***Examining Information on Mother-to-Child Transmission of HIV/AIDS: The
Influence of Organisational Concepts on Counsellor Training Documents in Areas of
High HIV Prevalence.***

By Manon Turcotte, B.A. (McGill)

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Department of Anthropology and Sociology
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Abstract

This thesis examines the information that parents in resource poor countries receive regarding mother-to-child transmission of HIV and infant feeding practices. Three counsellor training documents, produced by the World Health Organization/United Nations Children's Fund/Joint United Nations Program on HIV/AIDS, International Planned Parenthood Federation, and the Population Council, are examined in order to demonstrate how various concepts influence the information these organisations provide to the public. This thesis will also demonstrate how the inconsistencies in the mother-to-child transmission of HIV information provided to parents inhibits their ability to make informed choices regarding infant feeding practices.

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GLOSSARY

ACRONYMS

AIDS: Acquired Immunodeficiency Syndrome

ARV: Antiretroviral drugs

ELISA: Enzyme linked immunosorbent antibody

FPA: Family planning association

HIV: Human Immunodeficiency Virus

IMAP: International Medical Advisory Panel

IPPF: International Planned Parenthood Federation

MNC: Multinational Corporation

MTCT: Mother-to-child transmission

NGO: Non-governmental organisation

PLWHA: People living with HIV/AIDS

PMCT: Prevention of mother-to-child transmission

SRH: Sexual and Reproductive Health

STI: Sexually transmitted infections

UNAIDS: Joint United Nations Programme on HIV/AIDS

UDHR: Universal Declaration of Human Rights

UNICEF: United Nations Children's Fund

USAID: United States Agency of International Development

VCT: Voluntary counselling and testing

WHA: World Health Assembly

WHO: World Health Organization

CHAPTER 1

INTRODUCTION

The concept for this thesis began with an interest in the Nestlé boycott of the 1970s, when the multinational was accused of purposefully promoting its artificial milk products in resource poor countries, effectively killing millions of babies. An infant feeding debate ensued from the Nestlé boycott. Was the breast best? Was artificial milk nutritionally superior? Despite the fact that the boycott is no longer at the forefront, the breastfeeding versus alternative infant feeding debate still continues, but this time the transmission of HIV/AIDS is the main focus. The international community is ardently trying to determine if HIV-positive mothers in resource poor countries should feed their babies breast milk or non-human milk¹. An interest in this debate led to further research on the information mothers were provided regarding the risks of mother-to-child transmission of HIV in resource poor countries and, ultimately, if they are given enough knowledge to be able to make informed choices about infant feeding practices. This thesis adds to this debate by specifically examining the information that women are being given on mother-to-child transmission of HIV and on infant feeding practices in resource poor countries where HIV is prevalent.

Aim

In the last two decades, much research has been conducted on all aspects of HIV/AIDS. Scientists and researchers are constantly discovering new characteristics about HIV/AIDS, and, as a result, information about the virus and the disease changes

frequently. One of the major areas of research has been in the field of virus transmission. This mother-to-child transmission (MTCT) of HIV can occur in utero, during delivery or through breast milk. The exact risks associated with each stage is still unknown, but the fact remains that it does occur frequently, and women should take precautions to reduce the risk of transmission. However, in order to weigh the risks and take the proper precautions, women² must be armed with the tools necessary to make appropriate choices for themselves and their babies. Specifically, women must have the appropriate infant feeding knowledge to make informed choices regarding their babies' nutrition.

"International guidelines recommend that ... women should be given the information to make an informed choice about the risks and benefits of breast feeding and replacement feeding and be supported in their choice" (Sherr 1991: 5). In addition, women must have the freedom to make any choice they want, including the freedom not to choose the options presented to them. If both information and freedom are available, then women can make an informed choice.

Informed choice is defined as a voluntary, well-considered decision that an individual makes on the basis of options, information, and understanding. ... The concept of informed and voluntary decision making applied broadly to any health care decision and assumes that individuals have both the right and the ability to make their own health care decisions. (EngenderHealth 2003: 4)

Choosing which infant feeding practice parents feel is best for their babies is not a luxury but a *right* widely endorsed by the international community and various international agreements (EngenderHealth 2003: 3). However, the only way that this

¹ The term non-human milk refers to animal, artificial, powdered or canned milks.

² For the purpose of this thesis, the nouns 'mother', 'woman', 'parent' and 'parents' will be used interchangeably when referring to people receiving HIV/AIDS information and making infant feeding choices.

right can be effectively exercised is if parents are given all the pertinent information regarding HIV/AIDS and mother-to-child transmission, in a language that they understand, and the unconditional support of their choice by their social network and counsellors (EngenderHealth 2003: 3)

There are many issues that may impede women from receiving all the facts regarding HIV/AIDS, infant feeding practices and mother-to-child transmission, especially in resource poor countries. The lack of available information and trained counsellors, inadequate infrastructure and lack of financial support are the primary reasons why women may not be able to receive information that is vital to the decision making process. If they do receive some information on mother-to-child transmission of HIV, it is important to recognise the way that agencies, counsellors and health workers present this information can influence parents' decisions about infant feeding practices.

This thesis examines three counsellor training documents geared towards providing information to parents in resource poor countries. It examines why the information presented in the training documents is not consistent and reliable, while keeping in mind the fact that infant feeding choices must be made by parents based on their personal circumstances, and the information they receive through counsellors trained with these courses. The thesis will demonstrate that women lack the proper tools necessary for making informed choices about their infant feeding practices primarily because they are not receiving the adequate or consistent information needed to do so.

An analysis of the information presented in this thesis could potentially influence future counselling training documents by making organisations more aware of the

underlying messages that they communicate via the information they provide to the public. In addition, this thesis could help organisations find a balance between providing too much complex information and not enough.

Scope

In order to achieve the aim of understanding why mother-to-child transmission of HIV information is generally not consistent, this thesis analyses three training documents produced by different organisations: *HIV and Infant Feeding Counselling: A training course* (2000), by World Health Organization³/United Nations Children's Fund/Joint United Nations Program on HIV/AIDS (WHO/UNICEF/UNAIDS); *Programme Guidance and Counselling For STI/HIV Prevention in Sexual and Reproductive Health Settings: For Counsellors, Health Workers, Educators and All Those Working in STI/HIV/AIDS* (2002), by International Planned Parenthood Federation (IPPF); and, *Prevention of mother-to-child transmission of HIV: A short course for health workers providing PMTCT services in areas with limited resources and high HIV prevalence* (2002), by the Population Council. The scope of this analysis, or the corpus for this thesis, is limited to these three primary training documents, and not other training documents produced by WHO/UNICEF/UNAIDS, IPPF, and the Population Council or other organisations.

The thesis examines the mandate, objectives and structures of WHO/UNICEF/UNAIDS, IPPF, and the Population Council, as well as the mother-to-child transmission of the human immunodeficiency virus (MTCT of HIV) information these organisations

³ This thesis uses the British spelling of organisation in its text, but respects the official spelling of World Health Organization.

provide in their training document. An analysis of this information is achieved by examining how specific theoretical concepts have influenced the organisations, and the information they provide to the public.

By conducting this type of discourse analysis, the thesis proposes to answer an important question: *Why is the information concerning mother-to-child transmission of HIV different in the three training documents?* In order to answer this question, two more questions must first be examined: *What information is given to women about mother-to-child transmission of HIV? How does the conceptual approach to mother-to-child transmission, adopted by various organisations, affect the information that they provide to parents?* By showing that information is not impartial, but rather subject to an organisation's perspectives, it will become clear that if women are not all given consistent and reliable information about mother-to-child transmission of HIV, they will have difficulty making truly informed decisions about their infant feeding practices.

It is important to note that the organisations that produced the documents, WHO/UNICEF/UNAIDS, International Planned Parenthood Federation, and the Population Council, were not contacted directly. The organisations were not given the opportunity to explain the information they provide to people through their training documents. However, this is not necessarily a weakness of the thesis, as the organisations were therefore not able to influence this study with their comments. The training documents were analysed based on how they are presented to the public, and this thesis reflects my interpretation of these documents.

The research for this thesis was primarily done at the library and on the Internet, through journals and organisational web sites. The training documents were found by searching the Internet for information on mother-to-child transmission, HIV and counselling. They are readily available and could be retrieved by health workers in resource poor countries *if* they have access to the Internet. Though there might be some concern that many of the documents referenced in this thesis came from online sources, it is also important to note that with this age of information technology, the Internet can be a critical source of recent information for both researchers and health providers in developing countries. The information retrieved from the Internet comes from reputable organisations that have the capability of posting all of their information, research, documents and publications on their site.

This thesis is also limited by the fact that the three documents do not have the exact same goals. WHO/UNICEF/UNAIDS' document aims almost entirely at educating health workers about the risks and benefits of various infant feeding options in areas of high HIV prevalence. IPPF's training document is much broader as it strives to educate health workers about various aspects of sexually transmitted infections, including HIV/AIDS. However, the document does contain specific chapters on HIV and on counselling people on the prevention of mother-to-child transmission. Finally, the purpose of the Population Council document is to train counsellors on all aspects of mother-to-child transmission of HIV, including epidemiological and physiological components. Despite these different objectives, the three training documents can still be compared and analysed because they contain some information on similar key issues, and all have the basic aim of providing HIV/AIDS information to people in resource poor

areas. It is also important to acknowledge the fact that these training documents may not be used in isolation from others, and therefore may not need to contain all information relevant to the topic of MTCT of HIV.

