-and-out' kind of participant observer.

This study did bring for me to completion a lengthy 'distancing' process from the healthcare system, which may have started decades ago. My biological (and ecological) and, I hope, 'healing' orientations remain unaffected. Having witnessed the innumerable ways in which 'text' is manipulated, including so-called 'ethics', the ecological-biological text and the early healing orientation from my medical education provide some grounding as antidote against a generalized, pervasive and seductive relativism. Consequently, some of my statements are formulated more assertively than perhaps they should be. At the same time this may provide a better target for 'falsification'. I prefer to be proven wrong over being ambiguous. On the other hand, the ecological approach taken here has introduced inevitable ambiguities, which are declared as such.

It appears to me that my own experiences, my educational background, and my exposure to the victims of the contamination of the blood

supply have set me on a course of 'bringing back to life the Cretan snake-goddess' - metaphorically, of course. Therefore I am viewing the elaboration and understanding of ecological processes beyond current narrow, materialistic applications as essential benchmark or referential pattern against which the adaptiveness of our life-practices, values and knowledge can be gauged. As I say this, I remain worried that such a paradigm, if it should ever come into practical use, can again be abused, ideologically, instrumentally, economically, exploitively, and ultimately, oppressively; that it may open up new legitimations for the infliction of suffering. On the other hand, if our 'inner ecology' is included, it may be the most promising paradigm for the optimal use of our total cognitive endowment, as opposed to the maximal use of selected faculties. It may accommodate commonality as well as diversity. I have used this kind of 'bias' deliberately in this thesis. The result, I hope, is in the 'optimal direction', forfeiting attempts at 'excellence' in any of its dimensions or parts.

5) Confirmation or disconfirmation of the hypotheses.

a) Pain-related phenomena, thought processes and behaviours are phenomena of human consciousness and, as such, participate in 'human ecological processes'; they play a significant role in the ecological regulation of homeostasis and transformation in individual humans, social organizations and in the interactions of humans with the natural and human-made environments.

The first statement of the hypothesis is tautological and arises from what is normally included in the definitions of human consciousness. The claim of participation of human consciousness is not so much a matter of 'truth' or 'falsity', but rather a matter of justifiable or non-justifiable choice of including phenomena of consciousness in ecological thinking. The discussion in the introduction and the data would justify the inclusion of consciousness, and thus pain-related phenomena in ecological thinking. Their role in ecological regulation of human life-processes again arises from the definitions of consciousness and ecology. Whether the regulatory role is significant or not (in its success and/or its failure) was demonstrated from historical examples and accounts of the contamination of the blood supply.

b) This ecological effect of pain-related phenomena (such as suffering, empathy, compassion and the infliction of suffering) is shaped by specific forms of social organization and processes of civilization.....

It was argued that the conditions of civilizations arise from adaptations to large population aggregations and/or migratory incursions into established, cultivated territories; and that such conditions have led to an increasing (adaptive) use of sign-ordered, instrumental, hierarchical, rationalized systems of social organization. This, in turn, would have given rise to conditions in which symbolic orders and emotional experience would become less and less cultivated. This assumption was supported with the example of shamanic healing intervention and the extreme callousness with which victims of the contamination of the blood supply were handled. Bauman's argument of the Holocaust being the consequence of the entrainment of human consciousness in the systems of modernity was generalized as an effect of 'civilization'. While the two cross-culturally extreme examples (preliterate culture and late modernity) would support the 'civilization hypothesis', the thesis has not sufficiently addressed, diachronically and synchronically, manifestations of human social organization between the extremes. A few historical reference were given, such as from Chinese civilization, the Roman empire and Judaeo-Christian forms of social control. They gave some limited support to the hypothesis.

i) Late modernity is characterized by processes which seek to eliminate suffering, while it cannot be eliminated.

It was argued that late modernity is seeking to delegitimize the infliction of suffering, possibly as an 'ecological' response to the atrocities and oppressive conditions of the first half of the twentieth century, in the form of various human rights and other protective codes. The impossibility

of eliminating the infliction of suffering was explained by the transcendental natural operating environment, which will produce damaging side-effects from human engineering intervention. This issue is linked to the issue of 'limits of knowledge'. Thus the question whether the infliction of suffering (in particular from 'omission') can ultimately be eliminated needs to be explored further on this particular theoretical basis. For all practical purposes (as per example of the damages to the natural environment, and the contamination of the Canadian blood supply) it is reasonable to uphold this hypothesis.

ii) Late modernity is therefore characterized by processes which, therefore, seek to prevent or suppress pain-related phenomena from being experienced and/or publicly displayed, or failing that, to deny them.

The 'corporation' was presented as the best adapted and influential form of human organization in late modernity, to the point of being or becoming the 'locus of control' of organizing all other human experiences and endeavours. It was suggested, supported by analog processes which affect the natural environment, and exemplified with the processes of the contamination of the blood supply, that the corporate mode of 'survival' under conditions of delegitimated infliction of suffering leads to a variety of adaptations which can be summarized as the 'suppression of pain-related experiences and their public display'. It was shown that, historically, older legitimations of human-inflicted human suffering, such as mythification, mystification, 'social control', 'cost of progress' are still manifest. In

addition, however, new forms of legitimation of the infliction of suffering, on the basis of 'rational choice', are emerging. Thus the hypothesis should be extended to include this tendency.

iii) Late modernity is also characterized by processes which use mediated displays of actual suffering (through mass-media, courts or inquiries) to mitigate against suppressive strategies of denial.

This was demonstrated with activism amongst victims of the contamination of the blood supply. In addition, it was shown that institutional 'counter-victimism' has arisen in response to activism, which is seen as part of the multiple adaptations to the infliction of suffering under conditions of deligitimation.

c) Such modifications of the ecological role of pain-related phenomena are predicted to influence homeostasis (adaptedness, situational and cyclical adaptation) and development (transformational) adaptation of individuals, social groupings and the natural and artificial human-made environments and their mutual relations and interactions.

This hypothesis cannot be unequivocally affirmed, because we have no conceptions of optimal human adaptedness or adaptation, and because our Western standards of 'well-being' are based on a highly concentrated, massive exploitation of global resources. Perhaps the following can be said. Historically, any form of religious or ideological legitimation of infliction of

suffering has been used excessively and abusively. On the other hand, the total deligitimation of infliction of suffering, in particular from 'omission' is utopian, and leads to adaptations and new forms of legitimation. This is therefore not a good path to follow, as a contradictory prescription (or double-binds) will induce devious adaptations. In this sense, the late modern construction of pain-related phenomena will have a major impact on human ecology, in the sense of maladaptive, deviation amplifying processes, as suggested by Gregory Bateson. This is not just a matter of an obstacle, or an impasse to be broken, but a potential for chaos and horrendous damage. As the solutions cannot be sought in going around an obstacle or in breaking an impasse, some more fundamental reorientations are required (these will be suggested in the last section). The hypothesis, as stated, cannot be rejected. However, the nature of the influence of late-modern modifications of the suffering experience on human ecology need to be explored further.

6) The utility of this kind of analysis for anthropology

The theory constructed for this analysis was derived from various anthropological approaches to the 'inner' and 'outer human ecology'. It resulted in the proposition to equate 'human ecology' with 'culture', derived from the conception of 'cultural ecology'.

The boundary between 'the psychological and the environmental' was a key boundary dropped in this thesis. The human brain is the most important participant in the formation of culture (or human ecology). Discounting the processes of inner ecology can be predicted to lead to serious distortions in the conclusions reached about external ecology and vice-versa. (For instance, psychotherapy always tries to treat the individual, regardless of the severity of environmental conditions, while social intervention may try to fix social conditions, without sufficient or any accounting for psychological processes, or processes of 'inner ecology').

Apart from a possible general anthropological utility of the ideas advanced in this exploration, there are two specific areas of practical relevance which arise from the phenomena which constitute the contamination of the Canadian blood supply.

a) The globalization of Western corporatized, commodified health-care

The phenomenon of the contamination of the Canadian blood supply was possible in a context of Western late-modern civilization. The future markets for health-care products (as products or services), including those

produced by the Canadian industry, are developing countries. One of the central justifications for giving contaminated product was the argument that not to give any product at all would be even worse. This is a 'rational choice' derivative of the cost of progress, the notion that all change has its 'costs'. At the same time, because the infliction of suffering has been deligitimized, if at all possible, inevitable damaging side-effects will be concealed (which was not necessary in earlier stages of modernity).

What is possible in a Western environment becomes infinitely more possible in a developing environment. I maintain that dangers for the human organism are of the same kind as those which have been observed with the incursion of Western technology and thinking into the natural environment. In developing countries, it is all too easy to argue that their deprivations are so bad that any improvement, regardless of side-effects, is justified. Multinational pharmaceutical corporations have been reported to market useless products in gullible Third World Countries, while the World Health Organization attempted to develop a compassionate list of essential drugs (C. Laughlin, personal communication).

b) The limitations and constraints of human cognition.

On occasion, in this thesis, it was mentioned that human cognition (and thus adaptability) is neither infinitely malleable, plastic or elastic, nor are humans endowed with total freedom of choice. To claim otherwise, namely that humans can be anything that they want to be, and that they can be totally responsible for themselves, is, to say the least, irresponsible

(the share of genetic determination (not '-ism') is not the only issue here).

The significance of neurological constraints are discussed by neuro-structuralists. This thesis provides some examples, which demonstrate that such constraints, inborn or acquired in ontogenesis (developed or under-developed), do penetrate into every-day consciousness and action, into the 'profane' so to speak. They become more tangible in states of severe dissonance (see the Hershfield letter), in states of loss and grieving, or even in rational decision-making, when a systematized rationality (a professional paradigm) can easily override what one would consider 'normal' sensibility (as in the 'entrainment of medical professionals').

The introduction attempted to point out that earlier stages of civilization were by no means more 'humanistic' than our present times. This suggests that the neurocognitive processes which lead to atrocities in earlier times are similar to the atrocities in our times. It may be that we have been too much in awe of the 'artefacted' accomplishment of earlier civilizations, and have paid little or no attention to the quality of life, which may have been good for the elites but not for the common people. Atrocities as described in the bible, or as they occurred during major conquests, even as they happened in the course of the Holocaust, are glossed-over, glorified or denied.

Whether this human tendency (or capacity) is adaptive or maladaptive remains undetermined: all we can observe is an inability of societies to account for the atrocities committed on its own members in compliance with the directives given by its elites and leadership. This inability is likely to play a major role in the official conclusions of the Commission of Inquiry. The most significant early indicator was Judge Krever's position as one of the two leaders of the Royal Society study of AIDS in Canada who could

have initiated the seeking out of transfused HIV infected people: he did not, he could not, or he would not.

The most difficult cognitive issue is that, once rationalization of action and rational action converge, each starting from different motivations, they cannot be differentiated by the individual involved or an observer (there is no way that Robert Latimer can separate the feelings and motivations arising from mercy and self-pity). This confoundedness can be easily manipulated. Other 'human ecological circumstances' can insert themselves into rational choices, as well as processes of rationalization, in particular under conditions of authoritative directions such as '*with the knowledge available at the time*'. Neither the confoundedness of inner ecologies nor of outer ecologies are accounted for by philosophers (including prominent ones).

While I have argued that written codes are unecological, there may be grounds to hold on to (very few) fundamental codes, as the 'ecological handling' of such circumstances may never come into our grasp. Symbolically speaking, there may be situations where justice is best kept blind. There are other codes which, in their judicial application, are outright harmful, because they are violating ecological processes. I am suggesting that it might be helpful to look at social norms, cross-culturally, from this perspective. This field is so difficult and so important to our future that we must avail ourselves of all accessible sources of knowledge on this matter.

In any case, both, the circumstances of the contamination of the blood supply and those surrounding euthanasia of mental patients in Nazi Germany (of the most severe cases) should warn us how easily 'public opinion', 'professional consensus', the 'knowledge available at the time' can be

manipulated, in particular when the financial stakes are extraordinarily high. (About a week before closing this thesis I watched a euthanasia discussion on the Patrick Conlon Show (CBC). The only 'authentic' person on the show was a person with severe neurological problems, who would have been dead, if her family and her environment had it their way. She was viciously attacked and virtually shouted down by callers, but also by a professor of philosophy from the West, who offered his comments on the show. I found it impossible not to suspect a deep-seated wish in those who attacked her to do away with severely handicapped people; that they were all too willing to accept 'scientific criteria' to decide who should be done away with. I also have no doubt that all the callers, including the philosophy professor, believed that they were compassionate individuals, only having the best of these suffering 'creatures' in mind (one caller compared them to 'sick pets'). Unfortunately, they could not see or hear the level of their own passion with which they attacked the handicapped participant! The viciousness of these attacks on that very remarkable individual gave them away. They did not have a shred of compassion for her, and instead of listening to her, they insisted that she should listen to them! We may be in deeper trouble than we think we are.

Note: One of the main criteria for justifying the killing of the Latimer child was that the child was severely suffering, it could not make a choice, it could not communicate, and there was no hope of improvement, with the knowledge available at this time. Her 'quality of life' was not considered worth being allowed to continue. The severe schizophrenics who were killed by the Nazi doctors were suffering severe torment, they could not make a choice, they could not communicate, there was no hope for improvement 'with the knowledge available at that time', and their 'quality of life' was not sufficient to be considered worth maintaining. And if we consider that it is not true that the transfusion doctors made their decisions 'with the knowledge available at the time', and if one considers that many of these policy-making doctors would not inform the infected persons

because there was no treatment at the time (which was not true either), and ignored the risk of spread of the infection, why on earth would one entrust this profession even with advising on euthanasia decisions? And in the case of candidates for euthanasia, why would anybody be even be looking for knowlegde? Or worse, even: how would it ever be possible to look for knowledge, once these cases are systematically eliminated? What about Down's syndrome 50 years ago? Can we or should we 'push as many of these decisions into the womb', before these cases attain legal personhood? Are these really 'philosophical' questions, or is science and the interests it serves driving the philosophical agenda? Once euthanasia is established, would anybody even be looking for alternative solutions? What if such elimination becomes the duty of a 'productive and fiscally responsible parent'? What if our society becomes so difficult to live in that even lesser deficiencies would compromise the 'quality of life' to the point of not 'worth living'? Are we constructing 'continua' to make the impermissible permissible? Given the AIDS experience, can the doctors trust themselves? And given our propensity to selfishness and avoidance of suffering, can we trust ourselves?

7) Conclusions and recommendations

In summary, the contamination of the Canadian blood supply was the product of an encroachment of the natural environment on a field of human engineering (biomedical engineering). The following sequence of natural and human ecological processes took place:

1) The propagation of hepatitis (and some less significant viruses) by the 'blood system' vector (such viruses had been propagated through human to human contact earlier).

2) The 'discounting' of the sources (epidemics amongst donor groups) and effects of hepatitis viruses (chronic liver disease, occasional liver coma) by the blood industry; the limited use of screening procedures (hepatitis B surface antigen, liver-enzyme tests in Europe); the masking of economic discounting by discounting the risks against the benefits of hemotherapy;

3) The propagation of HIV by the same donor sources which had been the vectors for hepatitis; the origins of HIV (animal virus, green monkeys, central Africa) as the result of human/animal contact or as the result of another biotechnology remains unresearched or concealed; the same discounting which led to the spread of hepatitis B led to the propagation of HIV;

4) Because of the deadliness of HIV infections, camouflage was used by the industry to win time for the adaptation of its technology (scree-

ning, decontamination), and to develop new technology (recombinant technology) and thus to prevent 'death of the industry'; it was essential that public institutions co-operated with the industry to make this happen;

5) The disease and death toll was probably bigger than anticipated, and led to strategies of suppression of suffering and public display, to win time and to minimize cost of litigation, which was a second 'lethal threat' to the industry; again, public institutions had to co-operate and are still co-operating, because by not using their mandated regulatory powers they had become liable themselves. Consequently more people were infected.

6) As a result of the 'adaptations' to the incursions of hepatitis B and HIV, a third pathogen, hepatitis C was propagated and now constitutes another liability threat.

7) The public display of suffering by the victims of the contamination of the blood supply disrupted, but did not stop corporate and institutional adaptation. It resulted in an exposure of some of the above. In response, strategies are developed, aimed at minimizing future exposure to and cost of liability. This may be a very 'maladaptive development' (e.g. 'privatization of the blood program').