Methodology

The three training documents used in the analysis of this thesis were identified by researching materials directly related to the counselling of parents about mother-to-child transmission of HIV. These documents were specifically selected because they are produced by three different 'types' of organisations: from the large multilateral (WHO/UNICEF/UNAIDS), to the international (IPPF), to the national – American (Population Council). These training documents were read, analysed and compared. The information extracted from this analysis was placed in a thematic grid in order to highlight the information each organisation provides about key issues surrounding mother-to-child transmission of HIV (nutrition, breast milk, other milk, breastfeeding, counselling, HIV testing, antiretroviral drugs, and social stigma). This grid became very useful during the comparative analysis of the training documents, and quickly showed the variation in the information amongst the three documents. In order to simplify the analysis, these key issues were placed into three main themes: *mother-to-child transmission issues* (nutrition, breast milk, other milk, and breastfeeding); *procedural issues* (counselling, HIV testing, and antiretroviral drugs); and, *social issues* (social stigma). Next, background information concerning the key issues was researched in order to fully understand them, and the impact they have on mother-to-child transmission of HIV. In addition, a thorough research was conducted on the organisations that

produced the three training documents. This research consisted of reading the massive amounts of information each organisation provides on their web sites. Once this research was complete, a search for concepts began in order to determine how the organisations and their mandates were influenced.

Chapter Summary

As stated above, the aim of this thesis is to understand why mother-to-child transmission of HIV information is generally not consistent in the three training documents. The thesis undertakes to answer three questions: *Why is the information concerning mother-to-child transmission of HIV different in the three training documents? What information is given to women about mother-to-child transmission of HIV? How does the conceptual approach to mother-to-child transmission, adopted by various organisations, affect the information that they provide to parents?*

In order to answer these questions, the thesis begins, in Chapter 2, with an introduction to some of the critical issues that are relevant to the analysis of the organisations and their training documents, including scientific positivism, power, discourse, liberalism, and liberal feminism. Subsequent chapters examine how these concepts have influenced the mandates and objectives of the three organisations, and, as a result, the mother-to-child transmission of HIV training documents produced.

The section on scientific positivism describes how western-based science, with its ability to create new paradigms, has established itself as 'truth'. It is important to understand that those who 'create' these scientific paradigms (scientists, researchers and large corporations) have the ability to control and manipulate information they present.

This is true in the HIV/AIDS pandemic, where research is often tied to large pharmaceutical companies or multinational corporations that wish to benefit from the information they produce (i.e., a certain antiretroviral drug or infant feeding formula).

While scientific positivism is about the control of knowledge and its production, power and discourse, are about the control of access to information people have, and its dissemination. Discourse refers to the use of language, its structures and practices, and how discursive practices are employed to determine or influence the thoughts, attitudes, and the actions of people by making some things appear to be positive (i.e., in this study, for example, breastfeeding) and other things negative (i.e., all other forms of infant feeding). In addition, those who control discourse have the ability to influence social norms related to mothering (i.e., breastfeeding) and punishments for those who break those norms (i.e., social stigma). It is generally people with power, or perceived power (i.e., counsellors, scientists, organisations, etc.), which have the ability to use discourse to their advantage, influencing certain behaviours or ideas by manipulating knowledge with language.

Finally, the last part of Chapter 2 will introduce two additional strong social influences: liberalism and liberal feminism. Liberalism advocates freedom of choice for all people, while liberal feminism focuses on improving women's access to choices. Liberal feminists believe that women are equal to men and deserve the same rights and opportunities accorded to them, but, instead, women have been segregated to the private sphere of wife and mother. Liberal feminists want social reform that will provide women with equal treatment and the right to choose which sphere they want to contribute to, private, public or both. When examining the issues surrounding mother-to-child

transmission of HIV, it is important to introduce gender and the role that it plays in the pandemic.

This introduction to some of the concepts influencing the organisations, scientific positivism, power, discourse, liberalism and liberal feminism, is followed by an introduction to HIV/AIDS and mother-to-child transmission. Chapter 3 gives important background information on HIV/AIDS and MTCT. It provides information on the virus and its transmission, and the tests used to detect the presence of the virus or of the antibodies. The chapter also introduces how the pandemic has affected people living in resource poor countries, in particular, women and children. Finally, the chapter concludes with some information about the various infant feeding practices that mothers, or parents, may choose to adopt.

Chapter 4 provides an introduction to three main themes that reoccur in the three training documents: mother-to-child transmission issues, procedural issues and social issues. The chapter gives background information on key issues within the three themes, such as nutrition, breast milk, other milk, breastfeeding, counselling, HIV testing, antiretroviral drugs, and social stigma. These themes will be used in subsequent chapters to analyse the information that the three training documents provide to counsellors in resource poor countries about mother-to-child transmission of HIV.

Chapters 5, 6 and 7 analyse WHO/UNICEF/UNAIDS, IPPF and the Population Council, and their training documents. These chapters first introduce the organisations by examining their mandate, structures and objectives. The second part of the chapters, the General Analysis, examines which underlying concepts (introduced in Chapter 2) have influenced the mandate and objectives of the organisations. Finally, in the Specific

Analysis, Chapters 5, 6 and 7 examine the information that the organisations provide regarding the three themes (introduced in Chapter 4) that reoccur within all three training documents. This analysis demonstrates that parents are not given consistent information on mother-to-child transmission of HIV.

Finally, Chapter 8 summarises the thesis by answering the questions posed in this chapter: *Why is the information concerning mother-to-child transmission of HIV different in the three training documents? What information is given to women about mother-to-child transmission of HIV? How does the conceptual approach to mother-to-child transmission, adopted by various organisations, affect the information that they provide to parents?* It concludes that the information provided to people about mother-to-child transmission of HIV in resource poor areas is not consistent, and, therefore, does not allow for an informed choice.

However, in order to reach this conclusion, the thesis must first introduce mother-to-child transmission of HIV, and analyse the three training documents produced by WHO/UNICEF/UNAIDS, IPPF and the Population Council, using specific concepts. The next chapter will begin the thesis by describing the various concepts - scientific positivism, power, discourse, liberalism, and liberal feminism - that will be used in this analysis.

CHAPTER 2

CONCEPTUAL CONSIDERATIONS

This chapter provides the theoretical background for the analysis of this thesis. It introduces various concepts - scientific positivism, power, discourse, liberalism and liberal feminism - which have influenced the mandates and objectives of the World Health Organization/ United Nations Children's Fund/Joint United Nations Program on HIV/AIDS (WHO/UNICEF/UNAIDS), International Planned Parenthood Federation (IPPF), and the Population Council, and consequently, the information these organisations provide to the public in their counsellor training document. These concepts are used in the analysis on the organisations in subsequent chapters.

When examining the transference of HIV/AIDS and mother-to-child transmission information from certain organisations to parents in resource poor countries, various concepts become apparent and must be examined more closely. The first concept introduced in this chapter, *scientific positivism*, will examine how new paradigms emanate from scientific research and easily replace previously accepted notions or theories. It also examines how scientific knowledge can be manipulated to produce desired information. Finally, this section looks at how scientific knowledge and language are exclusionary and perpetuate the cycle of scientific positivism.

This is followed with a closer look at *power and discourse*. This section examines how language is used to influence people's attitudes, thoughts, and actions. It also looks at how people with power can manipulate and define knowledge through language and

limit the dissemination of information and people's access to it. Lastly, because the topic of mother-to-child transmission and HIV/AIDS primarily affects women and children, it is impossible to avoid discussing some gender issues. Accordingly, a short introduction to *liberalism and liberal feminism* explains how these concepts view gender oppression and the role of women in society.

Scientific Positivism

Scientific discovery has led to many important changes within all societies. From the discovery of microscopic organisms and viruses to the development of antibiotics and antiretroviral drugs, science has striven to improve the lives of everyone. Most societies, especially western societies, embrace science completely and base many of their decisions, from health care to public policy, on scientific theories. Science, when used impartially, can be extremely beneficial to all of humanity. Unfortunately, because of the complexity and cost of scientific discovery, research has traditionally been conducted by large, western based institutions or organisations that, as a result of the power they hold, are able to claim their discoveries and the knowledge they produce as universal truths.

Science maintains that it is founded on observed phenomena. Theories are hypothesised, scrutinised and tested. The results become "accepted truths" until further evidence discredits them. When contradictory evidence appears and begins to throw doubts on to the validity of a currently accepted truth, new paradigms emerge in order to explain these anomalies with a more comprehensive model. "To be accepted as a paradigm, a theory must seem better than its competitors, but it need not, and in fact never does, explain all the facts with which it can be confronted" (Kuhn 1970: 17).

When new paradigms emerge from scientific discovery, a scientific revolution occurs as some try to defend the existing theories, while others try to increase the supporting evidence for the new paradigm (Kuhn 1970: 18).

This circular chain of events is very evident in the HIV/AIDS pandemic. HIV/AIDS is a relatively new disease and, therefore, information regarding its transmission, its pathology and its treatment frequently changes. New discoveries and paradigms are constantly emerging, disproving once accepted truths and theories. This has created many challenges in the fight against the pandemic, especially in terms of diffusing HIV/AIDS information to people in resource poor countries. Health care workers and counsellors are not always provided with, nor do they have access to, new research or discoveries that create new paradigms concerning HIV/AIDS. Consequently, out dated or inaccurate information regarding HIV/AIDS and mother-to-child transmission is often given to parents.

Regardless of the dynamic nature of scientific information, or accepted truths, there is a very strong belief amongst western societies and scientific communities in the superiority of western-based scientific information over all other forms of knowledge, creating an ideology of 'scientific positivism'. Other forms of knowledge, such as local knowledge, are considered by western countries as unscientific (i.e., untested or unproven) and consequently, not reliable. As a result, western funded public health programs in resource poor countries generally only include material that is based on scientific information discovered in a research setting, as opposed to health information derived from individual experiences and local knowledge.

One need only survey the literature on ethnomedicine in a public or international context to discover Western medical

ethnocentrism in one of its more extreme and harmful forms. The approach that emerges from such literature seems to be: Prove native health beliefs wrong (or childish) ... then lead the natives out of darkness and get them to do what we want them to do, calling this “behavior change,” “health facilities utilization,” and “treatment compliance.” There is little recognition or acknowledgement (aside from some anthropologists) of the fallibility and malleability of biomedical models of illness and of treatment regimens and of the fact that these models are themselves culturally constructed. (Green 1999: 219)

Despite the great advantages and advances brought on by scientific information, there are two major problems with science, and both are related to power: Scientific data can easily be manipulated in order to support a particular theory or a desired outcome, and scientific knowledge is exclusionary (i.e., it is not available to everyone).

Scientific knowledge and data can easily be manipulated by those who produce and control them. As noted above, scientific knowledge is not as positivistic as it is generally believed. As there is rarely one truth, paradigm or theory that withstands all deconstruction and criticism, scientific knowledge should, therefore, be carefully scrutinised.

When the task of producing information is left to a select few, there may be concern that what is being produced is not necessarily what is best for all people but, rather, what is best for the organisations and institutions that have funded or conducted the research. The organisations and institutions have the facilities, the money and the power to acquire scientific knowledge, and they also have the ability to alter it in such a way as to reflect positively on some results and negatively on others. For example, researchers might praise the benefits of a new antiretroviral drug, while downplaying the side-effects associated with its use. “Power and knowledge are thus clearly linked. The recent

sociology and history of the [medical] professions demonstrate countless ways in which the possession of power enables a group to redefine what is knowledge and numerous examples of successful claims to the possession of knowledge resulting in increased power” (Wright and Treacher 1982: 6).

Medical knowledge is a good example of this. It is often developed by researchers working for large medical centres, or for large multinational corporations, and, in most situations, the research conducted is generally tied to large amounts of money (i.e., pharmaceutical companies financially supporting the research, development and testing of their brand of antiretroviral drugs - see McIntyre and Gray 2002). Medical knowledge is also produced in such a way as to reflect the social attitudes of western societies. “Medical knowledge, like most knowledge, is inseparable from social relationships and social experiences. It is unequally distributed, therefore, and connected to matters of power and control. In biomedicine, control is limited by the power held by the medical profession and more and more by medical institutions” (Lazarus 1994: 30).

While it is the medical professionals who distribute the information, it is the medical institutions and multinational corporations (MNCs) who fund the research and produce the information. As a result, there are at least two steps in which scientific or medical information can be altered by economic and social influences to reflect a particular opinion: first, during the production of the information, where it can be manipulated to meet a desired outcome; and, second, at its interpretation by medical professionals, where knowledge and language can be formulated in such a way as to control what people are being told and what they are understanding.

The second major problem with scientific knowledge is that it is exclusionary, primarily because of the highly scientific language it uses. Science is based on a western model of power through knowledge and language and, consequently, it is generally only accessible to those trained within a western model of education, which is also a reflection of scientific positivism. "The language of science is regarded as the language of oppression. Procedures involving hypotheses, operational definition, scales, evidence, and rules of disconfirmation are rejected. Positivistic research is said to serve the interest of elites" (Barrett 1996: 165). Power differentiation is the result of this disequilibrium of knowledge. The power created by controlling knowledge through language effectively keeps all who are not scientists at the dependence of those who are. In addition, those who possess power are in a position to maintain control simply by redefining knowledge by creating new paradigms (Wright and Treacher 1982: 6).

Science also follows a universalistic view by assuming that the knowledge it produces is relevant to everyone, regardless of his or her cultural situation or gender. As a result, health care and health information are often applied across the board with little consideration of the people it aims to help. The objective is to provide specific health related information that those with power feel is appropriate for a given situation. This type of universal information is particularly problematic in situations such as the HIV/AIDS epidemic. For example, women can be given similar medical information without much consideration for the local cultural attitudes, knowledge or language. "Science speaks a universal language of progress. But women express their diverse consciousness and practices in polyglot, multicultural languages" (Rapp 1997: 140). When health care information is presented universally, many of the recipients are not able

to utilise or comprehend, within their local framework, the information being provided. In addition, if the local language is not used when providing the information, much of it will be lost as the patients struggle to understand the very complex, scientific information.

[I]f public health messages can be framed in terms appropriate to indigenous ... beliefs, they would take advantage of common ground that already exists. They would make more sense than messages that rely on medical jargon such as “electrolyte imbalance” or “oral rehydration” currently found in health education messages in Africa and elsewhere. (Green 1999: 266)

Scientific positivism can easily manifest itself through a manipulation of the data and through use of language. It is not only the use of scientific language versus non-scientific language that creates a power dynamic between the scientific community and the ‘lay’ person, but is it also how the information is presented, or, in some cases, not presented. The next section will examine specifically how discourse, or language, can be used to control the beliefs and the actions of people who trust in it.

Power and Discourse

The power to control people using knowledge or language is very common. It is used by all societies through culture, religion, politics and science. Knowledge can be provided, or withheld, and words and tones can be used to emphasise a certain concept or influence people to think and act in a desired way. Those who hold power, the few privileged, are able to manipulate the knowledge through discourse in such a way as to serve them and their motives (Foucault 1979: 33). “... [P]ower is something that is possessed – something that some definite people possess - something that others do not

possess” (Foucault 1979: 59). The privileged also have the power to proclaim knowledge as truth, even if it is not. Discourse, the idea of influencing language by using power over knowledge, has the ability to perpetuate the cycle of power which “... seeps into the very grain of individuals, reaches right into their bodies, permeates their gestures, their posture, what they say, how they learn to live and work with other people” (Beasley 1999: 94). By having power, and controlling knowledge with language, it is possible to influence the thoughts and actions of people.

If people decide not to believe the knowledge provided through normally accepted discourse, and choose to act or think in a manner that opposes it, they can be socially reprimanded. In other words, by creating social rules using discourse, those with power normalise people’s behaviour in order to ensure that everyone acts and thinks the same (Escobar 1984: 379).

This type of power or control through discourse is particularly relevant in the ‘development’ of resource poor countries. Western countries tend to use negative language (underdevelopment, poverty, epidemic, risk, etc.) to classify the problems facing resource poor countries, which then allows the ‘west’ to formulate policies and truths about certain situations, and how these problems can be reformed using western ideology (Escobar 1984: 387). This produces “... a field of control of knowledge, through which ‘truth’ (and, so, power) [is] produced” (Escobar 1984: 387). This truth usually implies a western style remedy, which insists that recipient countries adopt western economic, political and, often, cultural models. Western countries can enforce these ideological changes by using their financial and technological influence (Escobar 1984: 385).

[N]ew types of power and knowledge are being deployed in the Third World which try to insure the conformity of its peoples to a certain type of economic and cultural behavior (broadly speaking, that embodies in the 'American way of life'). Through this process, ... the sociocultural systems are being progressively permeated and appropriated by the socioeconomic and cultural systems of the 'advanced' countries ... (Escobar 1984: 382)

In development, especially in public health, it is easy to integrate western values into the knowledge provided to people because science and medicine are social constructs, and, therefore, reflect the views of the culture creating it (Wright and Treacher 1982: 2).

Generally, medicine and medical language are highly valued because they stem from science, and science is supposedly based on truth/fact. Consequently, medical knowledge is usually uncontested, unlike politics and religion, which are based more on opinion and morality. Because medicine is presumed based on truth by the medical profession, and the scientific and lay communities, there is an expectation of acceptance and compliance by those who benefit from its knowledge.