8) The Red Cross was used (and is still being used) as 'patsy' for the Federal Government and its 'transnational industrial friends'.

While the encroachment of the natural environment on the human engineered environment is inevitable, (although measures for minimization

can be taken), the consequences from rational adaptations (adaptations in the context of the economic-scientific-legal-framework) are not at all inevitable, if motivations from beyond this frame work are allowed to come to bear. The over-reliance on the morality of 'rational choice', and the discounting of ethical 'inner authenticity' is at the root of 'rational' maladaptations. Therefore, the following is recommended:

a) Extension of protective codes

The immense progression of technology and the corporate paradigm in late modernity requires a re-evaluation and extension of existing codes and sanctions designed to protect humans and their life-world. The adaptability of corporate and entire industry entities needs to be balanced with ecologically meaningful constraining codes, which must also pre-empt subversion of such codes by corporate and political entities. However, codes by themselves are only prescriptions for enforcement. Neither a code nor its enforcement may suffice to bring about the necessary protection. The following two items are essential to bring about meaningful codes, and contribute to a life-world which is a meaningful correlate of such codes. Codes must be examined 'ecologically', as, by themselves, they may be unecological'.

b) Cultivating emotional responses (of 'the taken for granted', of 'inner authenticity').

To mitigate against the limitations of 'rational choice', emotional life,

including pain-related experiences, needs to be recultivated, in particular as it concerns the health-professions in their widest possible meaning. However, like in other spheres of social life, this is a matter of early childhood education and socialization. It cannot be readily 'injected', with a seminar or two, at a later age. The progressive technologization and science orientation of education is moving in the opposite direction. A re-evaluation and reintegration of the humanities as the basis for 'value-input' into systems of rational choice is needed. Otherwise, 'rational choice' will become an increasingly tautological system of rational choices rationalizing each other, rather than the well-being of humans. This recommendation must not be read as a suggestion to replace or eliminate 'rational choice'.

c) Development of a human ecology

This thesis meant to demonstrate that the development of a human ecological framework is a feasible project. It is urgently needed to bring about essential modifications to the processes of rational choice and 'sign construction' of our life-world. The cycle of meaning, double hermeneutic, but also the paradigm of corporate adaptability and neuro-structuralism were shown as suitable models for the exploration of correlates between inner and outer ecology. This is of particular urgency, as in the not-too-far-away future genetic codes for specific cognitive strengths and vulnerabilities (as for instance dyslexia) will be identified, and almost inevitably lead to 'eugenic' selection. Since the eugenic interventions would be structured by systems of rational choice, other cognitive faculties could ultri-

mately be lost with such a selection. While eugenics by organic criteria has been a long-standing practice of humanity, eugenics by cognitive criteria would profoundly alter the species, equivalent to an evolutionary selection which took place between *homo sapiens* and *sapiens sapiens*. The difference between Neanderthaler and Cro-Magnon may have been subtle, but phenotypically sufficient to make Neanderthalers disappear. However, that process occurred within a natural ecological environment. The genetic engineering process, on the other hand, would take place in an engineered environment and, therefore, be predictably maladaptive. One of the first targets of genetic selection would be any correlation between IQ and genetic code (which is, indirectly, already practiced in the way in which sperm donations are selected for artificial insemination). The target of German eugenics was intellectual performance. Thus eugenics would not be predicated group-specifically on race or sex, but it would be a universal selection paradigm. Other genetic characteristics which may be essential to human survival may be selected out. But since such characteristics may be of no current interest to 'rational society', they would be of little 'genetic' interest'. There is another side-effect: the smaller the genetic differences become (the narrower the bell-curve), the more intensive competition would become (the smaller the competitive difference, the larger (and possibly more damaging) the investment in competitive behaviour and selection. While this may be speculative at this point, some people are seriously thinking about it - strategically.

d) Mediated displays.

Although extremely badly handled in talk-shows, mediated displays

of suffering are essential to counteract active suppression of suffering experiences, their displays and the empathetic responses to them. It may take many generations before the first three suggestions may come about, if they come about at all. In the meantime, as it became evident during the contamination of the blood supply, display of suffering remains the only effective means of dealing with institutionally, professionally, economically or politically rationalized abuse.

Its benefits, I believe (and I think it needs to be explored) outweighs its drawbacks of political, 'single issue exploitation'. However, given the corporate control of the media and the 'atomization' of the television media, this may also reach its limits of effectiveness in due course. Newspapers and magazines may not be equally affected. They do not have the same impact as television, however.

Alternatively, networks of damaged people have had some limited success. They usually do not have the funds to accomplish the necessary legal and communications impact. In many cases their efforts become dependent on contributions from the very agencies which they are in conflict with. Therefore, in the long run, only more broadly organized approaches as suggested in the first three recommendations will have a chance of lasting impact.

The following statement is intended to emphasize the irrationality which underlies our rational pursuits. As we are busy creating our future, we do not or barely understand that which is creating it. We have to stop viewing ourselves as black boxes, no matter how fascinating the play with the dials and switches may be.

The conditions of our outer and inner ecologies transform each other. However, the primary choices for such transformations can only be made and need to be made with respect to our inner ecology. Therefore it would be a grave ecological error to believe that we can fix the 'global ecology', including global social problems, by studying the outer natural and social environment, without making an even bigger investment in the understanding of our inner ecology.

A first and very difficult step would be the disclosure of the inner ecology of those who have a lot to say about other people's 'inner and outer ecology', and how they should change it. It may just be possible that the 'leaders' need more help than those whom they (mis-)lead. At this point I do not believe that the members of any leadership have any awareness of themselves from beyond their exalted self-image. To break the spell, to 'break the mirror', this is where we must start, not with those who are dependent on them, and whose lives are (mis-)shaped by them. I trust I have demonstrated this in my own case. The 'elites' may find this outrageous. I hope they do.

Postscriptum

It may have seemed desirable at the outset this thesis to continue the research into the contamination of the Canadian blood supply upon conclusion and publication of the proceedings of the Krever Commission. This is no longer a priority in my mind, regardless of what the official findings of the Commission may be. I may not have firm proof of the various hypotheses presented in this thesis, such as 'smoking gun memoranda'. (Given the 'forensic audit' ordered by Benoit Bouchard, such 'smoking guns' are not likely to surface - unless some present or former government employee is keeping them in a vault or at home). The total agreement amongst all involved agencies; the corroborating indirect signs and evidence; the involvement of the liberal government in the early phases of the AIDS crisis and, again now, in the Inquiry; the background of Judge Krever; the associated financial transactions; my own understanding and experience in the 'system'; the Pitman case; as well as other circumstances elaborated in this thesis are sufficient for me to consider the hypotheses and conclusions as 'good enough' approximations of the na-ture of what happened, and of what is still going on. Since the redponsible political party is investigating itself, I am declaring 'no contest' at the level of 'direct evidence'.

This is not to say that the proceedings of the Commission will not be worth analysing, in particular to gain an understanding of how the overall process was played out and adapted to at the middle-and lower levels of the health-care system. However, the circumstances surrounding the contamination of the blood supply, its 'cover-up', and even the nature of the Commission itself, are all alarming signs which point to a much

greater systemic malaise in our physical, psychological and social well-being.

As I have discussed in this chapter, the simultaneous 'atomization' and 'corporatization' of our life-world, and the 'hyper-rationalization' of our life-processes by the economic-scientific-legal-regulatory complex are, in part, an adaptive response of corporatism and its incumbent elites to the human and environmental damage and 'victimization' which they are inflicting. On the 'outer ecological front', it is important to observe current policy processes, and to seek disclosure of the strategies which already exist in secrecy and which have already affected our future. I am particularly concerned over the impact of such processes on developing countries, which have even fewer 'defences' than the relatively well educated populations of Western, industrialized nations. If the processes have become incomprehensible to us, they must be impenetrable for the people of many developing countries. (A philosopher, unknown to me, has called this, pessimistically, the 'New Dark Ages').

The contamination of the blood supply provides an important 'snapshot' of these processes, a 'glitch' which was not supposed to happen or discovered. The snapshot became possible because the otherwise closely guarded and secret processes were dragged into the light by the victims of contamination. There are just too many of them (and the numbers keep growing too fast with hepatitis C) to keep the lid on. There is a need to understand the trajectories leading up to this event, in terms of external and internal ecological processes, including those which engage the heads of state of this and other industrialized nations. We also need to understand better what inner and outer ecological processes are at work now, which already have 'created' the blueprints for the next segment of those

trajectories.

We need not only to 'critically analyse' these processes, but to detonate the myths which are produced by the 'scientific, semiological and legal professions' on behalf of their 'masters-of-rational-choice' and 'masters-of-personal-point-of-view' alike. We need to subject these professions to critical analysis, wherever they may be busy dissembling and assembling 'our world of signs'.

The back of the secrecy needs to be broken. Given the extent of industrial espionage which is possible today, and given the extent and depth of scientific technological information networks, competitive secrecy may be little more than a feeble myth. Virtually all of the evil which humankind has ever experienced started out in secrecy. Our life-world is now totally surrounded by secrecy, and the little scraps of 'secrecy unveiled' concern the past, not the present and our future. Even S. Cameron's account of the Mulroney regime can only disclose an unchangeable past.

Corporatism, as we know it, needs to be driven out of the 'locus of control' it occupies now in the organization of our life-processes. The constraints for corporatism need to arise from a cultivation of our life-world which is grounded in our total experiential and cognitive endowment. The social-issue bones which corporatism has left us to gnaw on just won't do. It is essential now that the social sciences engage in real-time and futures analysis, (including a self-critical watch on the impacts and side-effects from their contributions to our double-hermeneutic processes), and that they become cognizant of the total ecological processes in which they are engaging. They may discover that they have already become obedient citizens in a corporately constructed life-world, doing what they are

allowed to do, not what they ought to be doing.

Appendix 1 Data on the Contamination of the Canadian Blood Supply.

Note: The left column is a verbatim quotation of the 'Summary of Events' prepared by Health and Welfare Canada (DOC 22). The right column contains comments and critiques.

1968

Health and Welfare Canada licenses the first coagulation (clotting) factor (Factor VIII) product for the treatment of hemophilia patients in Canada.

1973

Federal and provincial health ministers establish a Federal-Provincial Programme and Budget Review Committee to oversee the Canadian blood system. Provincial ministers commit greater financial support to the Canadian Red Cross Society for the operation of the system. By 1976, the provinces are paying 100% of the technical cost and 80% of the costs of the Donor Recruitment Program. The remainder is raised by the Red Cross through its own efforts.

At that time the funding of the blood program of the Red Cross had been in severe neglect, and a major budgetary upgrade was required (it was recommended by the Canadian Hematology Society). The federal document fails to mention that a 'Bureau of Biologics' in the Health Protection Branch of the Federal Ministry of Health was established in the late seventies, around the same time as Factor VIII concentrate was brought to the market. Hepatitis B immediately became a serious problem for hemophiliacs, followed by propagation of non-A non-B hepatitis (now known as hepatitis C). (See Ale-dort in Madhok et al (eds) 1987; Krassnitzky et al., 1970). Thus major risks were associated with an important biological product and left unattended.

1980

A German company, Behringwerke, produces a Factor VIII product heat-treated for Hepatitis B. The

Heat-treatment inactivates viruses but also leads to a loss in Factor VIII activity and thus to a loss

product is accepted for use in Germany in 1980, and in Japan in 1981 (the product is licensed in Canada in December, 1985 and in the U.S. in 1986).

in revenues from the sale of product. Mr. Heisig, President of the the Austrian Hemophilia Society indicated that the Children's Hospital in Vienna used the heat-treated product for new hemophilia cases as of 1980. None of these children were later infected with HIV. According to Dr. Oldenburg, the same happened at the hemophilia treatment centre in Bonn, Germany (DOC 46).

1981

Health ministers establish the Canadian Blood Committee to assume the role of the Federal-Provincial Programme and Budget Review Committee. The thirteen members comprise the ten provincial, two territorial and federal governments. Two years later, members agree to set up a secretariat; it is physically located in Health and Welfare Canada 'to facilitate staffing and fringe benefits' (record of June 14/83 meeting of the Advisory Subcommittee to the Canadian Blood Committee).

Note: This means that the Federal Government paid for the Secretariat, and as such was in some kind of conflict of interest as to being funder (although to a small extent) and regulator at the same time. This was corrected when the Canadian Blood Agency replaced the Canadian Blood Committee in 1989. There was also a federal representative on the Committee. The federal notes fail to indicate that the same report which recommended the formation of the Canadian Blood Committee (The 'Dr. Key-Report') also recommended the building of three fractionation plants in Canada (Connaught Laboratories, Armand Frappier and the Winnipeg Rhesus Institute, which was economic nonsense). The Red Cross (with the help of Cutter) had proposed a single plant in the preceding years and had federal support. (Personal recollection). The Executive Director of the CBC was a pharmacist and had a major role in the writing of the 'Good Manufacturing Practices' (GMPs) for the pharmaceutical sector in Canada. A similar document had been in existence in the U.S. (FDA, - Food and Drug Administration).

August, 1982:

Health and Welfare Canada's surveillance of AIDS in Canada reveals that, by August 1, 1982, eight cases of AIDS had been identified. Based on the possibility that AIDS could be transmitted by blood, the Bureau of Biologics in Health and Welfare Canada asks the Canadian Red Cross Society, and the Canadian Hemophilia Society to increase surveillance of Hemophilia patients for AIDS and report cases to the federal Laboratory Centre for Disease Control.

The Federal Government was still on track as the first few Hemophilia cases with HIV were observed in the U.S. and Canada during 1982. During the same year, there was increasing evidence that AIDS was caused by a viral agent, most likely a retrovirus. (See Shilts 1988, *passim*).

October 13, 1982:

The Red Cross holds a meeting of hemophilia-associated and other health professionals and public health authorities, including Health and Welfare Canada. The group concurs with the Department's view of AIDS as a serious potential public health problem.

(From Arenson, DOC 18) In October 1982, the disease now known as AIDS began to appear in hemophiliacs who apparently had no other risk factors for the disease. In October 1982 the National Hemophilia Foundation in the US issued recommendations directed at blood collection agencies. Blood agencies were urged as follows:

"In view of the relatively high incidence of AIDS in certain groups (specifically: homosexuals, intravenous drug abusers, and those who have recently resided in Haiti) and, in view of the potential risk of transmission of this syndrome by transfusion of blood products, it is considered prudent at the present time to urge all sources of factor VIII products to exclude from plasma donation all individuals who belong to these groups".

December 11, 1982:

The Canada Disease Weekly Report from the Laboratory Centre for Disease Control publishes a report of a pilot study on AIDS in hemophilia patients in Quebec, by a team of researchers that includes the Chairperson of the Canadian Hemophilia Society's Medical and Scientific Advisory Committee. Impending publication of this report prompts the Canadian Red Cross Society to issue an information letter to all centres in the Blood Transfusion Service requesting reporting of suspected AIDS cases and promoting liaison with all other clinical and laboratory groups that could assist in the identification of possible cases.

Arenson, DOC 18: As of August 1, 1982, there had been 8 cases of AIDS reported in Canada. Six of those had died. By December 1982, the number of cases had risen to 21. The death of one hemophilia patient had definitely been attributed to AIDS.

Personal note: I should stress here that at this point a likely link between the rising AIDS epidemic and the blood supply had been established. (See Shilts, 1988, Ottosen, 1993). This was not a simple extension of the epidemic into another group at risk, but the emergence of additional hazards in a product (Factor VIII concentrate) which had shown a similar pattern before with respect to hepatitis viruses. At that point the full weight of the Food and Drug Act should have come into force. The appropriate strategy was not 'surveillance' but the strongest possible intervention, until more data would have become available. The behaviour of the Federal Government did not just violate the mandate of health-protection, but also 'common sense'. Incremental response to acute danger is a misplaced, 'economic-rationally distorted' response, not an empathetic, adaptive, protective response. Governments need to become aware of their 'deviation-amplifying' political behaviours which, in the long run, may not be cost-effective at all. There are indications, however, as with the current handling of the hepatitis B epidemic in high-schools, that nothing at all has been learned from the contamination of the blood supply, and that the same old 'stepping-up', desensitizing tactics are still in use.