To assert that a given area of human life – and the knowledge associated with it – is medical, is, in our society at least, to claim that it has a technical status which removes it from all other intellectual activities and renders it immune to the principles which govern them. In consequence, a frequent strategy of professions, such as medicine, had been to claim that their activities and knowledge are not simply specialised segments of what is available to all – commonsense, morality, art, 'know-how', and so on – but rather have a special, technical status which sets them apart from everyday life. They are forms of reasoning that claim authority on the grounds that they demonstrate the means (e.g. particular therapies) to desired ends (e.g. restoration of health). They do not depend as do, say, religion or liberal politics in the modern West, upon the acceptance of a particular set of general values. ... The precepts of religion and ethics in the modern world are seen as contestable, but those of science as incontrovertible. (Wright and Treacher 1982: 6)

With the support of western-based scientific information, those with power are able to manipulate the knowledge being provided to people. For example, power expressed through knowledge and language is particularly evident in the HIV/AIDS epidemic. Parents are asked to make health related decisions for themselves and their children based on information they receive from health clinics and other public health programs. The information they receive at this time is often the only information they will ever receive on HIV/AIDS as they generally do not have the financial, technical or time resources needed to seek out other information from various sources before making informed choices. The local health clinic providing the information may have the 'monopoly' over what knowledge is being provided to the public. If a health clinic is being financially supported by a particular development program that, in turn, is being supported by a large pharmaceutical company, the health workers might be trained to discreetly promote, using particular language, certain types of drugs or certain medical procedures that would benefit the interests of the company. The same situation can occur when a specific ideology is being promoted by the clinic (i.e., breastfeeding as opposed to formula feeding). Information may be biased or presented in a certain way as to influence the parents into making a particular decision.

It is not always the big organisations or governments who use discourse and information to influence the thoughts and actions of people. At times, it is the person who is providing the information to the recipient. To continue with the example of the health clinic, the health workers, or the counsellors, may have their own personal opinions or biases that influence them to consciously, or unconsciously, use language that will steer the patient into choosing a particular action and/or accepting a belief. This is

especially true in resource poor areas where there is a lack of professionally trained health workers and counsellors.

Counselors⁴ are first of all people and secondly they are counselors. They have their own weaknesses, strengths, fears, anxieties, doubts and certainties. All these can either hinder or facilitate their work with clients. Counselors must therefore continuously engage themselves in self-exploration to be aware of themselves, how others affect them, and the effect they have on others. (Population Council 2002b: module 4, 10)

It is very difficult, if not impossible, to make an informed choice about infant feeding practices if the information received by counsellors and health workers is either biased or non-existent, or if the information provided to people making choices is influenced or biased by the concepts of the organisations who produced it.

Like personal biases and use of language and/or knowledge to control access to information, feminism also plays a role in the way mother-to-child transmission of HIV information is presented to women. The next section will introduce liberalism and feminism and the role it plays in influencing the mandates of organisations and the information they provide to people about infant feeding practices.

Liberalism and Feminism

It is impossible to examine a subject such as mother-to-child transmission and HIV/AIDS without looking at it from a feminist perspective. This section will briefly introduce liberalism and liberal feminism, as well as radical and Marxist feminism, in order to show, in the analysis of the three documents in Chapters 5, 6 and 7, how these

⁴ This is the American spelling of counselors.

ideas influence WHO/UNICEF/UNAIDS, IPPF, and the Population Council, and the HIV/AIDS information that is provided to people in resource poor countries.

A liberal ideology implies that all people, irrespective of gender, ethnicity or beliefs, should be free from coercion and have the ability to make choices they feel are best for them, as long as these choices do not negatively affect the freedom of others (Hayek, 2004: 1, 2). “Liberalism ... merely demands that the procedure, or the rules of the game, by which the relative positions of the different individuals are determined, be just (or at least not unjust)” (Hayek 2004: 8). Liberalism is a perspective that is primarily rooted in western societies, or in western democratic thinking, which favours individual rights over collective rights. It is also based on universal human rights, which state that all people are entitled to certain rights and freedoms.

Liberal feminism transposes liberal beliefs onto social rights, specifically, rights of women (Beasley 1999: 52). Despite the fact that women are equal to men, liberal feminists believe that women are not granted the same rights and freedoms as are allocated to men, and that artificial barriers have been socially constructed, confining women to the private sphere of wife and motherhood (Beasley 1999: 51). This discrimination is based solely on their gender. Gender “... constitutes an unwarranted disadvantage, a barrier to competition and the recognition of merit” (Beasley 1999: 53).

The reality is that most women are seeking gender equality and want to be treated the same as men in all aspects of life, public or private, but focus mostly on the public sphere, such as the “... legal, political and institutional struggles for the rights of individuals to compete in the public marketplace” (Beasley 1999: 51). They suffer from a kind of ‘penis envy’: They want what men have (Beasley 1999: 52). As a result of this

unequal treatment, liberal feminists want to reform society in such a way as to ensure equal treatment and equal rights for all people (Beasley 1999: 52). They believe that there is "...a need for some (possibly government) intervention in the competition between individuals for social opportunities and reject so-called *laissez-faire* liberalism which argues that freedom and justice are best served by nominal government and that a just and natural inequality will emerge if individuals are left to their own devices" (Beasley 1999: 53). With the help of the government, its policies, and its supporters, liberal feminists hope to make society a more equitable place for women.

While liberal feminism is usually synonymous with feminism (Beasley 1999: 51), there are other branches of feminism, specifically radical and Marxist feminism, which have been used to describe gender issues within the HIV/AIDS pandemic, and though they are not used in this analysis, they should be kept in mind. While liberal feminists believe that women have been treated differently than men simply because of their gender, they do not necessarily believe that all women have experienced the same degree of discrimination. Radical feminists presume that all women are the same, and are equally repressed, regardless of where they are from. "[A]ny woman ... has more in common with any other woman - regardless of class, race, age, ethnic group, nationality - than any woman has with any man" (Beasley 1999: 54). These shared experiences distinguish men from women, and, in fact, elevate women above men (Day n.d.: 2). While liberal feminists wish to be treated as men's equals, radical feminists want to celebrate their biological differences. Radical feminists' "... focus on the body as a critical site of oppression for women but also as representing women's differences and therefore to be celebrated, stands in sharp contrast to liberal feminism's general aim of

reducing or preferably eradicating attention to bodies and bodily difference as politically retrograde” (Beasley 1999: 57). Radical feminists argue that the discrimination due to gender is a result of a patriarchal system characterized by dominance, power and hierarchy (Beasley 1999: 57). All men are perceived as having power over all women.

Radical feminism demands a social revolution, which will change the power dynamics between men and women, without compromising their gender identity (Beasley 1999: 56). “The logical extension of radical feminism is separatism” (Day n.d.: 2). Unlike liberal feminism, which wants to assimilate women into a system created and dominated by men, radical feminists want to clearly define the differences between men and women and create a social order in which women would be celebrated and respected because of their gender (Beasley 1999: 54). However, it will be very difficult for radical feminism to effectively make this social change as it is “... inclined to be suspicious of government intervention, perceiving the state itself as being intrinsically patriarchal, and also tends to focus on the politics of the ‘private’ sphere, in particular sexuality, motherhood and bodies” (Beasley 1999: 57).

Like radical feminists, Marxist feminists, believe that gender based oppressions are deeply entrenched into the fabric of society and will be difficult to overcome. They also call for a social revolution that will allow them to rise out from under economic and gender discrimination. Within Marxist feminism, sometimes known as socialist feminism, there is “...a focus on labour and economics when exploring women’s positioning. Since labour is viewed as fundamental to all economic activity, (historically specific) analysis of the organisation of labour is crucial to Marxist feminist approaches” (Beasley 1999: 61). Marxist feminists believe that gender relations are not influenced by

ideas and attitudes about the biology of women, but instead, are shaped by the economic system (Beasley 1999: 61). Marxist feminist doctrine asserts that there are two main types of oppression: gender and economic class. This oppression is created by a political and economic system which values power and money, and the people who have it, and devalues those who do not, the working class. This creates a social hierarchy, whereas the privileged continue to accumulate power and wealth at the expense of the 'lower class'. Marxist feminists believe that the oppression of women is only secondary to class oppression. Power is not just associated with gender, but primarily with class and wealth (Beasley 1999: 61).

Within the capitalist system, women hold a 'monetary value'. They are necessary in order to make the capitalist wheel turn. They take care of the home, making sure that the 'breadwinner' is well fed, well rested, well clothed and well cleaned. Without women in the 'sidelines', men would not be able to work within the capitalist system. Unfortunately, women's role is considered the lowest level of the low class (Beasley 1999: 62). Men may be oppressed by the capitalist system, but women are doubly oppressed - by the system, and by men.

Because Marxist theorists believe that governments, particularly capitalist governments, purposefully oppress the poor, they mistrust the government, hierarchical class relations and its focus on power and money (Beasley 1999: 60). Like Radical feminists, Marxist feminists feel that only a revolutionary approach will destroy the oppressive nature of the capitalist system, and hence dismantle the power that the privileged have over class and gender (Beasley 1999: 61).

Feminism has many branches, including liberal, radical and Marxist. All three have unique positions, but they also share common ideas. All maintain that women are oppressed by men and their patriarchal societies. Both liberal and radical feminism believe that gender oppression is a result of a patriarchal society, while Marxist feminists blame the economic system (capitalism) for, first, class oppression and, second, gender oppression. Liberal feminists believe that, with some government intervention, social rules can evolve into more equitable freedoms for women. However, both radical and Marxist feminists distrust government and believe change is only attainable through social and economic revolt.