January 13, 1983:

An alert about the possibility of transmission of HIV through blood is issued by the American Red Cross, The U.S. National Hemophilia Foundation and other blood organizations.

On January 4, 1992 a meeting of blood bankers was convened by the U.S. Centres for Disease Control in Atlanta (CDC), where the CDC (U.S. Centres for Disease Control) urged blood bankers to take measures to prevent the spread of AIDS through the blood supply. At that meeting it transpired that donors with AIDS had given blood, that hemophiliacs had been infected with AIDS; that (88%) of individuals infected with the AIDS agent had also been infected with Hepatitis B (88%), that 10% of Ohio's Hemophiliacs were already sick with AIDS related symptoms, and 6 of a hundred had died from AIDS; that the gay organizations represented in Atlanta were in favor of testing for Hepatitis B as a surrogate test for AIDS transmisssion via blood donations. The blood banking community refused to act, including the FDA, in particular Dr. Bove, who tried to placate the public with misleading risk comparisons. At that point there was no longer a 'possibility', but a probability bordering on certainty that the AIDS agent had entered the blood supply and that AIDS would be transmitted via blood and blood products. The known transmissibility by intravenous drug use and sharing of needles supported this hypothesis). (Shilts 1988:220-223). Arenson (DOC 18) On January 13, 1983, a joint statement was issued by the American blood banking industry, including the Red Cross. It recommended restriction on donors with symptoms of AIDS (but did not require surrogate testing) and exclusion of high-risk groups.

January 14, 1983

The U.S. National Hemophilia Foundation issues recommendations for the prevention of AIDS in patients with hemophilia.

The government report fails to mention that these recommendations were the same as those previously issued by the National Hemophilia Foundation in the U.S. (See Arenson, DOC 18).

Between January 14 and 24, 1983

The Canadian Hemophilia Society and Health Welfare Canada organize a meeting to discuss similar recommendations for Canadian hemophiliacs.

(Arenson, DOC 18). By early February the commercial blood agencies in the U.S. had modified their donor screening practices in accordance with the recommendations of the National Hemophilia Foundation, incorporating questions about AIDS symptoms and AIDS risk groups. Voluntary agencies had resisted and relied on campaigns for donor self-exclusion.

February 3, 1983

The Canadian Hemophilia Society's Medical and Scientific Advisory Committee meets with the Director of the Bureau of Biologics and the Director General of the Laboratory Centre for Disease Control, Health and Welfare Canada. The Federal Government representatives are present specifically to advise the Committee on the development of recommendations similar to those issued three weeks earlier in the U.S.

We can assume that the American FDA (by omission) had control over the handling of AIDS with respect to the blood supply, and the corresponding Canadian Health Agency simply followed. Infact, the Canadian agency never did anything that would have been significantly advanced over the American counterpart.

February 8, 1983

The Hemophilia Society issues a press release to announce the appointment of a special scientific panel to study AIDS, as a basis for the Society to make an assessment of its impact on hemophiliacs. The President of the Society states: "Canadian hemophiliacs can be assured of the fact that this situation will be closely monitored, and that there is no need at this moment for any hemophiliac to consider any major changes, whether in the method of treatment or life-style, unless so advised by the treating physician. Just as quickly as new information becomes available, it will be disseminated to hemophilia communities."

February 17, 1983:

The Hemophilia Society circulates draft recommendations to all participants at the February 7 meeting. The Department makes no comments on the proposals. The draft recommendations are to be made final at the end of the month (the actual release date is not clear). The Society also drafts recommendations to the Canadian Red Cross Society and the Canadian Blood Committee.

Ever since the doctors who were treating hemophiliacs had become potential scape-goats. While they were depending on recommendations from the policy-making bodies, they had to make the final decisions on products which were potentially hazardous and were not removed from circulation by the Health Protection Branch of the Federal Government. This pattern of 'blame' has not changed to this date. The question is why the treaters did not, at any point, gang-up against their peers and policy leaders. Their acquiescence remains unexplained.

Since at least half of the products for hemophiliacs were from manufactured from U.S. paid donor plasma, the situation for hemophiliacs in Canada was not any different from American hemophiliacs. Notwithstanding the U.S. response, the issue had become a regulatory issue, not merely a matter of advice on part of the Federal Government. This is explicitly clear from the recommendations contained in a memorandum from Dr. Strawcynski, Chairperson of the Medical and Scientific Advisory Committee of the Canadian Hemophilia Society. (dated February 17, 1983; DOC 9). It is recommended that product from American plasma should be avoided, that previously untreated hemophiliacs should receive cryoprecipitate rather than Factor concentrate (which is produced from very large plasma pools from tens of thousands of donors), that blood donors should

be screened and that blood should be tested. These recommendations imply that a considerable number of hemophiliacs were already infected and Factor VIII concentrate was a seriously hazardous drug. From this point on the Federal Government was in default of fulfilling its mandate to regulate drugs and to protect the Canadian public from the transmission of HIV through blood and blood products. Health-protection was the responsibility of the Federal Government, not of a consumer advocacy group (the CHS-Canadian Hemophilia Society).

March, 1983:

The Baxter company receives a license from the U.S. Food and Drug Administration for a Factor VIII product heat-treated for Hepatitis B.

According to Shilts, the product price was increased by 50% (presumably for factor activity loss and for additional manufacturing procedure, Shilts 1988:345) Why did the Red Cross not use treated product immediately? (Arenson, DOC 18): on March 4, 1983, Edward Brandt, Assistant Secretary of Health, U.S. Department of Health and Human Services (HHS) promoted 'self-exclusion of donors from high risk groups. Neither surrogate testing, heat-inactivation or direct screening of donors was recommended. Thus the White House had taken a leadership role in the propagation of the epidemic through the blood supply by 'omission'.

March 29, 1983:

The Past President of the Canadian Hemophilia Society writes to the Executive Director of the Canadian Blood Committee to provide various items of information on AIDS gathered by the Society. The letter describes the role of the Society on the Advisory Subcommittee to the Canadian Blood Committee: "to provide advice under four identified areas:

Standards on drugs is a responsibility of the regulatory authority (Federal Government), not of the Canadian Hemophilia Society, which could only 'advise' the regulatory bodies. Such 'advice' could not override the statutory obligations of the Federal Government.

a) standards for blood, blood products, substitutes and policies to maintain and improve those standards.

b) new technologies, or new uses of existing technologies, affecting the blood system.

c) operational research in the blood area.

d) any matters referred to it by the Canadian Blood Committee.

Fall 1983:

With the encouragement of Health and Welfare Canada, The Medical Research Council funds a full national study of hemophiliacs (following the 1982 pilot) to determine problems in the immune response of patients with hemophilia treated with Factor VIII produced by a freeze drying process (lyophilization) and Factor VIII extracted by precipitation from collected blood (cryoprecipitate). Between 1983 and 1987 (the end of the study) the project provides a crucial continuing mechanism for surveillance of hemophiliacs.

All the Federal Government did was 'encourage to study the problem'. The government document makes no mention of the struggle that went on in the Red Cross with respect to donor screening. In April 1983 the Canadian Red Cross Society still had no meaningful donor questionnaire. At the same time M. Michael Worsoff, Counsel to the CRC Board of Directors stated that "the CRC had a moral and legal obligation to do all within reason to ensure the safety of its blood and blood products". (Arenson, DOC 18). In the U.S meanwhile, at least donor information and self-exclusion was on its way. The same was the case in Europe. Arenson also reports that on July 11, 1983, The American Red Cross reported to Dr. Roger Perrault of the Canadian Red Cross that CDC Atlanta were investigating about 15 cases of AIDS, where there was a history of blood transfusion.

November 23, 1983:

The Baxter company (also known in Canada as Hyland) receives a Canadian license to sell the first heat treated Factor VIII preparation (heat-treated for Hepatitis B) in Canada.

Arenson reports: The National Advisory Committee on AIDS met on November 9, 1983 (This was a federal committee advising the Federal Minister of Health). In 3 of the 4 cases where CDC Atlanta had been able to trace donors, the donors had been found to have suffered from AIDS. Dr. Tsoukas in Montreal had found that one third of the hemophilia patients examined had developed 'AIDS related complex'. Dr. Perrault expressed unwillingness to accept the data to step up the screening program of the Red Cross and blamed 'vocal groups', presumably homosexuals and Haitians. The Federal Government did not enter into this debate.

Spring, 1984:

Health and Welfare Canada alerts the public to the risk of HIV transmission through blood in a widely-circulated public information pamphlet.

Note: By the summer of 1984 there had been 5000 full blown AIDS cases reported in the U.S and 2300 had died. Still, the government did not intervene as a regulator. Arenson reports that in January 1984, The New England Journal of Medicine published reports of 18 transfusion related AIDS infections in the U.S. The study concluded that some cases of AIDS are caused by a blood borne agent, and that there is a carrier state in which an infectious donor is still well enough to be accepted. The Canadian donor deferral brochure was not distributed until April 12, 1984. Cutter had implemented hepatitis B-core testing as of April 2, 1984, as a surrogate test for HIV (DOC 18). (The Canadian Red Cross did not). Very likely, at the time, Cutter had untested stocks.

June, 1984:

The U.S. Department of Commerce issues licenses to five companies to begin production of HIV kits (this is not a license to use them in the blood system).

By then the virus had been isolated and characterized.

September 10, 1984:

The Canadian Hemophilia Society meets with representatives of the major suppliers of Factor VIII to the Canadian market (Armour, Cutter, Connaught and Travenol). The Society raises serious concerns about the availability of heat-treated product in the U.S. and its apparent unavailability in Canada, and about the general shortage of supply of Factor VIII. The Society resolves to voice these concerns forcefully at the October meeting of the Advisory Committee to the Canadian Blood Committee (Cutter and Armour later apply for, and are given, licenses to sell heat-treated product in Canada.)

So far no records have surfaced which clearly demonstrate that there was a shortage of heat-treated product. The veracity of this claim has been challenged by the Canadian Hemophilia Society and the former CEO of the Alpha Corporation. I already mentioned earlier that hemophiliacs could have been switched to cryoprecipitate and traded convenience for, without risk to life. Of course, it would have left the manufacturers sitting on their product inventories.

September 29, 1984:

The British Medical Journal publishes a report on heat inactivation of a murine retrovirus (a virus affecting mice) related to HIV, in a blood product.

(Arenson, DOC 18): On September 28, 1984, Abbott Laboratories offered an AIDS test, which has no restrictions on distribution in Canada. The National Advisory Committee on AIDS declines. (A test was finally implemented in November 1985 in Canada, more than a year later).

October, November, 1984:

The October or November Issue of "Hemophilia Ontario" (the record bears no date) reports on apparent reasons for shortages of Factor VIII in Canada (e.g. increased inspection by the Bureau of Biologics, lower yields at Connaught, and the destruction of products in the U.S/ because of suspected contamination. The Chairman of the Hemophilia Society's Factor Products Committee reports: "the Red Cross and the CHS have been working closely in protecting and maintaining this system. Please do not worry; your concerns are given the utmost attention." A related article prepared by the Red Cross on heat-treated Factor VIII notes that, while the risk of hepatitis infection from blood products is well-established, "evidence that coagulation factor therapy carries a significant direct risk of AIDS is considerably less conclusive." An editorial note at the end of the article reports on information just received that the U.S. Hemophilia Foundation is recommending the use of heat-treated products.

October 26, 1984:

The U.S. Centres for Disease Control confirm that HIV experimentally added to Factor VIII concentrate could be inactivated through heat treatment.

The most significant item in the reasons for shortage is the 'destruction of products' which were suspected to be contaminated. No such destructions had occurred in Canada. The information released by the Red Cross is perplexing, to say the least, when at the same time contaminated product was claimed to be destroyed in the U.S. Even more perplexing is that the Federal Government would let the Red Cross make such a statement, and that the writer of the government summary did not seem to be aware of the contradiction.

(Arenson, DOC 18): Meanwhile the FDA in the U.S still continues to promote the concept of 'self-exclusion'(Dec. 14, 1984!), instead of insisting on direct questioning of blood donors by a clinic nurse.

The limited effectiveness of self-exclusion is discussed by Roger Dodd (Madhok et al. (eds.) 1987). "Coercive and legislative approaches to the selection of donors have not been accepted in the U.S." But where did that leave the recipients? (With good reason, the Food and Drug Act is a 'coercive instrument' to protect the public under such circumstances).

October 30, 1984:

The Canadian Blood Committee's Advisory Sub-Committee meets. The Canadian Hemophilia Society representative on the Subcommittee raises the issue of the availability and quality of Factor VIII in Canada. The Subcommittee recommends that a consensus conference on the need for heat-treated Factor VIII be held at the earliest opportunity.

It must be stressed, over and over again, that hemophiliacs could have been switched to the safer cryoprecipitate.

November 13, 1984:

Health and Welfare Canada licenses Cutter Laboratories (U.S.) to sell heat-treated Factor VIII in Canada. Cutter has the manufacturing process in place.

November 16, 1984:

In a written directive to all Canadian, U.S. and European manufacturers of Factor VIII and IX, the Bureau of Biologics requires them to heat-treat all product for use in Canada by a method known to inactivate HIV. Introduction of these products was to occur as soon as feasible. The Bureau also issues a written recommendation to the Canadian Red Cross Society that untreated products be replaced with heat-treated products as soon as possible.

Regardless whether there was a shortage or not, given the knowledge that had been accumulated on AIDS by the end of 1984, it is still impossible to justify the non-use of cryoprecipitate instead of known hazardous Factor concentrate. With the exception of the letter from the Hemophilia Society in early 1983, there was no systematic effort to switch hemophiliacs back to cryoprecipitate. While some hesitation might have been defensible in 1982, in 1984/1985 infectious product was given with

(Note: the process of converting blood into Factor VIII or IX can be six or twelve months if the process involved is not already in place. The time can be reduced to four to six months if the manufacturing process is well established. In case of heat-treated Factor VIII, waiting for Canadian manufacturers to produce the product would have delayed its availability up a year).

full anticipation of the consequences.

November 26, 1984

The Red Cross informs Connaught Laboratories that, as of December 1, supplies of plasma otherwise destined for Connaught will be redirected to Cutter Laboratories.

December 6, 1984:

The New England Journal of Medicine publishes a letter from Canadian researcher (C. Tsoukas et al.) reporting preliminary findings of a study of Canadian hemophiliacs. The research suggests that 56% of Hemophiliacs are sero-positive for HTLV-III (HIV). The preliminary findings are based on 54 subjects, and the findings vary widely across subsets of the study group.

One can assume from these data that the majority of severe hemophiliacs was infected with HIV and had been so earlier (see earlier data on AIDS related complex).

December 10, 1984:

Acting on its Advisory Sub-Committee's recommendation from October 30, The Canadian Blood Committee convenes a consensus conference to discuss the implementation of the Bureau of Biologics' requirement for heat-treated coagulation products. The participants include representa-

It is difficult not to be judgmental regarding this 'consensus conference', and not to be critical about consensus conferences in general. Faced with a known infectious product, an alleged shortage of a safe product alternative, the Bureau of Biologics still did nothing to interrupt the

tives of all provincial and territorial ministries of health, The Canadian Hemophilia Society, The Canadian Red Cross Society, The National Advisory Committee of the Blood Transfusion Service of the Red Cross, The National Advisory Committee on AIDS, the Bureau of Biologics and the Laboratory Centre of Disease Control of Health and Welfare Canada, blood product manufacturers and other medical professional organizations.

The Bureau of Biologics of Health and Welfare Canada presents a position paper to the conference. As tabled the paper cites the preliminary data from the December 6 New England Journal of Medicine. In presentation, reference is made only to a 'considerable percentage' of hemophiliacs who are infected. The presentation reviews the Bureau's November 16 directive for replacement of non-heat-treated product, the status of heat-treated product licensing, and Bureau procedures for premarket testing of the new product.

Among other things, the conference:

- endorses introduction of new products by May, 1985, and full replacement of non-heated products with heat-treated products within eight weeks afterward (the first product is in fact released for sale by the Bureau of Biologics by March 15), and targets full replacement of products with heat-treated products by July, 1985.*
- asks the Bureau of Biologics to expedite licensing of new heat treated products.*

distribution and prescription of a known hazardous product, while a perhaps less than ideal, but definitely safer product alternative was available.

At the same time it must be considered that the donor screening procedures (and thus for plasma that went into production for Factor concentrate) were still woefully inadequate in 1985 (see Arenson: Dr. Perrault writing to the Secretary General of the Canadian Red Cross Society on February 19, 1985 (!!!): "...it was clear that the pamphlet pilot run had not been successful for a number of reasons and the Working Group agreed to review the information to be given to the donors, assuring its transmission and the need for acknowledgement". In addition, the Red Cross had not implemented surrogate testing for HIV and thus Canadian plasma was below the standard which even the manufacturer, Cutter, used for its own plasma-collections.

It should also be noted here, that the Federal Government had a definite responsibility for whole blood transfused: some of the raw material for Factor VIII came from plasma recovered from whole blood collections (the red cells are packed and the plasma is separated). Thus whole blood was raw-material for Factor VIII concentrate, which was licensed, and whole blood was thereby implicitly regulated. To this day the Federal Government insists that whole blood was not regulated. This is a very serious 'misrepresentation' of the facts to the Canadian public.

- recognizes that the Red Cross would direct blood supplies to facilities licensed to produce heat-treated Factor VIII until Canadian facilities were also licensed.

- recommends that the use of new heat-treated product and remaining stocks of non-heat-treated product (up to their complete replacement in July) be based on criteria to be developed by hemophilia treaters who are members of the Medical and Scientific Advisory Committee of the Canadian Hemophilia Society.

If a hazardous drug is on the market (and contaminated Factor VIII was a hazardous, if not deadly drug, licensed by the Bureau of Biologics) the direction for the non-use and withdrawal of the drug has to come from the Bureau of Biologics, and it is not up to the treating physicians whether such drug should be used or not. For instance, the Tylenol crisis was a responsibility of the manufacturer and the government, not of pharmacists or other shops which might have had the drug on the shelf.

January 25, 1985:

The Red Cross reports to the Canadian Blood Committee on progress in implementing the decisions of the consensus conference. All blood going to Cutter Laboratories is dedicated to production of heat-treated Factor VIII (earlier decisions by the Red Cross had also diverted blood from Connaught to Cutter for this purpose). Purchase contracts provide for first product delivery by late April.

February 18, 1985:

The Bureau of Biologics receives the first two lots of Cutter heat-treated Factor VIII, for review (the process normally takes four to six weeks).

There never seems to be any notion that the entire matter of contamination was an emergency, and that the 'normal' review process needed to be speeded up. Given all the preceding circumstances such bureaucratic 'thoroughness' is absurd, if not cynical.

March 2, 1985:

The U.S. Food and Drug Administration licenses the first HIV antibody test kit. United States blood collection agencies announce their intention to begin screening for HIV as soon as possible.

The FDA confirms 99% implementation of whole blood screening by the end of March; by July only 3 or 4 facilities have still not implemented screening. With respect to source plasma for Factor VIII products the story is somewhat different. 90% of (commercial) collection facilities are screening by July, but 100% implementation is not achieved until November.

March 7, 1985:

A task group of the National Advisory Committee on AIDS in Canada recommend that the Red Cross prepare a plan for the implementation of HIV screening.

March 15, 1985:

The first supply of heat-treated product (Cutter) is released by the Bureau of Biologics for sale in Canada.

March 18, 1985:

The Bureau of Biologics receives a third lot of heat-treated product for review.

This entry makes no mention of the earlier offer made by Abbott.

Pre-license use of the test would not have been a problem, it could have been done on an experimental basis. The spurious reasoning for delaying testing is discussed in Chapter 5. To put things in comparative perspective in Canada, by July (and until November) nearly 0% of Canadian facilities had implemented the test.

The Red Cross needed no direction from the National Advisory Committee on AIDS to prepare for screening, long before the date of licensing: this was its own duty. And it was the duty of the Health Protection Branch to ensure that the Red Cross would proceed in this fashion.

Note: it should be remembered that the Bureau had licensed a heat-treated product in 1983, almost two years earlier. Cutter was one year behind the other manufacturers, yet was given preference.

April 1, 1985:

The first HIV antibody test kit goes on sale in Canada. This is followed by a second kit on April 18.

April 12, 1985:

Health and Welfare Canada licenses a second manufacturer (Armour) to sell heat-treated Factor VIII in Canada.

April 19, 1985:

The Medical and Scientific Advisory Committee of the Canadian Hemophilia Society meets to address the issue of criteria for use of the new product. The criteria developed by the Committee are approved by the CHS Board of Directors on April 20, 1985.

April 25, 1985:

The Chairman of the Hemophilia Society's Board of Directors writes to the Director of the Red Cross Blood Transfusion Service to inform him of the criteria to be used to give preference to individuals for heat-treated Factor VIII during the transitional period.

May 1, 1985:

The Canadian Red Cross Society presents its blood screening plan to the Canadian Blood Committee and the National Advisory Committee on AIDS. The plan suggests an August 1 start date for screening, subject to budget approval by the provinces, through the Canadian Blood Committee.

On many occasions during the Krever inquiry it became apparent that blood centres continued to adhere to the criteria of using infected material, even when they had considerable amount of safe product on stock. The Medical Directors explained this by saying that they had to follow orders.

The Canadian Red Cross makes the first of its purchased supplies of heat-treated Factor VIII available through its Blood Transfusion Centres; the criteria approved by the Hemophilia Society guide its distribution.

They also blamed the 'criteria' as product of the National Hemophilia Society, without mentioning that the 'consensus conference' had already conveniently set up the treaters as scape-goats.

May 15, 1985:

The National Advisory Committee on AIDS endorses the Red Cross plan, including the provision that HIV positive donors will not be advised until alternative diagnostic test sites are in place, to avoid having the Red Cross used as a testing service.

June 5, 1985:

The Canadian Blood Committee approves the Red Cross plan in principle, subject to consultation with provincial ministries of health. Final approval is to be given by June 30.

June 10, 1985:

The Canadian Blood Committee informs the Red Cross that the screening plan cannot be given final approval until other issues "beyond the Red Cross national blood program" had been dealt with; these issues are to be discussed with provincial authorities.

The Ministry of Health had the power to over-ride any other concerns. On matters of drug-safety it could force the provincial governments to act.

June 11, 1985

The West German manufacturer Hoechst is given a Canadian license to sell a Factor VIII product produced with a new wet-heat-treatment process.

The Behringwerke product had always been wet-heat treated since 1979 (!). So the process was not 'new'. (DOC 46).

June 12, 1985:

The federal Deputy Minister of National Health and Welfare invites provincial and territorial representatives to a meeting to reach a consensus on matters requiring immediate action and on who will be responsible for these actions.

June 28, 1985:

The Red Cross informs Health and Welfare Canada that as of July 1, "full conversion to heat-treated products will occur". The Red Cross adds the assurance that: "All supplies of non-heat-treated coagulation factor products remaining after July 1st will be withdrawn from use and both health-care facilities and patients will be advised to return inventories they still hold." The Red Cross issues a press release to this effect the same day.

The Red Cross advised health-care facilities, but failed to advise individual patients. This would become particularly significant for those patients who were not in constant contact with a hemophilia treatment centre. The Federal Government never verified that the recall had taken place and was not at all involved in notifying the public.

July 1, 1985:

Heat-treated Factor VIII fully replaces the old product in Canada.

July 4, 1985:

The consensus meeting of provincial/territorial representatives takes place in Ottawa. The representatives agree that:

- **the Red Cross screening plans should be implemented by October 14, if the Canadian Blood Committee approves the budget by July 12. (Some Red Cross blood Transfusion Centres begin screening over the summer).**

- **each province is to designate one or more laboratories to provide HIV testing for the public.**

For the second time, on a life-and-death issue, the Federal Government chose not to enforce the law but to go with a so-called 'consensus'.

July 17, 1985:

All Canadian Blood Committee members but one (Ontario) approve the Red Cross screening plan. Ontario approves on August 1.

August 1, 1985:

The Canadian Blood Committee informs the Red Cross that the screening plan is approved. Full implementation date becomes November 1.

November 1, 1985:

The entire Canadian blood system is now screened for HIV antibodies, and a network of alternate test sites for diagnostic purposes is in place.

January 1986:

Connaught Laboratories is given a Canadian licence to sell heat-treated Factor VIII.

1987

Health and Welfare Canada provides funding to the Canadian Hemophilia Society for a study of the impact of HIV on hemophiliacs and their families. The study provides important insights into the social, psychological and economic difficulties encountered.

July 1987 (or before):

The Canadian Red Cross implements an active 'look-back' program to identify persons who may have received blood or blood components from donors who subsequently test positive for antibodies to HIV. The Red Cross Blood Transfusion Service notifies hospitals of prior shipments of blood or blood components obtained from donors who currently test sero-positive for HIV (if the donor has returned for a subsequent donation). The hospital is requested to notify the patients treating physician for direct action by the blood transfusion service.

No explanation has come forth why it took the Red Cross twenty months after testing of donors for HIV had started to institute such a policy. No concerted effort was made to find recipients of infected blood, while the hospital records would still have been retained. The look-back was inadequate, as by the time the Red Cross began testing and actively excluding donors, infected donors who had donated previously would not likely be present at clinics any longer. The other question is why the Federal Government did nothing to alert the public that a significant number may have been infected.

December 15, 1987

The Bureau of Biologics informs the Canadian Blood Committee of its recommendations to blood fractionators that dry-heat-treated coagulation products be replaced as soon as feasible with wet-heat-treated products because this process is recognized to be more effective in virus inactivation. The Bureau notes that a wet-heat-treated product is already licensed in Canada (the [German] Hoechst Behringwerke product in June 1985).

The Government report again fails to recognize that heat-treatment for disinfecting product was the first choice of treatment since the Behringwerke product had been licensed. The commercial interest in avoiding activity loss at the expense of safety is rather obvious here.

January 6, 1988:

The Canadian Blood Committee approves a Red Cross request for funding to purchase supplies of wet-heat-treated product, but reserves final judgement on approval of any products pending further consultation on viral hazards and transmission.

The Canadian Blood Committee had no authority what-so-ever on this safety-related matter.

April 28, 1988:

The Canadian Blood Committee asks the Bureau of Biologics for clarification of the Bureau's recommendation on conversion to wet-heat-treated products. The Bureau responds on May 3 confirming its previous advice, recommending against any further purchases of dry heat-treated product, and providing additional technical information.

It was not the Bureau's job to 'advise', but to enforce. The question here is this: why was no recall ordered? While the purchase of product is not recommended why is the use still recommended? If a product is not good enough to be bought, how can it still be good enough to be used?

September 1988:

The Canadian Hemophilia Society presents a request for catastrophic relief to the Federal Government on behalf of HIV-infected hemophiliacs in Canada.

The Government report fails to mention that this initiative was the result of a study of the Royal Society commissioned by Health and Welfare, which neglects to address the issue of notification of potentially infected transfused persons. This study was co-chaired by Dr. Michael Chretien and Justice Krever. (DOC 1)

June, 1989:

Health and Welfare Canada provides funding to Professor J. McDonald for a study of a) the impact of HIV on non-hemophiliac blood transfusion recipients and b) the feasibility of means for voluntary identification by affected persons. With federal funding this leads to the establishment of the HIV-T support services for this group under the auspices of the Canadian Hemophilia Society.

It is difficult to comprehend why the Federal Government would assign a victim group to the Hemophilia Society which is heavily implicated by this document. When was the McDonald report published? I became aware of it for the first time in 1992, as presented in the CBC Prime Time special on the blood scandal. No action was taken in response to this report.

One more time: it was the Federal Government's responsibility to find product-infected people, not to study the problem.

September, 1989:

Blood is classified as a drug and placed on Schedule D to the Food and Drugs Act, thereby giving additional authority to the Bureau of Biologics to extend regulatory control beyond blood products to all blood sold or distributed in Canada. (Note this qualification 'sold' makes blood a drug and makes it a responsibility of the Federal Government, whether there is a regulation or not.

This is the most seriously misleading positions of the Federal Government. A considerable amount of Factor VIII was and still is produced from plasma collected from whole blood donations. As this was raw-material (or 'ingredient') for a product which was licensed and regulated, the Bureau already had a regulatory responsibility with respect to blood collections. (Whole blood would be an 'ingredient' for the final product. (Ref.: publication by Furesz and Boucher, DOC 36). Up to this point the Federal Government had not been involved in any matters pertaining to the safety of whole blood and blood components.

September, 1989:

Provincial and territorial ministers of Health approve the establishment of the Canadian Blood agency, a federally incorporated not-for-profit corporation, to replace the Canadian Blood Committee. The Federal Government is not involved in the new agency.

This finally achieved a separation of funding and regulatory responsibilities.

December 1989:

After unsuccessful efforts to achieve a collaborative approach with provincial and territorial governments, the Minister of National Health and Welfare announces a program of compassionate financial assistance for HIV-infected hemophiliacs and blood-transfusion recipients. The plan provides \$120,000 tax-free to each living beneficiary and estate of deceased persons who qualify. The Minister expresses the federal government's view that complementary assistance should be provided by the Provinces.

Of course the provinces knew that drugs were a federal responsibility. They also depend on federal transfer payments. They also had acquiesced through the Canadian Blood Committee.

The following data are excerpts from a document prepared by Mr. Jerald Freise, Chairperson of the HIV-T Group (as of March 18, 1993): "Silent Partners; Canada's Blood System and the failure to notify those who received HIV contaminated blood product. (March 7, 1994).

October 24, 1992

(Page 11)

Hemophilia Ontario resolves to ask the Ontario Government into a public inquiry "to address the causes and persons responsible for the HIV infection of the blood supply"

November 1992

The Federal Minister of Health announces in the media that he does not see much benefit from an inquiry as it would not lead to any answers and that neither the Red Cross nor the Canadian Hemophilia Society had asked for an inquiry. (Personal recollection).

November 26, 1992

The parliamentary Standing Committee on Health strikes a subcommittee to hold public hearings under the chairmanship of Dr. Wilby (progressive conservative Member of Parliament). Two initiatives transpired from the report of this subcommittee: a judicial inquiry in the Canadian Blood system and initiatives for provincial compensation of infected individuals. A third initiative was the tracking of blood-infected

children by the Hospital for Sick Children in Toronto (Dr. Susan King), which did not come out of that subcommittee, but was personal initiative by Dr. King.

February 1993

A compensation package is offered by the provinces (largest contributors), the Red Cross, fraternalists and insurers under condition of signing a waiver for criminal and civil suits and meeting a deadline. The majority of victims accept the package and sign the waiver.

The waiver and deadline are quite unethical since the package does not constitute an out-of-court settlement, but a 'compassionate package'. There is nothing 'compassionate' about blackmailing ill and dying people in this fashion. The deadline also made it impossible for the victims to get the benefit of information transpiring from the Commission of Inquiry into the Canadian Blood System

November 1993

The Inquiry into the Canadian Blood System (with Justice Horace Krever as Commissioner) receives applications from victims and organizations and begins its sessions. I made an application for standing which was denied (DOC 47).

This collection of data had to be highly selective, as by now about half-a-million pages of evidence has been accumulated in the course of the Krever Commission. Thus this appendix can only highlight the main events and point to the contradictions and inconsistencies in claims. Testimonies of national and federal agencies are still outstanding and will not take place before 1995. By then, mostly a great deal of record retention will have expired. This may become particularly significant with respect to commercial records. Up to this point the plasma industry has been virtually invisible.

There is a second story which concerns the transmission of hepatitis C through blood and blood-products. Hepatitis had been a long-standing problem in blood transfusion, but no infectious agent was identified until the late eighties. Specific tests did not become available until 1989.

Most hemophiliacs were infected through their product first with Hepatitis B and later with Hepatitis C. Surrogate tests (hepatitis B core antibody testing and a liver-enzyme test) could have eliminated most of Hepatitis B, at least 50 % of hepatitis C and the majority of HIV infections as well.

The hepatitis issue did not become public until the Krever Inquiry. A Hepatitis C group was formed under the leadership of Dr. Alan Powell. A chronic state may be reached after a long period during which people may not be aware of their condition. Now it has almost the same attention as HIV infections. Infected people, even with very advanced liver disease, have not received any compensation.