Summary

This chapter introduces the ideas of scientific positivism, power, discourse, liberalism and feminism. It shows that scientific positivism controls how information is produced and manipulated by the creation of new paradigms, while discourse controls how the information is disseminated and how people can be influenced by the information they receive. Finally, the last section of the chapter introduces the concepts of liberalism and feminism, and how these perspectives explain the role of women in society. The concepts introduced in this chapter will be used, in Chapters 5, 6 and 7, to analyse the organisations and the information they choose to provide to the public. However, before organisations and the training documents are introduced, it is important to understand more about HIV/AIDS and how mother-to-child transmission occurs. The following chapter will provide some introductory information about HIV/AIDS and some of the issues that surround mother-to-child transmission of the virus.

CHAPTER 3

HIV/AIDS AND MOTHER-TO-CHILD TRANSMISSION

The previous chapter introduced the specific concepts that will be used to analyse the three counsellor training documents that WHO/UNICEF/UNAIDS, IPPF, and the Population Council produced. This chapter will provide important background information on HIV/AIDS and mother-to-child transmission needed to understand the information provided in the training documents analysed in chapters 5, 6, and 7.

Mother-to-child transmission of HIV through breastfeeding, and the information concerning it, is the primary focus of this thesis. Specifically, the study focuses on three training documents that were produced in order to provide parents in resource poor countries with information about the virus, the disease and how it is transmitted. Before beginning the analysis of the organisations that produced the training documents, as well as the information found within them, it is beneficial to understand the virus and the disease, and how it is transmitted from mother-to-child. This chapter will begin with an overview of HIV/AIDS and how the testing for either the HIV antibody or antigen is conducted. This will be followed by a description of the demographics of people living with HIV/AIDS. This information will lead into a discussion on how the virus is transmitted from mother to child. Finally, this chapter will give a brief overview of the various infant feeding practices that parents can adopt.

HIV/AIDS

The Virus

Acquired Immune Deficiency Syndrome (AIDS) was first identified in the USA in 1981 and has since become a world wide pandemic. AIDS is caused by the Human Immunodeficiency Virus (HIV) and can be transmitted via unprotected sex, shared needles, contact with blood, and during pregnancy, labour and breastfeeding. The virus damages a person's immune and nervous systems by attacking CD4 cells and macrophages, weakening the body's ability to defend itself against diseases. In a healthy person, CD4 cells organise the body's overall immune response to foreign bodies and infections, while macrophages engulf and destroy infections and ensure that the body's immune system recognises them in the future (UNAIDS 2003: I-6). Once the virus finds a host, it replicates itself by infecting cells until the immune system is triggered into producing a large number of antibodies. "HIV infection results in the progressive depletion of the immune system, leading to 'immune deficiency'" (UNAIDS 2003: I-1). As the viral replication progresses, the person is increasingly vulnerable to opportunistic infections, that is, infections that are easily defeated in people with healthy immune systems. Relatively simple infections such as pneumonia or food poisoning become life threatening to an immuno-compromised person.

Left undiagnosed or untreated, the majority of those infected with HIV will develop AIDS within 8 to 10 years from the initial infection (UNAIDS 2003: I-4). Once AIDS has developed, the immune system is no longer able to fight off opportunistic infections. Early testing and detection of the virus can dramatically increase the time between infection with the virus and the development of AIDS.

Testing for HIV/AIDS

Testing for the presence of HIV is a rather complicated process. It involves science and statistics. HIV can be detected in two ways: from the antibodies produced by the immune system in response to the virus; or from the virus (antigen) itself. The antigen can be detected as early as two or three weeks after initial infection, while an antibody test is generally only effective after six months. Testing for the antigen is more accurate but requires complex and costly laboratory procedures and is rarely done except by blood banks and specialized laboratories. As a result of the constraints of antigen testing, the majority of HIV testing is antibody based.

There are two main types of antibody tests: laboratory based and rapid testing. The most common laboratory antibody tests are the ELISA (enzyme linked immunosorbent antibody) and the Western Blot. Both of these tests involve placing some of the patient's blood on strips of paper lined with the HIV antigen. If there are HIV antibodies in the blood, they will bind to the antigen on the paper, creating distinguishable stripes. Generally, an ELISA test is done first because it is easier and less costly to perform, and if the result is positive, the more specific test, the Western Blot, is conducted in order to confirm the result (CDC 2003b: 1). The ELISA and the Western Blot both require specialized laboratory machinery and trained technicians, making it difficult to set up in resource poor countries (CDC 2003b: 1).

In the last few years, scientific advances have made rapid testing available in resource poor countries lacking the proper medical personnel and infrastructure needed to set up laboratory facilities (UNAIDS 2003: I-9). Rapid testing for the HIV antibody only

requires a drop of blood or saliva and a test strip, much like a home pregnancy test. Results are usually available within 15 minutes, and are about as accurate as the ELISA test, but should always be confirmed with a second test if the result is positive. It is extremely important to note that the HIV tests are not infallible. All tests should be conducted twice, using different methods, in order to confirm the results and reduce the probability of patients receiving either false-positives or false-negatives.

There are many factors that may affect a positive or a negative HIV result. Lyme disease, syphilis and lupus, to name a few, are all known to give positive results using ELISA (MedLinePlus 2003). This is not a significant problem if confirmatory testing is available, but if it is not "... statistical analysis of the data shows that a very small number of people who are not infected with HIV-1 will have reactive test results (that is, tests that show HIV infection). As the test becomes widely used in outreach settings, false-positive results may occur" (CDC 2003a: 1). It is also possible that a negative result may appear if not enough antibodies have been produced at the time the testing is done, or that the test used is not made to identify that specific strain of the virus. For example, most rapid tests only detect HIV-1, not HIV-2 because resource rich countries have very few cases of the latter, and have not refined their tests enough to detect the HIV-2 strain (CDC 2003a: 2).

Determining which HIV/AIDS test to use in a specific situation depends on more than just financial and logistical constraints. Statistical data, as well as the objectives for testing a population, are also relevant to determine the most efficient test for the specific circumstances. Statistically, the higher the prevalence of HIV infection within a certain population, the higher the risk of being HIV positive, the greater the number of tests

conducted and, consequently, the higher the chance of getting a false result. In this case, a high number of false-negatives would be suspicious as a large number of positive results would be expected (WHO 1997: 82). In order to ensure the most precise results possible, it is important that:

[T]he accuracy of different HIV diagnostic tests are measured according to their sensitivity and specificity. A test with high sensitivity is one that can detect even minute amounts of antibodies. A test with high specificity is one which identifies all negatives correctly (i.e. produces no false positives). All tests have a margin of error. Tests with high sensitivity should be used when the objective is to minimize the number of false negatives, such as in the screening of donated blood. When the objective is to minimize false positives, such as in confirming whether an individual is HIV-infected, tests with high specificity should be used. (UNAIDS 2003: I-12)

Regardless of which test is used, there is a notable margin of error. In resource rich countries, testing for the antigen is preferred over testing for the antibody, as there is less chance of a false result. In addition, all specimens of blood are tested using two different methods in order to assure accurate results. Unfortunately, because of fiscal restraints, these options are not available to all countries, and, consequently, many people may be unaware that they are living with HIV/AIDS.

People Living with HIV/AIDS (PLWHA)

Though AIDS was first detected among gay males in the United States, and at the time thought to be a disease strictly associated with this group, it was soon clear that HIV/AIDS affects all people, in all countries. As the pandemic continues to progress, it has become apparent that people in resource poor countries are the most affected by the

disease: physically, socially and economically. It is presently estimated that more than 95% of the 38 million people with HIV/AIDS live in resource poor countries (HIV InSite 2004). The disease has hit these regions hardest because of the lack of infrastructure, money and education needed to fight its spread.

Vulnerability to HIV infection arises from circumstances that are beyond the direct control of the people involved. Such circumstances include poverty, low social status, inequality, gender discrimination, discrimination, marginalization, and criminalization. Among other things, these circumstances also reduce or deny a person's access to HIV information, services, means of prevention and support. (UNAIDS 2003: I-12)

Of all the affected resource poor areas, sub-Saharan Africa is suffering the most severely from the AIDS epidemic. More than 29.4 million people infected with HIV/AIDS, or about 70% of *all* cases, live in sub-Saharan Africa, with a reported 3.5 million new cases per year (Fredriksson and Kanabus 2003: 1). Within sub-Saharan Africa there are huge variations in the rate of infection amongst countries. For example, in Somalia and the Gambia, the HIV prevalence is under 2%, while in Botswana and Zimbabwe a staggering one person in three (33%) has HIV/AIDS. (Fredriksson and Kanabus 2003: 2).