Appendix 2

Pain-Related Phenomena Interpreted from the 'Fleu-de-Lys'

Introduction

Kant claims that one "*needs to maintain a due sense of difference between...inner authenticity...and publicly accountable reason*". (Christopher Norris, 1993:303, slightly paraphrased). If 'publicly accountable reason' is granted priority over 'inner authenticity', then this Kantian dichotomy would provide the context from which a violation of the Self or the Other can be legitimated from 'reasoned public accounting'. It ignores the possibility that what is meant to be differentiated may in fact be inseparably confounded; and that by suppressing the 'inner authentic', so as to give priority to the 'publicly accountable reason', the confounded portion of that 'publicly accountable' may be suppressed as well.

Such perspectives on our experiences and behaviours are becoming increasingly important as we are confronted with more and more conflict between rational choice and, at times, intangible sensibility. Pain and suffering experiences are 'authentic experiences'. The 'sequestration of pain and suffering' and of emotional experiences in general is the product of 'public accountable reason'. From an ecological view-point this could be considered to be a form of 'ecological deregulation'. We ought to look at the practice from 'publicly accountable reason' with ecologically vigilant

suspicion.

'Passionate expression' and 'immediate empathetic response' are perceived as disrupting 'accountable reasoning' (such as imputed from 'imperatives' of power, economics, science and technology) and as threatening to what has been declared authoritatively to be the 'reasoned public good' (which can be and is 'accounted for' in the strict sense of the word, by evidential data and algorithms of reason). We should suspect that the 'reasoned public good' may not necessarily be in the 'best public interest', authentic experience and spontaneous response are perceived as threat and disruption, without contributive value.

In contrast, the poetry written by anthropologists and assembled in 'Reflections', exposes pain and suffering of 'ego' of the anthropologist and empathy for the cultural Other with little inhibition from 'public accountability' (see Prattis, ed., 1985; additional work on anthropological poetics see Brady, ed., 1991; for a commentary on 'Reflections' see Blair et al., 1994). According to Prattis, much of this poetry was written without intent of publication and 'public accountability'. Yet, tendentious art of this kind is likely produced with some imagined audience presumed capable of some empathy and sensibility in mind.

Prattis argues that this poetry is important data which would not be captured with conventional ethnography. 'Rational', scientific discourse, as we know it, is intended to sequester emotional content (as 'subjective'). By its intent and purpose it is not suitable to communicate emotional experiences. The scientific text 'sequesters' emotion, it can be rationally analysed but not experienced; poetic text 'integrates' emotions, it can be experienced but not rationally analysed.

The obvious 'problem' is how to synthesize these two modes of cogni-

zing: we ought to try, at least, to find ways of synthesizing our inner authenticity with public accountability. But if we treat this as a 'problem', we may be setting ourselves back on the track of 'problem-solving' and public accountability, leading to more 'publicly accountable reason', not to true synthesis. (It seems to me that this infinite regress towards rational choice and public accountability is one of the roots of the exponentially growing dominance by the 'rational-logical-legal' constructions of our life-world).

I would submit then that this dilemma cannot and should not be 'rationally' solved', but must be given, from time to time, to processes of our inner synthesis (or 'inner ecology'), over which we may retain some conscious control, but not 'rational control'. Juries, for instance, are instructed by the judges to use the 'weight of the evidence', not their 'inner, authentic feelings' in their deliberation. Nevertheless, some juries follow their inner 'authenticity' and end up 'hung' (If juries are not to follow their inner authenticity, why bother having juries? 'Expert systems' could do the job just as well, if not better).

In most legislatures, the staged 'emotional debate' follows the bureaucratic, rational production of a piece of legislation, it does not precede it. While inner authenticity is not entirely excluded from this form of public accountability, it is after-thought rather than precedent. It may be acted or simulated rather than experienced and enacted. Perhaps the sequence needs to be reversed.

The challenge is in the expression and communication of 'inner authenticity'. Poetry is only one form of a wider array of representational tools, referred to as the 'arts'. Every art-form has its own medium and thus (sense-) specific symbolism and range of communicative facility. All

forms of creative (put, to some degree, also performing) artistic expression have in common a personal subjective view-point and expression of the artists, representing their specific experiential (and thus emotional, and I would suggest, 'inner ecological') state at the time of production (See Berman 1991: 329-344, on the '*two faces of creativity*'). They are not necessarily conforming with is 'publicly accounted for as correct'. Science, which has some very specific 'artist dimensions', such as the 'elegant proof' or the 'controversial claim') may get some contribution from such cognitive faculties. Isaac Newton was a hermetic before he became a scientist and 'invented' rather than 'discovered' the relational harmonies of physics, and 'disenchanted' the world (Berman 1984:107-125).

To make sure that we do not forget the confoundedness of the two, it needs to be stated that conformance with what has been publicly accounted as correct, may, in part, also be authentic.

'Synthesis' of the 'inner authentic' and the 'publicly accountable'.

The synthesis between artistic (experiential, emotional, 'authentic') and scientific (experimental, logical, 'accountable') cannot be achieved by one or the other alone, lest we move into infinite regress in either direction. There is no reliable 'third position or frame of mind' from which this synthesis could be achieved. If we assume that inner authenticity and the publicly accountable are somehow confounded in each other, then we must also assume that we carry in us biological algorithms which make such an inner synthesis (confoundedness) happen. One would expect then, that some of the 'inner authentic' can become rationally configured and be integrated

into the 'publicly accountable', and that some of the publicly accountable reason can become 'authenticated'. (For instance, 'law' represents the publicly accountable, whereas 'justice' represents the 'inner authentic publicly accounted for'.

The 'confounding' is likely to happen 'non-consciously', through transformations in our neuronal networks of which we have no conscious awareness or objective evidence. (Therefore, objectivity on anything is a false claim). Neuronal networks are not (yet) directly accessible and we must resort to ('subjective') experience, ('objective') observation, and to the patterns of knowing which arise from these processes. The conscious outcomes of these processes, provide, nevertheless, a pattern from which models of such inner processes can at least be sketched. The development of the mandala described in this appendix is an attempt at such a sketch.

The construction of a mandala to access 'synthetic processes'

The nature of mandalas

The construction of mandalas is a cultural universal. Mandalas can be seen as 'cosmograms', high-level representations of our life-world, as high-level conceptions of the constitution of our consciousness. All mandalas are characterized by some kind of orthogonal symmetry, some sort of circular enclosure and rotational axis. Some forms may include a central symmetry, rather than linear symmetry. Mandalas could be seen as productive expressions of fundamental neural cognitive structures which arose in evolution as orientational adaptations to the individual organism and the

environment (social and otherwise), which have been retained amongst the cognitive faculties of (biologically) modern humans.

The various symmetries (or asymmetries, like the spiral) allow us to arrange life-phenomena in coherent, complementary assemblies. In doing so, we can comprehend the totality of our life-world or a major dimension of it 'at a glance', without elaborate rational and comparatively inefficient representation (without this 'symbolic efficiency', our lives may actually be unlivable). Thus universal sets of life-phenomena can be ascribed to or inscribed into the mandala, relationally and in transformational progression.

Origin of the mandala developed for this discussion.

Derek Blair's and Iain Prattis' paper on exploitation in anthropological fieldwork (1993) proposes a synthesis of *Logos* (rational thought), *Eros* (care for and love of others) and *Poetics* (creative cognitive processes) as constituents of consciousness, with Poetics playing the role of mediator reconciling the other two. Upon reflection on this triangular configuration, 'triangular' *felt* wrong, and I felt that '*Ego*' should be added, to arrive at an orthogonal, mandala-like configuration. I also had an intuitive notion that there may be something amiss in the Christian 'Trinity', a construction of the Church Fathers; similarly there may be something amiss in the Freudian 'trinity' of Id, Ego and Superego. I added 'Mary' to the Christian cosmos. I found nothing in the Freudian terminology that could fit under 'Eros'; 'Libido' is an extension of 'Ego'.

In the orthogonal configuration, *Eros* (as reflection on the Other) finds its counterpart in *Ego* (or Narcissus, as reflection on the Self) along

the horizontal reflective ('internally productive') axis; *Logos* finds its new counterpart in *Poetics* along the vertical 'productive' ('externally productive') axis.

Fig. 14 *The Productive-Reflective Cycle of Human Consciousness*

The transformational extension of this mandala

Logos does not just stand for rational thought, but also for rational action. 'Action' transforms Ego and Eros ('artefaction') in the direction of predetermined 'central tendency' or in the direction of change from such a 'central tendency'. The reflection on these transformations, mediated by the unconscious 'Poetic' ('creative'), informs *Logos* for further action or cessation of action. Upon completion of the 'cycle', *Logos* acts again, upon renewed reflection the transformative (adaptive or adaptational) cycle continues. (On an overview of the relationship between artefaction and consciousness see Laughlin, 1989) (Note: 'cycle' is not quite the right term, as

there is never a return to an earlier state. We do not have a term in our vocabulary which signifies an 'iterative transformational process', referring to an adaptational process rather than to cyclical, oscillating adaptedness). The unconscious and the conscious (or the rational and the emotional, or the subjective and the objective, the 'engineered' and the 'ecological') are not alternatives, opposites or complements. Rather, the irrational, subjective, unconscious, and I would now add the emotional, are experienced and enacted at the material level and rationalized. These rationalizations, products and enactments, in turn, transform the way in which the unconscious informs our conscious state. Thus the ecological and engineered constructions of our life-world become progressively confounded in each other - unless the life-world is exclusively experienced in one or the other way, by circumstance or by intention (and never completely so).

I took a second approach to the construction of the mandala, which was independent of Derek Blair's discussion but showed some congruence with it: a construction from four basic self-referential narratives, or references to ourselves, embedded in ecological, time-related paradigms:

- 1) **Statements of relations (adaptedness):** I am (Poetics), I (do) control (Logos), I have (Ego), I know/understand/belong (Eros);
- 2) **Statements of transformation (adaptation):** I become (Poetics), I (do) change (Logos), I get (Ego) and I learn/'socialize' (Eros);
- 3) **Statements of loss (suffering):** I hurt (Poetics), I am changed/controlled (Logos), I lost (Ego), I do not know/understand/belong (eros).

The expressions of the healing process move from 2) to 1) and result in the old status of relations (recovery of the old 'steady-state'), or in a new status of relations (and achieved transformation into a new 'steady-state').

Most people will express their life experiences in a given situation in at least some of these terms, as some kind of balance or imbalance, in particular if a substantial loss has occurred (when they are 'suffering'). With respect to the 'contamination of the Canadian blood supply', the ascribed elements of the mandala are arising in the accounts of experiences, actions and rationales of victims and institutional managers.

The 'fleur-de-lys'

Fig. 15 *The Fleur-de-Lys as Mandalic Symbol for the Productive - Reflective Cycle of Meaning*

The mandala was modified by inscribing it into the symbol of the fleur-de-lys. This symbol is more evolved, flexible and dynamic. It displays additional elements to be reflected on. The flower, as living entity, is intuitively more suitable to contemplate on illness, pain and suffering as transformational processes than the abstract symbol of the circle and its stark orthogonal co-ordinates.

The lateral petals offer a metaphor of dual reflection, on Ego and other. Additional elements for contemplation are the rectangular mirror-like shape in the middle, symbolizing the juncture between the conscious and the unconscious. The conscious petals cross through the mirror into the unconscious, providing a central symmetry (as in Yin-Yang) in addition to bilateral symmetries. The anther filaments provide additional axes of symmetry. They can also symbolize sensing and perception of Self and Other including the environment. The crossing-over is a universal in symbols which express or imply a notion of infinity = totality:

Caduceus

Yin-Yang

Fleur-de-Lys

'infinity'

rings

Fig. 16

Duality and Symmetry in Symbols of Human Consciousness

The lily has certain similarities with the tripartite tree of life (root, stem and leaves) of the Kabbalah. (For possible Judaic origins of the French lily see Baigent et al., 1972; see also note in references. However, no derivation from kabbalistic symbologies is attempted or intended here).

The circle represents the boundary of the phenomenal self (the 'internal operating environment') or the boundary of the referent noumenal universe, a partially filled conscious and unconscious space (the 'cognized environment'): 'knowing to be' is 'being'.

Associative extensions of the cardinal elements of the mandala

The cardinal elements of the mandala (Logos, Poetics, Ego and Eros) can be associatively extended as indicated earlier. I should stress that the lily is not a 'model' in the scientific sense, but an object of contemplation by which complex experiential and productive phenomena can be explored in complex contexts, relationally and transformationally. The following are personal, intuitively arrived at associations, which would differ from individual to individual and certainly from culture to culture. Associative commonalities could be tested for cultural and structural origin.

The horizontal, reflective axis**Eros**

I know
 I learn
 I forget
 Idealism
 Community
 Co-operation
 Empathy
 (Jesus)
 (?)

Ego

I have
 I get
 I lost
 Materialism
 Individualism
 Competition
 Pain
 (Mary)
 (Ego)

The vertical, productive axis**Poetics**

I am
 I become
 I change (intransitive)
 Mediation
 Paradoxical, contradictory
 Influence, Autonomy
 Tolerance
 Co-operation
 Archetype
 Intuition
 (Holy Ghost)
 (Id)

Logos

I do, make, act, speak, write, take..
 I change (transitive)
 I depend
 Control
 Logical
 Power
 Intolerance
 Competition
 Technology, design
 Modelling, planning
 (Father)
 (Super-ego)

While these associations reflect many dichotomous structures, dichotomies can be arranged in a more complicated (relational), but also more complex (transformational) pattern. Thus some of the limitations inherent in structuralism as proposed by Levi-Strauss can be overcome.

Additional symmetries

There are additional symmetries along the two diagonal axes, which may split ('sequester') and pair the major elements, resulting in complementary (not integrated) partial selves, which may be substituted (but not completed) with the opposite partial. Intro/extroversion and the feminine/masculine are shown here as examples. Complementarity in social relations can thus be seen as a situationally adaptive arrangement; however, once the situation changes, the formerly adaptive complementarity may become maladaptive. An example is the division of labor in the 'traditional family' and the difficulties which arise for mid-life of a couple.

The sequestration may expose dominant Logos and dependent Ego, segregated from an authentic Other and from Poetics. A combination of the two complementary configurations represents an imbalanced, patriarchal (or matriarchal) male-female relationship. The 'feminine' is restricted to an Other-oriented, dependent, and possibly exploited, even abused emotional constitution of consciousness (without constructive enactment of emotions). The 'masculine' is reduced to selfish, materialistic, instrumental rationality of a domineering, exploiting and possibly abusive consciousness. The consequences of a male tendency to suppress emotions and empathy, and the concealment of female suffering from domination in domestic privacy have been widely discussed. In a wider sense such maladaptations can be observed in the relationship between the patriarchal/matriarchal 'state' and the 'people', a condition which has become eminently evident in the 'situation' of the contamination of the blood supply.

Fig 17 *Feminine and Masculine Restrained Consciousness*

Note: By shifting the symmetry to the other diagonal axis, the mutual complements of introversion and extraversion become apparent. Except in state of severe illness (katatonia/depression, and mania), nobody is entirely introverted or extraverted, but oscillates on a continuum between and in distance from the two extremes. Similarly, nobody is entirely feminine or masculine, but shifts or oscillates situationally and developmentally on a continuum. In the vicinity of the extreme states, behaviour becomes destructive (and thus painful) for Self and/or Other.

Fig. 18 *Introverted and Extraverted Restrained Consciousness*

Pain related phenomena interpreted from the fleur-de-lys

The experience of suffering in individual social development

I will give one example here. The 'Hero's Journey', one of the most meaningful archetypal contexts for the transformational significance of suffering, can be mapped into this symbol:

- the dependent, insecure, self-reflecting Narcissus;
- passing through the atonement of Logos ('compliance', 'obedience');
- the encounter with hostile and helping others (Eros), (overcoming fear of breaching of compliance with status quo and authority; community);
- the journey through the 'underworld' (scarring, chaos or transformation; non-conscious process; 'autopoiesis') (poetics);
- re-emergence: scarred-egocentric, rigid; or chaotic, other-oriented, self-effacing, 'doormat'; or transformed, adapted, centred.

'Turning to the many images of the hero slaying the dragon, it is the dragon who is ultimately the hero's own fear, just as the hero personifies the state of mind that can overcome fear. The hero myth as a symbolic drama of inner conflict is then valid in any age, for men and women, whenever and wherever the situation of unconscious bondage to fear prevails. Jung writes:

"In myths the hero is the one who conquers the dragon, not the one who is devoured by it....Also, he is no hero who never met the dragon, or who, if he once saw it, declared afterwards that he saw nothing....." (Baring and Cashford, 1993: 296):

Fear in its many experiential and behavioural manifestations is indeed a common source of 'sequestration': 'looking the other way' or claiming 'to have seen nothing', the yielding to fear, the subconscious (or conscious) fear of authority, excuses such as having had to follow orders. The dragon may be 'imagined', a 'simulacrum', a 'paper dragon'. Some 'dragons', however, are on the outside and very real. Psychoanalysts (ever since Freud) have a tendency to overestimate and overvalue the 'imagined' and underestimate and undervalue the 'real'; others (hyper-rationalists), perhaps in reaction to and in fear of psychoanalytic insight, have the problem in reverse.

The 'heros journey' as interpreted from the fleur-de-lys differs from Joseph Campbell's interpretation (see Campbell in 'The Hero with a Thousand Faces, 1968:245-247), as 'getting past' logos is a condition for the embarkment on the journey (logos can be male or female). The controls of logos are an 'angel with a flaming sword', and most people do not get past this angel. In the story of the contamination of the blood-supply, almost nobody got past the angel. Those who ventured, are still atoning logos, obediently.

Loss of integrity in Ego and Other.

Pain and suffering are experiences of loss, loss of integrity of the Self, of a possession, of capacity to act, the loss of Other, the loss of control. Any one of the petals can be depicted as defective, reflexively inverted towards logos, shrunk or severed from the whole flower. For the purpose of this discussion I will assume that the unconscious is more fixed than the conscious. (At this stage of my orientation the problematic of a conscious-unconscious, mutually transforming dialectic is too difficult to explore).

Thus whatever loss or damage may occur in the upper petals, the poetic (creative) unconscious is assumed to have the capacity to restore the conscious, or at least induce logos to action which will take us on the path of restoration. The conscious realization of these poetic restorative processes may be painful and may need to be experienced repeatedly in the process of individual development (the mirror tends to reconstitute itself as we remain oriented towards the material world and our material self-image. We respond too often to our pain with rational solutions - 'problem-solving').

Pain itself may arise as a symbolic phenomenon (as per its anatomical location), if an injurious situation is ignored by logos and/or ego. The unconscious is pushing the conscious logos into evasive or confrontational healing action (e.g. headaches, lower backpain, so-called conversion-syndromes, which signify the conversion of 'mental' distress into physical pseudo-disabilities, e.g. blindness, or 'pseudo-paralysis', and more serious conditions such as arthritis or ulcers).

Turning to the link between losses and the experience of pain and

suffering, we need to address the question why, if we loose, for instance, a valued possession, status, control, a loved one, we experience the loss as grief, as suffering, even physical pain. Any constituent of our conscious experience has concurrent existence and linkages in the unconscious. It is also verified and checked with its noumenal counterpart - intentionally (like the scrouge counting his money to reassure himself that it still 'belongs' to him), or non-consciously, and unintentionally, when the noumenal loss is not consciously experienced, or when a sudden loss occurs.

Once the noumenon is lost, has vanished, (or is assumed to be lost), the integrity of the Self is compromised, and an 'alert' state of pain and suffering sets in - and thereby a complex search for healing (which could be a replacement of the lost noumenon with a new one). ('Separation-angst' is a manifestations of this phenomenon, which teaches us 'impending loss', a kind of suffering when the loss is temporary). The loss may occur in Ego (and the extended ego with all its perceived possessions), or in the cared-for Other, with respect to the ability or capacity to act, communicate, control or produce. (see Festinger on cognitive dissonance, 1957).

Very profound experiences of loss may occur when the loss is in the poetic, in the 'non-conscious internal operating environment', for instance after brain damage (onset of Alzheimer, certain locations of stroke, in particular when the self-reflective functions remain intact). The emotional 'pain' experienced from the loss of or damage to the Other may be the same as loss of extended ego (the 'Other' as an extended 'possession') or as 'other ego' (authentic Other).

Loss of 'possessed other'

Loss of 'authentic other'

Fig. 19 *Ego-centered and Other-Centered Grieving of Loss of Other*

If we assume that the 'Other' can have a phenomenological existence in its own right within the Self, then the 'Other' is not just a 'possession' or object to be used, or an 'instrument'. It stands in a dialectical relationship with Ego, which is unconsciously mediated. The emergent action from 'experiencing the Other as suffering' may be like the healing of the Self by helping and healing of the Other. If the Other is simply an extension of the Ego (a 'possession'), then there may not be an empathetic response at all, but rather a grieving response to the loss or injury of Ego and one of its possessions. Instead of helping the Other, the Other may be blamed, insulted, violated. At best it may be 'repaired'. 'Defective' children of 'perfect' possessive parents know all about that.

Learning empathy is learning to realize the full authenticity of the Other. This is possible only if one has realized the full authenticity of the

Self through the full experience of the Self. (This is basic to the Hindu belief of seeing God in the Other; Prattis, personal communication). Our daily experiences and reflections normally do not reach that kind of scope and depth. A serious hardship, a painful experience may force the conditions necessary for reflection. In the state of suffering, the Self is imposing itself severely on our conscious awareness and forces us to deal with ourselves. Once we have reached this kind of self-awareness and corresponding self-authenticity, it becomes very difficult not to grant the same authenticity to the Other. Our capacity for empathy must be the result of 'entrainment' from experience of whatever archetypal material is available to us (Laughlin 1990). Without experience, such an entrainment cannot take place, and possibly, unless it happens at a critical point in individual development, it may be irrevocably missed: our archetypal potential (of inner authenticity, and accepting the authenticity of the Other) may never unfold.

The publicity of pain and suffering

The public space of civilization is the space of rules and norms and thus the space of Logos. The suppression of pain and suffering prevents not only the authentic experience of the Self, but also an authentic presentation to the public. I have argued that the denial, suppression or 'sequestration' of suffering (also the mediated, manipulated display) in our culture may be linked to rational, authoritative politics, to 'logos' claiming omnipotence and at the same time punitively inflicting pain, as in the Judaic interpretation of pain, suffering and misfortunes being God's punishments).

Suffering and cosmology

The lily can serve as a cosmogram, a cosmos in transformation, producing and reproducing itself, a symbol of production, dissemblage and recombination towards higher complexity, alternating and overlapping phases of disruption and creation, rather than smooth transmutation. (Hindu mythology resembles this sequence with periods of homeostasis between the transformational events: Brahma, the Creator; Vishnu, the Preserver; Shiva, the Destroyer; from Campbell, 1991(b):184-187; first published 1962). I have argued elsewhere that homeostatis and transformation are not mutually exclusive phenomena, but simultaneous processes. A consciousness which has not learned to account for and accept this condition of life cannot attain its potential, it cannot fill the material and spiritual space available and it may find life and death futile.

Suffering for the respectively 'unentrained' consciousness would thus be a meaningless experience in the course of a meaningless life in a meaningless cosmos. The occurrence of a painful experience could thus result in withdrawal, aggression, or the destruction of Self or of the resented Other. Alternatively, it may result in the relentless suppression of suffering, by drugs or other strategies of sedation, pain-killing, purely physiologically strategized endorphin-shedding practices or endless rationalizations ending in cul-de-sacs. Neither destructive nor suppressive strategies can contribute to the healing of the 'wounded Self'. Since biomedical or cognitive healing approaches do not recognize their own lack of cosmological context, they cannot recognize their related shortcomings.

Sign-constructed (non-symbolical) physical or chemical cosmologies, as they are constructed by science, are useless, because we cannot con-

construct a coherent, meaningful life-world with it: our brains are not constituted to construct a 'livable' life-world from molecules 'in there' and galaxies 'out there'. Or: we organize our life-world in correspondence to the rising and setting sun: then we may give some thought to the laws of gravity manifest in our solar system. Our 'reality' of life-experience keeps us at the centre of the universe, although we know the 'truth' that we are not.

Thus, if we were to attempt to reconstruct a cosmology, we must create conditions for it to happen from within, precisely where all other cosmologies arose. This cannot be done in a 'planned fashion' or CEO-manner "*I want a cosmology on my desk in two weeks*" (I have been asked once to deliver a 'management philosophy on Monday'). Rather the developmental conditions for our children have to be such that it can take place. To put small children in front of PC-monitors, to eliminate art education, to put families up in apartment silos, to feed children processed food, to entrust them to professional 'care-givers', and to instill into them the illusion that they can be everything they want to be, to make them 'educated consumers' and citizens solely preoccupied with self-protection, self-esteem, responsibility for self, self-realization, are not conditions under which the equation consciousness = cosmos becomes possible. The result is seriously deformed consciousness and a cosmos which does not make sense and offers no answers. The Ego of the Self becomes purely self-referential and thus tautological: it makes no sense outside itself and the Other can be nothing else but a possession, a tautological extension of Ego. Under conditions of dissonance (when the actual does not match the expected), in the absence of a higher order 'sense', suicide and violent behaviour may be on the rise.

The 'helping Logos'

The influence of a mediating unconscious is most annoying for a mechanistically regulated society. Logos can only deal with logical (e.g. legal) or quantitative propositions, or with a binary logic, not with continua, fluidity, paradoxes, contradictions, the kind of propositions which arise from the simplest interaction between two individuals. Characteristically, Logos helping the Other does so by controlling the Other, and by disempowering the Other before 'granting' help. Logos, without being informed from a mediating unconscious, is without soul, emotionless, and threatening. Even when programmed to diminish suffering, its net-effect may still be more and different kinds of suffering. (Western economies have prolonged life, but for a growing portion of the population it means impoverishment, social marginalization, or invalidity and institutionalization; the ambiguous nature of the social security as a 'safety-net' and as a 'net trapping people in poverty and oppression' is another example. The only alternative offered is, from time to time, as a matter of rational choice, to cut the ropes which hold the net).

Comments

The fleur-de-lys is suggested as an organizing concept in a dys-organized technological life-world, rather than as an oppositional concept. I have used this symbol contemplatively throughout the development of this thesis. Without it, the complexities of this exploration might have been overwhelming. There have been only occasional references to this appendix,

otherwise it has remained submerged, in order not to fragment the various discussions. I am attaching it since it was an important organizing paradigm for this thesis and should, therefore, be disclosed.

Appendix 3: Autobiographical Notes

Summary statement of motivation for this thesis

To utilize my educational background (medical and social sciences); my professional experience (medical, technical/scientific and managerial, including substantial paradigm shifts in professional practice), and personal life experiences (e.g. poverty through most of childhood, emigration, divorce, resister to corporatism in human services) in challenging the commodification of our life-world and the extension of corporate control over physical, mental and social health and illness, in particular where such controls lead to institutional abuse and violation of the human being.

Author's experiences and competences

In this section I shall describe how my own life-course was interwoven with the events surrounding the contamination of the blood supply. I will also try to answer some of the questions which may be on the Committee's mind regarding my background and motivations, in particular those which relate to what has become known in media and legal circles as my 'credibility problem' and my reputation as being a 'shadowy figure'.

Education and experience

- 1) A completed medical education (University of Vienna-Austria, completed training in internal medicine). This included clinical and laboratory research, in-patient and out-patient services; surgery; exposure to specialties like clinical pharmacology, metabolic disease, gastroenterology hematology;
- 2) Military training and thus exposure to the most 'evolved systems of coercion';
- 3) Extensive experience in medical administration, process control management, strategic and policy management, computer systems, quality assurance, organizational design for large complex organizations, infrastructure planning, strategic and directional planning; in this capacity I was required to work with a wide range of professions;
- 4) Experience in the management of charitable organizations and humanitarian service;
- 5) Relations with governments and commercial enterprises;
- 6) Voluntary, extra-curricular engagements in the not-for-profit sector;

- 7) Multiple experiences and contacts with the global 'blood system';
- 8) Teaching at the graduate and undergraduate levels;
- 9) Professional consulting assignments in strategic planning;
- 10) Undergraduate education in sociology, undergraduate and graduate education in anthropology (Carleton University); occasional lecturing in the anthropological aspects of medical technology.

I believe that my medical and managerial knowledge and experience, augmented with a social sciences education has provided me with the knowledge and experiential bases to carry out this and similar projects. For most of my working life, I have worked independently, 'inventing' my jobs as I went along. I was never handed a job description or 'objectives'. With three exceptions, I generated all my own 'assignments'. With one exception (a study on hemoglobin levels blood donors) I completed all of them successfully.

Elaboration of personal involvement and motivation.

Personal involvement

I was not involved in the specific decisions which led to the contamination of the blood supply. Therefore I do not consider myself liable

in any way or to any degree. However, I was a participant in the Canadian 'blood-system' (and thus in the larger health-care system). My life and career experiences were directly linked to events surrounding the contamination of the Canadian blood supply. At present, I am helping the victims of the contaminated blood-supply. On account of my background and my work with victims I have to consider myself a 'hostile witness' and a threat for the institutions which are now held accountable through civil litigation and the Inquiry on the Canadian Blood System (the 'Krever Commission'). However, I have also attempted to make constructive recommendations to the parliamentary inquiry and to the Krever Commission.

My professional competence is not, and has never been, in question. The strategy of institutional lawyers and public relations advisors has been the destruction of my personal credibility. (A prominent lobbying firm is presently managing what I refer to as 'public manipulation' for the Red Cross and the Federal Government, at a one million dollar fee. This level of financial muscle means 'no contest' for me).

Similar tactics were used with other individuals who were considered 'hostile' by the 'system'. For instance Dr. Gail Rock, former Medical Director of the Ottawa Blood Centre was fired in 1988, and had to wait until 1994 to obtain a court ruling of 'wrongful dismissal'. The Red Cross had succeeded in delaying court action on part of Dr. Rock for six years and is now appealing the court decision. The internationally best known example, with respect to AIDS, is Dr. Don Francis of the CDC (Centres for Disease Control in Atlanta), whose career came to an abrupt end after he had taken personal initiatives in battling the AIDS epidemic and an adversarial position vis-a-vis the blood establishment. Similar discrediting tactics

had been used in the past on Dr. Pierre Blais, the activist in the silicone breast implant issue.

Such tactics are not at all unusual and are commonly used by institutions in their 'handling of whistle blowers' (Glazer & Glazer, 1989). It is bad enough to take a stand against public institutions. To take a stand against one's own professional peers is violating a tacit code of professional solidarity and may never be forgiven (this phenomenon is not restricted to the medical profession; it is well known amongst police forces, for instance). In a military context, this practice has been fictionalized in the movie 'A Few Good Men'.

My own situation is somewhat different from the standard paradigm of the 'whistle-blower'. My professional expertise in infection prevention, quality assurance, corporate control systems and computerized blood banking systems is well known, but was never engaged in the handling of the HIV crisis or the prevention of hepatitis transmission. Therefore I was never part of the 'insider-circle'. In particular on matters of quality assurance and protection of the public I was known to have an uncompromising attitude. In the late seventies I ordered 600 blood collections destroyed, because there had been an error in the labelling (unit identification) process at the blood donor clinic. The national office of the Red Cross was furious. On a different occasion I had told a reporter that the Red Cross had serious organizational problems, which I considered at least in part responsible for the mishandling of a blood shortage in Toronto in the late seventies. According to Dr. Perrault, National Director of the Blood Transfusion Service at the time, this led to considerations of firing in the upper ranks of the Red Cross. 'Fortunately', the Mississauga train derail-

ment happend and my comment to the media ceased to be at issue. In late 1986, or at the beginning of 1987, I proposed to the planning committee of the Board of Governors of the Red Cross to establish an ethics committee as one of the key committees of the newly configured Board of Governors. At the time I had learned that the Red Cross had a substantial investment portfolio (approximately \$ 20,000,000) and could have used that money to speed up the implementation of HIV testing, when the government was delaying funding. I told the committee that I considered the inaction of the Red Cross as unethical and that, because of it, some people would die from HIV infections. My request for an ethics committee was denied, because the volunteers felt that this was taken care of by virtue that they were volunteers. I resurrected the ethics committee issue with the Red Cross's planning committee in 1989, just a few months before I was fired.