Women make up more than half of the near 30 million infected people, and the vast majority of them are between the ages of 15 and 49 (Fredriksson and Kanabus 2003: 4). As a result of a lack of social, economical and political power, women are more vulnerable to infection than men. They are often discriminated against and have little access to, amongst other things, education, employment and health care (Fredriksson and Kanabus 2003: 10). "Gender inequalities increase the vulnerability of ...women to HIV

infection. Vulnerable populations: (1) are denied their human rights and/or (2) have limited access to HIV information, health services and means of prevention, such as condoms (male and female) and/or (3) have limited ability to negotiate safe sex” (UNAIDS 2003: I-12).

The fact that women between the ages of 15 and 49 are more susceptible to HIV/AIDS threatens to send the pandemic spiralling further out of control. Not only are these women becoming infected, but also because they are in their prime child bearing years, they are unintentionally contributing to the spread of HIV/AIDS by transmitting the virus to their babies. WHO and UNICEF have stated that over 800,000 children under the age of 15 contract HIV each year, and that 90% of these cases are a result of mother-to-child transmission (UNICEF 2002b: 1). By the end of 2000, UNAIDS estimated that 1.3 million children, the vast majority of them African, were living with HIV/AIDS and that 4.3 million children had already died of the disease (WHO 2001: 3). The rate of HIV/AIDS among children continues to increase, and AIDS has become one of the main causes of childhood death in resource poor countries. Ninety percent of children with HIV/AIDS acquired it from their mothers, either before, during or after birth. This is known as mother-to-child transmission (WHO 2000:1).

Mother-to-child Transmission

Mother-to-child transmission (MTCT), or vertical transmission, describes the transference of HIV from a mother to her child in utero (through the placenta), during delivery (through cuts or abrasions caused by a difficult delivery or the use of forceps/vacuums) or through breastfeeding. Due to the presence of maternal HIV antibodies in the baby's blood, it is difficult to determine at precisely what moment a

baby becomes infected with the virus, and what degree of risk is associated with each event (Anonymous 1997: 1).

Before birth, babies normally receive a variety of antibodies from their mothers. These antibodies help protect the babies from diseases after birth, until their own immune systems have developed. If a mother has HIV and has developed HIV antibodies, one of the following three things could happen to the baby during pregnancy: 1) The baby could receive both HIV and HIV antibodies; 2) The baby could receive HIV antibodies but not the virus itself; 3) The baby could receive neither HIV nor HIV antibodies. (Red Cross 2003)

Maternal HIV antibodies can take up to 18 months to leave the baby's system, making it impossible for antibody tests to determine the HIV status of the baby. Only very specific, expensive antigen tests can diagnose if the baby is HIV positive or if she simply has maternal HIV antibodies. As more sophisticated tests are uncommon in resource poor countries, it is almost impossible for a mother to know the HIV status of her baby at birth.

However, it is estimated that the rate of MTCT during pregnancy or delivery ranges from 20 to 25%, while breastfeeding is responsible for anywhere between 15 to 45% of MTCT infections (WHO 2000: 5). The exact rate of mother-to-child transmission through breastfeeding is even more difficult to ascertain, as there are many factors that can dramatically alter the probability of transmitting the virus. Factors such as maternal viral load, the type of milk ingested, and length and type of breastfeeding all affect the incidence of transmission.

A newly infected woman, or a woman who has developed AIDS has a high viral load. When there is an abundance of viral cells in the mother's system, there is an increased

risk of transmitting the virus to the baby through breast milk (WHO 2001: 4). In addition to the level of maternal viral load, the kind of milk produced by the mother appears to influence the rate of vertical transmission. Breast milk can be classified into four types: colostrum, front milk, mature milk and hind milk. There is currently some debate about the correlation between HIV and colostrum. Colostrum is the breast fluid that is secreted in the first two or three days after birth. It is known to contain a high number of proteins, calories and antibodies beneficial to the baby. However, some studies have shown that colostrum might also carry a high concentration of HIV (Ruff et al 1994 and Van de Perre et al 1993). Therefore, if a baby is breastfed immediately after birth, her chance of contracting the virus increases. Other studies have shown that the amount of virus in the colostrum is counterbalanced by the maternal antibodies that are also present. More information on colostrum and HIV will be given in Chapter 4.

It has also been observed that the length and the type of breastfeeding can affect the rate of mother-to-child transmission of HIV. The longer an HIV positive woman breastfeeds, the greater the chances are that she will transmit the virus. "Based on a compilation of studies, it is estimated that MTCT rates ... range from 15 to 30% in the absence of breastfeeding, to 25 to 35% if there is breastfeeding through 6 months and to 30 to 45% if there is breastfeeding through 18 to 24 months" (WHO 2001: 3).

It appears that the type of breastfeeding a baby receives also contributes to the rate of vertical transmission. There can be a huge difference in the mother-to-child transmission rate depending on if the baby is exclusively breastfeed, predominantly breastfeed, or given complementary food alongside breastfeeding. However, more research needs to be

done on the different types of breastfeeding practices in order to expand the knowledge of MTCT of HIV via breastfeeding (Coutsoudis et al. 1999: 2).

Infant Feeding Practices

There is no doubt that breast milk is the optimum food for a baby.

It promotes development of newborn's gastrointestinal and immune systems and, by enhancing immunity, lowers the risk of diseases such as meningitis and infections of the respiratory system. Breastfeeding protects babies from diarrhea, the major cause of infant death in developing countries, and provides excellent nutrition without potential infection from unclean water. (Anonymous 1997: 1, 2)

Unfortunately, breastfeeding is not always an option for (or desired by) all mothers, who must rely on other infant feeding alternatives.

Infant feeding is culturally specific, and difficult to describe. "The dynamics of infant feeding are complex. An infant can be exclusively breastfed for a period, receive other food due to a change in circumstances, and then return to exclusive breastfeeding. This complexity is difficult to capture unless there is a continuous assessment of the infant feeding patterns" (WHO 2001: 12). Essentially, infant feeding can be broken down into five categories: exclusive breastfeeding; predominant breastfeeding; breast milk substitutes; complementary feedings; replacement feeding. In exclusive breastfeeding, the baby only receives breast milk from her mother or wet nurse, either directly from the breast or expressed. No other liquids or solids, with the exception of vitamins and medicines, are given to the baby. Predominantly breastfed infants ingest mostly breast milk, but are also fed water, teas, fruit juices, vitamins and medicines, while children who consume animal milk (cows, goats, camels, etc.) and commercially available infant

formulas are receiving breast milk substitutes. When breast milk or formula is thought to have become nutritionally insufficient for the baby, she is also given complementary feedings of foods, either manufactured or locally prepared. Lastly, replacement feedings involve providing a baby, who is not receiving breast milk, with all her nutritional needs either from breast milk substitutes and complementary feedings (WHO 2001: 8).

Each infant feeding category has its risks and benefits, and a mother must weigh the options and make a choice that is best for her and her baby. After considering all her options, an HIV positive woman who chooses to breastfeed puts her child at risk of contracting the virus; but a woman who does not breastfeed denies her child the benefits of breast milk. "[T]he HIV-related negative effects of breastfeeding may be, on a statistical level, more or less cancelled out by the immunological benefits of breastmilk -- in addition to the numerous other nutritional, physiological, psychological and other health benefits of breastfeeding which accrue to both infant and mother" (Halperin 1999: 2). Alternatively, a woman who chooses to give her baby other foods in addition to breast milk may be putting her child's life further at risk.

Ingestion of contaminated water, fluids, and other food may lead to gut mucosal injury and disruption of immune barriers. Since mixed feeding is unlikely to involve hygienic food preparation practices, bacteria and other contaminants may be introduced into the gut and result in inflammatory responses and subsequent damage to the mucosa. HIV-1 is less likely to penetrate intact and healthy gastrointestinal mucosa than damaged mucosa. (Coutsoudis et al. 1999: 8)

A mother who gives her baby infant formula, by choice or necessity, may inadvertently increase her child's chances of dying from malnutrition or dehydration, as, in resource poor countries, it is rare to find clean, accessible drinking water in order to

mix the formula. Ingesting the water contaminated with parasites can cause severe diarrhoea, leading to dehydration and death. If there is accessible water, there is often not enough money to buy the fuel needed to boil the water and sterilize the bottles or feeding cups. In addition, as a result of lack of money, formula is often extremely diluted in order to make it last longer, putting the baby at risk for malnutrition.

These few examples of the risks involved in the various infant feeding options clearly demonstrate that women need to be provided with as much information as possible before they can make a decision. The HIV/AIDS and vertical transmission training documents, analysed in the following chapters, strongly advocate that all women should receive HIV/AIDS and MTCT counselling and HIV testing before they make any decisions concerning infant feeding. It is important to stress that regardless of what the training documents may advocate, women should be given all the relevant information concerning infant feeding and MTCT, and “specific guidance in selecting the option most likely to be suitable for her situation. The final decision should be the woman’s, and she should be supported in her choice” (UNAIDS 2000).

Summary

This Chapter gives important background information on HIV/AIDS and mother-to-child transmission. It begins with some basic information on HIV/AIDS and how various tests determine the presence of antibodies or antigens. The Chapter also discusses who is predominantly affected by HIV/AIDS and how it is transmitted from mother to child. Finally it discusses the various infant feeding practices that parents can choose to adopt depending on which they feel carries the less risk to them and their baby. The following

chapter introduces the three main themes relevant to mother-to-child transmission of HIV (mother-to-child transmission issues, procedural issues, and social issues) that are found in all three documents, and which will be used to analyse the training documents.

CHAPTER 4

A REVIEW OF THE KEY ISSUES RELATED TO MOTHER-TO-CHILD TRANSMISSION OF HIV

This chapter will introduce three key themes (mother-to-child transmission, procedural and social issues), which encompass various issues related to mother-to-child transmission of HIV. Together with the background information provided on various concepts (scientific positivism, power, discourse, liberalism, and feminism), as well as on mother-to-child transmission of HIV, the three counsellor training documents will be analysed in the three subsequent chapters.

In an attempt to provide parents in areas of high HIV prevalence with information regarding HIV/AIDS and mother-to-child transmission, various non-governmental organisations (NGOs), international aid agencies, governments, multinational corporations (MNCs), etc., have developed educational courses and training materials for the use of health workers and counsellors. Through medical and antenatal clinics, health workers and counsellors interact with mothers and babies, and are often the primary educators of medical issues, including HIV/AIDS. Having them pass on information to those who need it might be the most powerful tool against the spread of the virus.

In order for the information to be effective in the fight against HIV/AIDS it must be up to date and accurate. Unfortunately, this can be problematic as AIDS is a relatively new disease, and is still being intensely studied. There is a staggering amount of research being conducted on all aspects of the virus and the disease, from antiretroviral drugs to the social ramifications experienced by those who are infected. As a result of these

studies, what is known about HIV/AIDS is constantly changing; new paradigms are appearing, making it almost impossible to stay apprised of all the new HIV/AIDS information, especially for health care workers with limited access to information. Consequently, the information that counsellors and health workers provide to people is often inaccurate or outdated, either because something (such as a drug) has proven to be ineffective or, worse, is contributing to the spread of the disease. Unfortunately, this information is being passed on to parents, influencing their infant feeding choices. If they are not receiving the newest, most accurate information, are they able to make an informed choice? For example, it was once believed that a person could contract the virus through mosquito bites or using public toilets. It is now known that this is not true. But, what other misinformation might be passed on to the public? This is a particularly important question in the case of mother-to-child transmission of HIV, as millions of mothers and babies are affected by the information provided to them.

In order to determine if women in areas of high HIV prevalence have the information necessary to make informed infant feeding decisions it is imperative to examine what type of information they are receiving. For this purpose, three training documents were chosen for analysis: *HIV and Infant Feeding Counselling: A training course (2000)*, produced by the WHO/UNICEF/UNAIDS; *Programme Guidance on Counselling For STI/HIV Prevention in Sexual and Reproductive Health Settings: For Counsellors, Health Workers, Educators and All Those Working in STI/HIV/AIDS (2002)*, produced by the International Planned Parenthood Federation; and, *Prevention of mother-to-child transmission of HIV: A short course for health workers providing PMTCT services in areas with limited resources and high HIV prevalence (2002)*, produced by the

Population Council. These documents are available on the Internet, and thus are readily retrievable for those with Internet access.

All three training documents were created, at least in part, to provide health care workers or counsellors with the information and the communication skills necessary to educate people about HIV and mother-to-child transmission. Through training courses, basic information on topics such as bottle sterilisation and cracked nipples can be conveyed to local health workers and counsellors during training sessions. These counsellors and health workers, in turn, educate the community with the aim of decreasing the rate of vertical transmission.

In order to properly analyse the three documents it is important to examine what type of information each document contains, or does not contain, and, therefore, what information health workers and counsellors are passing on to the community. Before this can be done, three major themes appearing in all three training documents must be introduced, as it is the information provided within these specific themes which will be used in the analysis of the documents. The first section, or theme, *mother-to-child transmission issues*, includes what information is given about maternal nutrition, milk (breast and other) and breastfeeding; the second section covers *procedural issues* such as counselling, HIV testing, and antiretroviral drugs; and the third section, *social issues*, includes what information the organisations provide on social stigma. The following three chapters will introduce and analyse the mandates and the objectives of each of the organisations that produced the training documents, as well as examine the information the documents provide to the health workers and counsellors concerning the specific themes. This analysis will draw out which concepts have influenced the organisations,

and, in turn, the information that the organisations produce and provide to health workers and counsellors, and ultimately, the people who need it to make choices regarding infant feeding practices.

Mother-to-child Transmission Issues

There are many issues surrounding mother-to-child transmission of HIV/AIDS, but not all of them appear in the three training documents, or are applicable to the scope of this analysis. This section will introduce maternal nutrition, milk (human and non-human), and breastfeeding as common themes appearing in all three training documents.

Researchers are constantly discovering the role nutrition plays in the progression or delay of illnesses and diseases. For example, vitamin A is essential for the normal growth and development of teeth, bones, vision, epithelial tissues and for the immune system (Thomas 1985: 1861). In nature, it is found in green leafy and yellow vegetables, as well as in egg yolks, oranges and pineapples. A vitamin A deficiency could lead to blindness in children, and increase the risk of disease and death from infections. In addition, vitamin A deficiency in pregnant women can cause night blindness and can increase the risk of maternal mortality. “Nearly 600 000 women die from childbirth-related causes each year, the vast majority of them from complications which could be reduced through better nutrition, including provision of vitamin A” (WHO n.d.c). Supplements of 20,000 International Units (IU) are often given out by health workers at local clinics every 4 or 6 months (WHO n.d.g). However, studies have shown that pregnant women should not be given doses higher than 4,000-8,000 IUs as there is a

chance of birth defects such as heart disease and cleft palates and lips (Rothman et al. 1995).

Currently there is a medical debate as to whether or not vitamin A supplements actually increase or decrease the rate of mother-to-child transmission of HIV through breastfeeding. There are studies presently underway to determine if vitamin A supplements play a role in the reduction of mother-to-child transmission of HIV through breast milk (WHO n.d.f). However, research conducted by Dr. Wafaie Fawzi, and colleagues, of the Harvard School of Public Health found that a high level of vitamin A may actually increase the replication of HIV in infected cells, therefore increasing the rate of mother-to-child transmission during pregnancy and through breast milk (Fawzi et al. 2002).

More research needs to be done on MTCT and vitamin A before guidelines are set in place. Even if vitamin A only slightly increases the risk of mother-to-child transmission, it could be important information for an HIV-positive woman who is given vitamin A supplements while she is breastfeeding.

Maternal nutrition is not the only dietetic issue influencing the rate of vertical transmission. The nutritional properties of milk, human and non-human, is also a topic that dominates within the three training documents. As noted in the previous chapter, there is no doubt that breast milk from a healthy mother is the best food for a baby. The antibodies and the nutrients made by the mother's body are perfectly designed to meet all of a baby's nutritional requirements. However, HIV is transmitted through breast milk. The question that remains is whether or not infected breast milk is better or worse for a baby than animal or artificial milks.

Colostrum is, in a real sense, the *crème de la crème*. It is a thick, yellow milk secreted by the breasts during the first few days after delivery and is the precursor to mature breast milk. It contains more proteins, antibodies, anti-infective properties and white blood cells than mature milk. Despite its undeniable benefits, colostrum's role in mother-to-child transmission of HIV is hotly debated within the medical community. Studies by Ruff et al. (1994) and Van de Perre et al. (1993) have shown that colostrum contains a higher level of HIV cells compared to mature milk. These studies contend that if babies ingest colostrum from an HIV-positive woman, their risk of contracting HIV is increased. Conversely, other studies such as those conducted by Lewis, et al. (1998) found the opposite: mature milk has more HIV than colostrum. These studies stress that babies born to HIV-positive mothers in resource poor countries should be fed colostrum in order to help them fight off the potential HIV virus. Still a third group of studies contends that there is a higher concentration of the virus in colostrum, but that there is no real evidence showing an increased risk of vertical transmission of HIV as a result of colostrum consumption. These studies indicate that babies should be breastfed within the first hour of birth, in order to receive the full benefit of colostrum and its anti-infective properties (AIDS action n.d.).

The issue of colostrum is obviously complex. It is difficult for a woman who has all of this information to make a choice she feels is best for her baby. Consider the dilemma for women who are only given some of this information, or worse, none of it. Until more studies prove or disprove this theory, some researchers (Mok 1993) suggest that discarding colostrum and early milk in resource poor countries may limit HIV transmission, saving the lives of millions of babies.

If a woman (HIV-positive or negative) chooses not to feed her baby colostrum or any breast milk because of the risk, she must be given information on how best to feed her child with breast milk substitutes. There is a selection of breast milk alternatives, but not all of them may be accessible to parents in resource poor countries. Babies can be fed a variety of fresh animal milks, as well as canned evaporated milk, full cream powdered milk or commercial infant formula (WHO 2000: 33). However, it is very important for health care workers and parents to know that the protein and mineral contents in animal, canned or powdered milks are not the same as in human milk, and that sugar, water and micronutrients must be added in order to make it more balanced for the baby (WHO 2000: 34, 35).