By the mid-eighties, all of this made me a 'potential whistle blower', while virtually all of my former colleagues were knowingly or inadvertently caught in various degrees of potential complicity and thus liability with respect to the contamination of the blood supply. From then on a variety of efforts were made to get me to resign or to fire me. (This was confirmed by one of the members of the executive committee of the Board of Governors of the Red Cross; it was independently confirmed by the consultant from Ernst and Whinney, who was assisting in the staff reorganization at the National Office of the Red Cross). After three years of repeated attempts to fire me or to get me to leave, I was finally fired upon an allegation of sexual harrassment. As my former supervisor, Dr. Perrault, conceded just a few weeks before the allegation of sexual harrassment was made, that I was one of two people *'who were still left, who knew how it*

all hangs together". He was the other one. I knew the blood-banking business, the commercial plasma business, hemophilia treatment, the infection risks, Red Cross operations, and government relations, policy and legislation. Just a few additional facts would have enabled me to understand quickly what had happened with respect to transfusion related hepatitis and HIV infections. I was fired around the same time when the first two AIDS related law-suits were filed against the Red Cross in 1989. At that point it was no longer possible to keep me away from the HIV issues or to keep the HIV issues away from me. My last advice to Dr. Perrault, when I learned about the law-suits was that the Red Cross would have to "*get the best public relations money can buy*".

Between 1987 and 1993 virtually all of the personnel of the head-office of the Red Cross were replaced. Many key replacements were former employees of the Federal Government. I believe that my case was handled in a particularly severe fashion because, although I had not participated in the contamination of the blood supply, I was knowledgeable of the system. This made me a serious threat to the credibility of the system and would have added to liability pressures at the time. Therefore I assume (and so do others) that my credibility needed to be destroyed.

In my case three major discrediting tactics could have been used, two of which have actually been used:

- 1) The accusation of being 'paranoid' (the 'disgruntled employee' accusation). I was fired in 1989 by the Red Cross. This tactic has been used by the leading Red Cross lawyer with television reporters. (Mr. Jerry Freise of the HIV-T overheard an interview with one

of the television reporters at the opening of the Krever Commission).

2) The 'political correctness tactic' (I was fired on grounds of allegations of sexual harrassment). This has been used by the Red Cross with the Canadian Broadcasting Corporation, in a dispute of 'balanced reporting on the Red Cross', following interviews I had given to two CBC Radio reporters. Fortunately, I had informed the CBC of the circumstances of my firing prior to the Red Cross intervention. According to my last supervisor, the former Secretary General, the alleged harrassment was a 'frame', engineered by one of my former supervisors, whose mission had been before to get rid of me (confirmed by the two individuals mentioned above). I have enough clues to safely assume that at least two of my supervisors were involved. Last year I also had the 'frame' confirmed by a close relative of the alleging women. I never denied that there had been sexual liberties and overtures. These were not only consensual, but they were ostensibly being sought by the other party. Eventually I had some doubts as to her motivations and decided not to have an affair. In hindsight, from repeated remarks of the alleging women, it appears now that I was being set-up for more serious charges of sexual assault or rape. The Red Cross offered a high enough severance pay to make it impossible for me to sue for wrongful dismissal and thus avoid court proceedings.

3) **Claims of 'mental instability'.** This may have been used already through gossip campaigns, but I have little direct evidence of it. I had suffered from post-traumatic stress syndrome after 1979, and was on Xanax medication until I was fired in 1989. I have not been on any medication since. During my first few years in Canada I experienced depressive states (I presume, in part from 'chronic culture shock', in part from a number of unexplainable occurrences in my work place: I also learned three years after I had accepted the offer move to Canada that I was not eligible for the job for which I had been hired - but my superiors never told me). Then, within the span of roughly two years the following occurred:

- . I became a Canadian citizen, and had to surrender the Austrian citizenship;

- . I decided to separate from my wife (she did suffer from a personality disorder);

- . My father died;

- . My separation took place with totally uncalled-for involvement of my supervisor, the details of which I cannot reveal to protect the individuals involved. The most bizarre event occurred when my supervisor in the Toronto Blood Centre threatened me with loss of job, if I would go ahead with the separation: ***"This blood centre is a feminist outfit, and no matter how bad your wife is, it will be your***

fault and you will loose your job."

- . I divorced and had to surrender custody of my daughter;**
- . I was moved to a job for which I was not qualified;**
- . I remarried;**
- . I was moved to yet another job for which I was not qualified.**

The various intervention of my supervisor in the middle of a separation created intolerable ambivalences. I suppose my adaptability was overtaxed by this accumulation of distressing factors.

Two years after my firing (1989) I realized that I was probably blacklisted and would not find employment. I was forced into bankruptcy and had to apply for social assistance. I found no avenue open to me to work again and somehow regain some credibility. The only meaningful option I saw left was to go back to university, which was made possible with the help of a friend. However, with numerous trips to the food-bank and to the welfare office, the economic and social situation for my family deteriorated rapidly. I must consider myself today a member of the Canadian 'underclass', a state which is becoming painfully obvious from the restricted circle of friends to which my children have access.

Once I decided to work for the victims of the contamination of the blood supply (early in 1993), several tactics (from intimidation to harass-

ment) were used to discourage me from testifying and going public. At this point I am the only individual from the Canadian 'system' who is still taking a public stand against the Red Cross, the Federal Government and the commercial plasma industry (given an opportunity, of course). The odds would indicate that I must be the one who is wrong. There used to be a few others, but they have been silenced by various interventions. A group in California, which has been working for the last ten years to help victims of transfusion related infections (The Medicine and Law Foundation) indicated to me that my history is not unique, and that sexual harrassment allegations have been used when it was not deemed sufficient to remove an individual from his post, but when it was believed to be essential to keep him out and far away from the blood system. Defence against such tactics is extremely difficult if not impossible. The Foundation has advised me to leave Canada. In their opinion I will not ever be able to get on my feet again in this country. I should mention that in the spring of 1993 the Red Cross, 'given my economic circumstances' offered me to work for their legal team (and get paid for it). This would have relieved me from most of my predicaments. However, at that point I had learned enough to form an opinion that some of my supervisors had been criminally negligent. Consequently, I found it impossible to work in defence of the Red Cross. Other former 'resisters' either held on to their jobs or took whatever was offered to them, just to work again. The above mentioned colleague - Canadian, female, MD, PhD, Fellowship in hematology, 100 publications - had been black-listed for a full six years.

My own responsibility for these 'discrediting labels'.

I am taking responsibility for moving to Canada. To emigrate at the age of 32 coming from a non-English speaking country, without a network in Canada, without seeking connections with the Austrian or German community, was destined to be a doomed undertaking leading to 'rapid downward mobility'. Upon arrival I was 'culturally incompetent' and would have failed most IQ tests. In such a situation, one is almost instantly 'illiterate' at reading of social cues. (I should stress that this is not comparable with an anthropologist working in a different culture: he or she is never fully and permanently existentially dependent on the other culture. The anthropologist can and usually intends to return to 'home-base'). I have already mentioned the effects of chronic 'culture shock'.

Since I did not seek connections with my 'piece of the cultural mosaic', I had effectively surrendered control of my life to the organization for which I worked and never gained it back thereafter. Soon after I had arrived in 1974, the Red Cross had moved onto a precarious course with respect to transfusion related infections. (It began to switch Canadian hemophiliacs to a concentrated product, although it was known that this would increase the risk of hepatitis transmission substantially). Although I had no knowledge of it, there were some signs indicative of serious problems in the Canadian Red Cross: for instance, my supervisor at the Toronto Centre, one year after my arrival, began to suffer from severe 'black depressions' and strange behaviours. Today I understand that she was violently opposed to the Red Cross policies regarding infection control,

but did not have the nerve to fight it publicly. She may have been instructed not to communicate with me on these matters. Before I started working for her, I had helped her with some post-transfusion hepatitis publications, as it used to be a shared field of expertise and interest. Then, one year after I had started to work in the Toronto Blood Centre, I was suddenly cut off from any work or debates on transfusion related infections. At the time I wrote it off as 'turf-protection'.

I should have been alerted by such signs and inquired. Dependency, misguided faith, ignorance, naivete, stubbornness and so forth kept me in an untenable position. The lack of cultural background understanding from enculturation during childhood and adolescence can never be fully substituted by adult learning. There is an anthropological study of a South-American Indian chief who was raised by whites, and then, as chief, ended up being a deviant amongst his people; he could never recover from this deficit and was never able to function as a credible chief. His tribe began to connive against him.

Today (but not then) I am fully aware of these circumstances. I should have remembered at least the xenophobia which was prevalent amongst medical students towards Arabic and Iranian students during my medical school years in Vienna. This is not a simple matter of racism or discrimination: the myriads of small deviations from the local norms displayed by a foreigner in speech, behaviour and beliefs is endlessly irritating for the 'native'. If such an individual also holds a position of some power and relative economic advantage, the irritation may change into jealousy, hostility, resentment, conniving behaviour, or worse.

I was the wrong person, in the wrong place, at the wrong time,

6 of/de 6

PM-1 3½"x4" PHOTOGRAPHIC MICROCOPY TARGET
NBS 1010a ANSI/ISO #2 EQUIVALENT

PRECISIONSM RESOLUTION TARGETS

Today I must wonder, since Xanax is known to be sexually disinhibiting, to what extent it played a role in my sexual entanglement. My own doctor was of little help: he kept me on Xanax, told me that the Red Cross, in his opinion, was *run by a bunch of psychopaths*, and that 'he would not sell me life insurance while I was working there', but he never warned me of the side-effects of Xanax.

Thus, apart from deciding to move to Canada and then ignoring the warning signals, I am not sure what to take responsibility for. I have not inflicted any damages on anybody, for which, if I did, should take responsibility. On the other hand I find myself massively damaged, discredited, black-listed and oppressed by the very people whom I personally consider to have been criminally negligent (and not solely on the basis of my own judgement, but on the basis of consultations with others). Even today, my life is still controlled by the people who were responsible for the contamination of the blood supply, in Canada, in the U.S. and in Europe. Of course, I am not the only one whose life is controlled by them. Being a resister who is holding out, and being the major bread-winner of my family, my lot may just have been the most miserable one.

As to the three 'discrediting tactics' I wish to state that I am not paranoid, and a lot of things were explained to me by well-meaning Canadians and Americans. They were not primarily the product of my own speculation. I am not disgruntled. As I began to understand the larger picture, I realized that my supervisors were rather small players in a much bigger economic game. I did not commit sexual harrassment, not even from the 'argument of power': by the time the alleged harrassment happened, I had been through two years of work harrassment and had no 'power'. The

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person who made the allegation knew my 'canned' status better than I did. I do not believe that I am mentally unstable. Personally, I have never compromised my principles of best possible service and protection of the public in whatever I tried to do. The wife of the former Secretary General was kind enough to tell me, after I was fired, that I was probably the only 'normal' person at the National Office of the Red Cross. This is of course statistical nonsense, but it gives me some comfort. I do not consider distress as a reaction to severely and chronically distressing situations to be conditions of 'mental instability'. Having experienced the damages which may descend upon a resister, and acquired an awareness of the larger, economic, scientific and political contexts, I had three personal choices to consider:

- 1) I could leave the battle-field altogether and take up art. (It seems that I could make a living with it).
- 2) I could give up and pretend, like others have, that I have '*learned my lesson*' and am willing now to '*go with the flow*'.
'learned my lesson' and am willing now to '*go with the flow*'.
- 3) I can try to build on the understanding I have gained and put it to use for the benefit of the public.

I can no longer take the second option. I simply could not live 'in the flow'. I can no longer be an obedient participant in it. As to the choice between 1) and 3), I feel that I have an ethical obligation to put my understanding to work, no matter how feeble, limited, or ineffective such an

individual effort may be. However, even this limited effort requires additional skills and knowledge. To acquire these skills I embarked on my studies of the social sciences.

It has been suggested to me that I should choose a simpler thesis, removed from the issues described above. I have an acute sense of urgency, however, because corporate strategy has already leap-frogged the issue of the contamination of the blood supply. Some of the same people who were responsible for it are operating already under new rules or writing new rules (e.g. Dr. Perrault, who is now President of a lobby group of the biotechnical industry seeking 'reasonable regulation of biotechnology'). At this point, the contamination of the blood supply is little more than *history to be buried, not revealed*'. Therefore, I should stay with the issues, as they unfold (to the extent that I can access relevant information), and integrate my studies as closely as possible with my field of political activity.

There is a strange irony in this whole matter. Had I stayed in Austria, I would have been under contract with one of the major commercial plasma fractionators (Immuno A.G.). Thus I might have been directly implicated in the contamination of the blood supply in Austria. The HIV crisis was handled almost identically in Austria and in Canada. Paradoxically, I must consider myself fortunate to have moved to Canada. Given a choice between my current predicament and being a participant, even unwittingly, in the contamination of the blood supply, I prefer the lot I have.

My motivations for this thesis.

I wish to state unequivocally that my involvement of this issue is not motivated by personal 'revenge'. Of course I cannot ignore that the same people and circumstances responsible for the contamination of the blood supply also had made a significant contribution to the loss of my own career and well-being. However, today it is not the individual actors who are of interest to me, but rather the social, cultural conditions, and ultimately, the neurocognitive processes, which underly occurrences like the contamination of the Canadian blood supply. This does not change my personal opinion that some of their actions represented a serious and callous disregard of life and safety of their fellow human beings, leading to death or serious injury, for which the actors should be held accountable. In this respect, I found the parallels with the Nuremberg Tribunals helpful for the analysis of the actions and rationalizations of responsible health officials.

I find it impossible to retreat into obscurity and find a way to 'live comfortably'. Most definitely, I cannot participate in a transformative health-care process which I consider dangerous and damaging for the public. I believe that I have an obligation to my fellow human beings to use my understanding of past and current trends in the health care sector and my own experiences to the best of my ability and for their benefit. I am not a hero, I have to think of my family as well. Yet I consider the risks which are emerging from a totally commercialized and corporately controlled health-care system to be serious enough 'not to look the other way' or 'to walk away' (AIDS was the first massive alarm signal - very few people are hearing the alarm).

During the AIDS crisis I was not cognizant of what is going on. Today I know and understand what is happening. While false faith in my supervisors, ignorance and stone-walling prevented me from participating and intervening in the HIV crises, I have no such justifications and excuses today.

I feel that there is really no choice for me in this matter, as long as there is any room at all for me to act (granted, there is not much room left), and as long as there are any means at all at my disposal, no matter how limited. I am not entirely alone in this, there are some like-minded people in the U.S. and in Canada, including physicians. There are some significant networks amongst the Canadian victims.

The question why I gave up being a practising physician.

I have been asked this question many times. I did not give up my career as practicing physician for reasons of misconduct, or malpractice, or 'fear of practicing'. When the Red Cross offered me the job in Toronto, I took it because I was already affiliated with the blood industry, I liked adventure, and I was able to put an ocean between personal (not professional) circumstances. Two years after I had left Austria, I was asked by my former medical supervisors in Vienna to come back if things did not work out in Canada. I was too stubborn and too naive to accept the offer. I also had become 'addicted' to the vastness of Canada. Most of all, I remember not wanting to follow a predictable path from graduation to grave - and paid the price for it.

To seal my fate, I applied for Canadian citizenship which forced me to give up my Austrian citizenship - as per the neutrality agreement signed by Austria in 1955. There are no other 'deep' or 'hidden' motivations for my departure from medical practice.

I have no particular objection to the 'biomedical' way of healing. It can be very beneficial for humankind. I have no particular objections to 'alternative medicine' either. I do have very strong objections to the commercialization and corporate control of any kind of healthcare. I most strongly object to the willingness of the medical profession to be progressively co-opted into the corporate system of control, without showing even the slightest resistance. Most of all, I object to 'medical ethics' becoming an econo-scientific-legal algorithm aimed at minimizing the cost from litigation ('health-care by evidence').

These are the bases from which I am taking a critical stance towards my former profession and the 'medical-industrial complex', without losing sight of the good it does or can do. This awareness has prevented me from re-entering into my former professional field and contributed to the particular choice of academic training at this stage in my life. I have been extensively involved in issues of 'corporatism' invading a humanitarian venture such as the Red Cross. Over the years I have internalized (as strategic planner in the Red Cross) the destructive nature of the commercialization of domains which should never be commercialized. As I am investigating the contamination of the blood supply, my intuitive fears have met with a reality which is many times worse and more advanced than what I had anticipated. I believe I can justifiably extrapolate this humanitarian/corporate conflict to medical practice.

I have departed from my career path in a rather reckless, adventurous fashion. I am finding myself now on a path from which I cannot turn back to the point of departure. I hope I have adequately and truthfully expressed my motivations. I may wish at times that I did not have to carry the bundle of 'credibility problems'. I may have to accept them as 'conditiones operandi sine qua non' for the kind of endeavour I have embarked on.

I am prepared to answer any question, on any detail, which any of the committee member may have, without hesitation. I have plenty of flaws and I have made plenty of mistakes. But I have never lost sight of the 'primum nil nocere' (first of all do not do any harm) and my obligation to do my best 'to help those who cannot help themselves' (this line is from the movie '*A Few Good Men*'). I do not wish to return to an environment in which such fundamental orientations are not shared or are knowingly violated.

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The academic value of this book may be seriously in question. However, the proposed connection between the Hasmonaean empire in Palaestine and Southern France, the Jewish Diaspora, which is probably as ancient as the Jewish People, and the spread of early Christianity through the Jewish communities in the Mediterranean are rather plausible. Since the Middle-Eastern symbology is derived from a vast pool of different influences, it may represent or contain many common denominators for human symbolic expression. Thus a possible connection of the fleur-de-lys to Middle-Eastern symbologies adds attractiveness to the symbol.

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Documents

Note: The following is a complete of list of documents which served as background information or as direct references. Most, but not all documents are quoted in the thesis. A few documents which I am obliged to keep confidential have been marked as such.

(DOC 1) AIDS: A Perspective for Canadians. Summary Report and Recommendations. Royal Society of Canada. Michel Chretien (Chairman), Horace Krever (Co-Chairman). Date of transmittal: April 27, 1988.

(DOC 2) Silent Partners. Canada's Blood System and the failure to notify those who received HIV contaminated blood product: A personal perspective and statement of fact. Jerald Freise, HIV-T Group; March 7, 1994. Submitted to the Commission of Inquiry into the Canadian Blood System.

(DOC 3) Consumer Organization Calls for Independent Testing of Polio Vaccine for Link to AIDS. National Vaccine Information Center/Dissatisfied Parents Together (NVIC/DPT) Vienna, VA. Release June 15, 1994.

(DOC 4) Proposed Rules of Procedure and Practice for the Commission of Inquiry on the Blood System in Canada. Commission of Inquiry on the Blood System in Canada. (Not dated).

(DOC 5) Draft Record of Decisions Eighth Meeting of the Advisory Subcommittee to the Canadian Blood Committee, Ottawa, Ontario, June 19, 1986. (Excerpts).

(DOC 6) Record of Decisions Tenth Meeting of the Advisory Sub-Committee to the Canadian Blood Committee, Ottawa, Ontario, October 14, 1987. (Excerpts).

(DOC 7) Record of Decisions Eleventh Meeting of the Advisory Subcommittee to the Canadian Blood Committee, Ottawa, Ontario, October 25, 1988. (Excerpts).

(DOC 8) Record of Decisions 12th Meeting of the Advisory Subcommittee to the Canadian Blood Committee. Ottawa, Ontario, November 29, 1989. (Excerpts).

(DOC 9) Recommendations for physicians treating patients with hemophilia. Letter of transmittal by H. Strawczynski, M.D. Chairperson, Medical and Scientific Advisory Committee of the Canadian Hemophilia Society; dated February 17, 1983.

(DOC 10) Minutes of Meeting Task Force on AIDS-associated retrovirus testing in Canada. Laboratory Centre for Disease Control, Ottawa, Ontario; March 7, 1985.

(DOC 11) National Advisory Committee on AIDS, Minutes of Meeting, May 15, 1985. (Excerpts).

(DOC 12) Record of court decision in Pitman vs. Dr. Stanley Bain, the Toronto Hospital and The Canadian Red Cross Society, concluded on February 2, 1994, at the Metropolitan Toronto Court House, Justice Susan E. Lang presiding.

(DOC 13) Product Recall Procedures; Health Protection Branch, Health and Welfare Canada. Original dated January 1, 1984, date whited-out and over-written with a new date: February 19, 1993. Letter of transmittal by Brian Foster, Chairman, Crisis Management Committee, Government of Canada to the Directors of the Drugs Directorate.

(DOC 14) Premarket Clearance of Drug Products. Technical Report No. 4; Program Evaluation Study of the Drug Safety, Quality and Efficacy Program, Health and Welfare Canada. R. E. Overstreet, Ph.D. et al. November 30, 1988, revised April 19, 1989.

(DOC 15) 'Living with HIV'. Prepared by Johanne Decarie, with an addendum by her husband Bill Decarie.

(DOC 16) Tragedy and Challenge: Canada's Blood System and HIV. Report of the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women.(1993)

(DOC 17) Communique prepared by William and Johanne Decarie, Presented to Mr. Don Boudria on November 24, 1993.

(DOC 18) Pittman vs. The Canadian Red Cross Society; The response of the Canadian Red Cross Society to the Threat of Transmission of AIDS through Blood and Blood Products; Summary of documents. Prepared by the law firm of Kenneth Arenson, counsel for Mrs Pitman. 1993.

(DOC 19) Information on Hepatitis C; Compiled by Alan T.R. Powell, Ph.D., President of the Canadian Association of Transfused Hepatitis C Survivors. (1994)

(DOC 20) Letter Krassnitzky/Corbet, M.D., Medical Officer of Health, Ottawa-Carleton Region; September 27, 1994.

(DOC 21) Letter Krassnitzky/Stewart, M.D., Associate Medical Officer of Health, Ottawa-Carleton Region; October 4, 1994.

(DOC 22) Record of events related to the provision of HIV-free blood products for Canadian Hemophiliacs and screening of the Canadian Blood Supply. (September 27, 1994). (Fax: Oct. 13 '93 12:55PM HWC Comm/Media Relations).

(DOC 23) Resume, Olaf Krassnitzky

(DOC 24) Food and Drug Act

(DOC 25) Silver Medal Award, Austrian Red Cross Society

(DOC 26) RNAO A nursing perspective on events at the Hospital for Sick Children and the Grange Inquiry. Registered Nurses Association of Ontario. April 1987.

(DOC 27) IIASA Annual Report 1992; assorted publications.

(DOC 28) Preliminary release of hepatitis C study by the Red Cross.

(DOC 29) McMaster University, Faculty of Health Sciences. Transmittal of Faculty Draft Mission, etc. from Peter Maurer (Administrator) to Dennis McCalla (Vicepresident); dated November 2, 1987. (Confidential)

(DOC 30) McMaster University, Faculty of Health Sciences. Transmittal of Strategic Plan Dr. O Krassnitzky to D. Stuart M. MacLeod, MD, Ph.D., F.R.C.P. . dated January 7, 1988. (Confidential)

(DOC 31) McMaster University, Faculty of Health Sciences. Discussion Paper on the Future of the Faculty of Health Sciences. Dated February 1985.

(DOC 32) Pamphlet from the Ontario Ministry of Health regarding hepatitis B immunization of Grade 7 school children. (1994).

(DOC 33) "Red Cross at the Crossroads": speech given by Mr. George Weber, Secretary General of The Canadian Red Cross Society to the Canadian Empire Club on February 19, 1987; Chairman: Nona McDonald.

(DOC 34) "Federal Control of Blood-Borne Diseases" A discussion of the Federal Duties and Powers during the contamination of the Canadian blood supply. Draft prepared by Dr. Michele Brill-Edwards. Not signed and not published. Included in this reference collection with her permission.

(DOC 35) Letter Anonymous to Senator Bob Graham. Letter is dated August 5, 1993, initialled by the FDA on September 27. The letter is on American Red Cross letterhead, Blood Services, South Florida Region, Miami Florida. The letter was released by fax copy from Senator Graham's office on March 16, 1994.

(DOC 36) "Regulatory Control of Blood Products in Canada". Paper presented to The Joint LABS/CSL Symposium in Standardization in Blood Fractionation including Coagulation Factors; Melbourne, Australia, 1986. Published in *Develop. biol. Standard*, Vol. 67, pp. 221-228; Basel, Switzerland: S.Karger.

(DOC 37) "Tainted Blood". Letter to the Editor of the Globe and Mail, June 6, 1994, from N.B. Hershfield, MD, Clinical Professor of Medicine, University of Calgary.

(DOC 38) "A Cybernetic Model of an Organization". Draft of a document concerning the organization and plan of the Canadian Red Cross Society. Dated March 1985.

(DOC 39) Draft of presentation to the parliamentary subcommittee on transfusion related AIDS (Dr. Olaf Krassnitzky). Sent to Dr. Wilby, Chairperson, via Mr. Ken Arenson in February 1993.

(DOC 40) *Copy of letter sent to Mr. Wilby, Mr. Arenson and Ms. Kent announcing withdrawal of my testimony before the parliamentary sub-committee for health reasons.*

(DOC 41) *"Canada's blood collection system should be reorganized, critics say." Report by Peter P. Morgan, MD., PhD., consulting editor, and Lynne Cohen. (Special reports and documents. Canadian Medical Association Journal, 1990 143(8) 762-768. This report contains interviews with Dr. Gail Rock, Dr. Raymond Guevin, Dr. Andrew Kaegi, Dr. Noel Buskard, Dr. Roger A. Perrault, Dr. Hauser.*

(DOC 42) *"Letter from Johanna Pindyck, M.D. of the Greater New York Blood Program, to Dr. John B. Derrick of the Canadian Red Cross Society" regarding confidential self-exclusion form; dated August 5, 1983.*

(DOC 43) *"Central Ontario Internal BTS/BDR Study". Letter of transmittal from Dr. O. Krassnitzky to Dr. R.A. Perrault, dated July 5, 1985.*

(DOC 44) *"How to Prepare a House Response". Parliamentary Relations Office (PRO). Departmental Secretariat. Health and Welfare Canada.*

(DOC 45) *Written Submission to the Chairperson of the Parliamentary Subcommittee on transfusion related HIV infections. (Testimony Dr. Olaf Krassnitzky, given on March 18, 1993, in Ottawa).*

(DOC 46) *Notes from Dr. O. Krassnitzky to Johanne McDuff, reporter of CBC (Telephone conversations with Dr. Braun, President of the German Hemophilia Society in Munich, Germany, Dr. Oldenburg of the Hemophilia Treatment Centre in Bonn, Germany, and Mr. Heisig, President of the Austrian Hemophilia Society in Vienna, Austria. March 1994.*

(DOC 47) *Application for standing before the Commission of Inquiry on the Canadian Blood System. (Dr. Olaf Krassnitzky).*

(DOC 48) *Letter to the Editor (unpublished) of the Globe and Mail from Dr. Olaf Krassnitzky, regarding the 'hijacking' of the Canadian Red Cross Society by the Federal Government and the Pharmaceutical Industry.*

(DOC 49) See DOC 33

(DOC 50) Order in Council regarding the establishment of a Commission of Inquiry on the Canadian Blood System.

(DOC 51) See Feinman et al.

(DOC 52) See Blajchman et al.

Glossary

AIDS (acquired immune deficiency syndrome)

Syndrome caused by a retrovirus (HIV 1) which attack a class of white cells (helper T-lymphocytes) and the central nervous system. After a lengthy latency period infected during which the immune-defences are progressively compromised, individuals fall ill from so-called 'opportunistic infections', caused by micro-organisms which are normally not pathogenic; some individuals suffer from dementia.

Albumin

Major protein component of blood plasma; essential for maintaining circulating blood volume; it is also a so-called 'transport protein' for small molecules. Diminished with liver and kidney disease and burns.

Antigen/Antibody

Antigens are compounds which induce an immune-response in humans, in the form of antibodies or cellular responses by white cells.

Autologous transfusion

Transfusion of the patient's own blood.

Blood components

Parts of the blood which are extracted from whole blood collections such as frozen plasma, platelets, cryoprecipitate.

CDC

Centres for Disease Control in Atlanta, Georgia.

CHS

Canadian Hemophilia Association

CRCS

Canadian Red Cross Society

Cryoprecipitate

When plasma is frozen rapidly and then thawed slowly at low temperatures, it exhibits a white precipitate which contains most of the Factor VIII OF that plasma collection. Once separated from the plasma it is used to treat Hemophilia A.

Cytomegaly virus (CMV)

Virus to which almost half the population has been exposed. It may become a serious pathogen in newborns, immune-suppressed individuals, such as transplant recipients, or AIDS.

Directed donations

Donations from family members and friends on behalf of a patient.

ELISA test

Rapid screening test for the presence of HIB antibodies. The presence of antibody is a key marker of HIV infection. It does not provide immunity, however.

Factor VIII concentrate

Various Factor VIII preparations which contain the factor in high purity. The material is freeze-dried ('lyophilized'). In contrast to cryoprecipitate can be stored above freezing temperatures. It is therefore portable and allows hemophiliacs to travel without restriction.

FDA

Food and Drug Administration in the U.S. Similar to the Health Protection Branch of the Federal Government in Canada.

Fractionation (of plasma)

The industrial separation of various proteins from plasma (e.g. Factor VIII, Albumin, gammaglobulin). Also referred to as 'blood products'.

Gammaglobulin

Pool of natural occurring antibodies circulating in the blood (produced by the 'B-cell' line of immunocytes).

Hepatitis A

Inflammation of the liver, affects mostly children, enteral transmission; caused by hepatitis A virus.

Hepatitis B

Inflammation of the liver, may lead to coma, chronic liver disease, liver cancer. Transmitted sexually and via blood (intravenously, or small skin punctures). If infection occurs perinatally, a chronic, asymptomatic carrier state may develop. Caused by hepatitis B virus.

Hepatitis C

Similar to Hepatitis B. The transmission routes may be more varied, however. Caused by hepatitis C virus.

Hemophilia

Three types: A, B and Von Willebrand's disease. Hemophilia A is the most common. It is sex-linked congenital, transmitted from carrier mothers to male offspring. The disease may vary in severity. The most severe cases have almost no clotting factor VIII and used to die young if left untreated. Before modern therapy arrived, hemophiliacs would suffer frequent bleeds into the major joints from minor traumas, which would eventually cripple them and require major joint surgery.

HIV

Human Immune-deficiency Virus. A retrovirus which destroys human lymphocytes (T-helper cells), but also brain tissues. The destruction of lymphocytes leads to opportunistic infections. The viral infection, the specific tissue destruction and the opportunistic infections are referred to as 'AIDS' (Acquired Immune Deficiency Syndrome).

LCDC

Laboratory Centres for Disease Control; Health and Welfare Canada.

PET scan.

Positron Emission Tomography.

Plasma

The liquid portion of blood, which is 'fractionated into various' protein preparations such as albumin or Factor VIII.

Plasma Fractionation

Industrial separation and purification of plasma proteins.

Platelets

Small cellular elements which aggregate around a wound or lesion and participate in the initiation blood coagulation.

Retrovirus

The genetic material of a retrovirus is made of RNA which must be 'transcribed into DNA before it can become part of the genome of an infected cell and reproduce the virus. This is accomplished by an enzyme called 'reverse transcriptase'. HIV is a 'retrovirus', because of this 'backward' transcription'.

Reverse transcriptase

Enzyme to transcribe viral RNA into DNA ('backward transcription'). For viral reproduction, DNA is transcribed into RNA ('transcriptase' - 'forward transcription').

Surrogate test

Test for a non-specific diagnostic disease marker (when a direct, specific marker is not available).

Addenda

(ADD 1) This thesis does not include a discussion of 'deep ecology' (Noess) and advanced transpersonal anthropology. The main body of the discussion in the thesis deals with the 'sensed world', and the level of complexity encountered at that level.

(ADD 2) The discussion did not do justice to Rappaport's accounts on the relations between the operational and cognized environments. This will have to become a separate project of linking the model developed in this thesis with other major approaches in human-ecological modelling.

END

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