Regardless of which type of non-human milk is given to babies, parents must ensure that they will have access to a continuous supply. In addition, they must carefully consider the time and costs associated with purchasing the milks (if they do not own the animals), the utensils and the fuel needed for its preparation.

In resource poor countries where HIV/AIDS is highly prevalent, many parents, after careful consideration, decide that breastfeeding is the safest option for their baby. In most cases, where the mother is healthy, breastfeeding is the best option for both her and the baby. Breastfeeding has been proven to act as a natural birth control (amenorrhea) and can help to protect the mother against ovarian and breast cancers (WHO 2000: 9). In addition to the physiological benefits of breastfeeding, it promotes a physical bond between the mother and the baby, which seems to encourage social development in the child.

However, if a mother is HIV-positive, breastfeeding can have some detrimental effects on her and on the baby. Some studies have made a connection between breastfeeding and the decline of health in HIV-positive women. It has been documented that breastfeeding can make the mother weaker and accelerate the progression of HIV to AIDS. In a study, Nduati et al (2001) found that the mortality rate amongst HIV-positive women was higher in the breastfeeding group than in the formula feeding group.

For all women trying to make an infant feeding decision that is best for both them and their babies, this type of information is crucial. Certainly a mother does not want to transmit the virus to her baby, but she also does not want to make him/her an orphan. She must have all the accurate information possible in order to properly weigh the pros and the cons of each feeding option. And generally, this information comes from local counsellors.

Procedural Issues

Information about HIV/AIDS and mother-to-child transmission is vital to the lives of women and children, but it is only effective if it is properly provided through counselling and accompanied by options, such as HIV testing to determine status, and treatment. This section will provide a brief introduction to three types of procedures common in the three training documents: counselling, HIV testing and antiretroviral procedures.

Health workers and counsellors are often the best information conduits in resource poor countries. They are the ones who are at the front line of the HIV/AIDS pandemic, providing information and answering questions from the community in which they work. Counsellors have a unique relationship with their clients. They are there to offer the

information needed to make an informed choice. Ideally, counsellors should be well trained in interpersonal communication and equipped with the current and accurate information that their clients need about a certain topic or situation. Unfortunately, the reality is that counsellors are rarely professionally trained. However, many of them have participated in some type of training course, which provides them with some of the counselling skills needed to provide accurate and impartial information about vertical transmission of HIV. Because counsellors hold an important position within many societies, they often have the 'power' to influence their clients. The counsellors' advice is trusted by people who seek help and information about their particular situation. This is why it is very crucial that counsellors be properly trained, but more importantly, be well informed.

Counselling is extremely important in areas of high HIV/AIDS prevalence. It is absolutely necessary in order to provide information to people who are infected with HIV, or are at risk of becoming infected. Proper counselling can inform people about their risk of having HIV, the benefits of being tested for the virus, mother-to-child transmission, antiretroviral drugs, etc.

Counselling is a helping relationship. When you counsel a mother, you listen to her; help her to understand the choices that she has to make; help her decide what to do, and; help her to develop confidence to carry out her decision. Counselling means *more than advising*. Often, when you advise someone, you tell him or her what you think they should do. Counselling also means more than *education* and *providing information*. Providing information may be part of counselling, but not the only part. A counsellor does NOT make a decision for a woman, nor push her towards a particular course of action, nor enforce a health policy. (WHO 2000: 9)

Counselling is supposed to be a two-sided discussion, where the client discusses her situation with the counsellor, who in turn offers all the information that will help the client make an informed choice. However, counselling is not without its problems. As discussed in the Chapter 2, one of the greatest difficulties in providing counselling to women in developing countries is that HIV/AIDS information is constantly changing. Information on the disease, transmission, and treatment is being challenged on a regular basis as the latest research studies become public. In order to have a truly vigilant or informed choice, the information must be up to date. When there is not enough information, decision makers are usually more reluctant to make choices because they are concerned "... that some crucial bits of information not yet available might make them regret whatever choice they make" (Janis and Mann 1977: 10). For example, the precarious nature of HIV information has had a major impact on infant feeding guidelines for infected mothers. "A recurrent stumbling block to implementing the [AIDS awareness] programme has been agreeing to a policy of what advice we should give regarding the best method of feeding" (Sherr 1991:2). The fact that HIV/AIDS experts cannot agree on accurate information can lead one to believe that parents are not being properly informed. A counsellor from one HIV mother-to-child transmission program might provide parents with information that differs from the information given out by another counsellor working under another program.

In addition, the mother-to-child transmission of HIV information can be biased in a multitude of ways. Counsellors are encouraged to remain as neutral as possible and to strive to be unbiased as they assist their clients in the decision making process. However, counsellors are human, influenced by morals, values, and societal views, all of which

may affect the information they provide to parents (i.e., a pro-life counsellor might fail to discuss the abortion option with a pregnant client).

Generally, counsellors who misinform parents do so because of these unconscious biases or because they themselves have outdated or inaccurate information. However, occasionally, there are counsellors who do not have the clients' best interests in mind. For whatever reasons, these counsellors are malevolent. 'Hobson's choice', "... refers to a situation where an authority acts in a way that virtually restricts the number of choices to one, or arbitrarily assigns an alternative without reference to the person's wishes in the matter" (Janis and Mann 1977: 262). Unfortunately, because counsellors are often respected and trusted, have may hold power, many people will accept the information that the counsellors give them (Janis and Mann 1977: 268). The counsellors might also be encouraged by training documents or financial supporters of the health clinics to provide particular types of information. For example, the clinic may be financially supported by a pharmaceutical company, and, therefore, the counsellors may be asked to promote the company's brand of drugs to its clients. Additionally, an aid organisation might encourage counsellors to promote a certain ideology or belief to the clients, or restrict certain information to some clients. There appears to be a trend within HIV and mother-to-child transmission training documents whereby information about various infant feeding practices are only given to women who are HIV-positive. This occurs because the health professionals are afraid of a "spillover" effect. Spillover is the term used to describe HIV-negative or status unknown women who choose not to breastfeed their babies, in a sense, mimicking HIV-positive women who are not breastfeeding. Health workers and counsellors working at a clinic generally follow the procedures

recommended by the organisations or governments who fund the clinics primarily because they do not have access to other sources of information.

In addition to potential counsellor bias or external influences, language also plays a role in what information clients are receiving from counsellors. At times, counselling is not provided in a language that the client understands. Using scientific language, or non-local language can create confusion and miscommunication. It is very important to provide information in an appropriate language during counselling sessions.

[I]nternational health programming rests on the idea that truth is independent of language and that knowledge is merely contained in the packages that are words. The task in international health education, then, is to move bits of information from one social location to another by finding the right words in another language in which to package it. (Pigg 2001: 483)

Unless information is provided in a known language some of it, or maybe even all of it, will not be understood by the client.

All people, be they HIV-positive or HIV-negative, have a right to bias free, accurate and comprehensible counselling to decide which infant feeding practice carries the least risk for them and their baby. Despite the fact that all people, regardless of status, have the right to all information, it is still very important that everyone, particularly women of childbearing age, be aware of their HIV status. As discussed in the previous chapter, a big part of HIV and vertical transmission programming includes voluntary counselling and testing (VCT). If a mother does not know her HIV status, it will be more difficult for her to make appropriate choices. Many people refuse to be tested because they are afraid of the result, and what that would mean for them socially, physically, or emotionally. Others feel that there is no point in knowing the status because in resource poor countries,

there is so little access to any treatment, such as antiretrovirals and drugs to cure opportunistic diseases (IPPF 2002c: 35).

Fortunately, progress in the research and development of antiretroviral (ARV) drugs has been very positive. In the last few years, new drugs have been shown to dramatically affect the development of the disease. For example, the drug Nevirapine decreases the rate of HIV reproduction, slows the destruction of the immune system, and appears promising in the fight against vertical transmission of HIV. One dose is given to the woman when she is in labour, and another is given to the baby within 72 hours of its birth (AIDS.org n.d.). This regime is much simpler than the older option, zidovudine (AZT), which required many doses of drugs for both the mother and the baby. In addition to the new drugs, recent international regulations about ARVs patents and accessibility to the drugs have begun to make a difference for people living in resource poor countries. For example, since the "Cheap drugs" bill in November 2003, Canada has allowed the production and distribution of generic HIV/AIDS drugs that, until late 2003, could only be produced by the pharmaceutical company holding their patent and sold at a highly inflated price.

Unfortunately, there are other drawbacks with the use of ARVs. There is still little research on ARVs and their possible effects on the human body. Scientifically, not enough time has elapsed since the use of ARVs on the public began to properly document the potential long term and side effects associated with them. Some early research is showing that ARVs may be detrimental to the health of mothers and babies. For example, some studies suggest that once Nevirapine is given to a patient, the virus can become resistant to the drug unless it is used as part of an anti-HIV drug combination.

Not only can the virus become resistant to this drug, but also to others in the same family, making ARV therapy useless to the patient (AIDS Treatment Data Network 2000). In addition, severe kidney problems and liver toxicity have been observed as side-effects to Nevirapine (MedlinePlus 2003). This may not be as severe in resource rich countries where doctors and medicine are available, but it could be fatal to someone in a resource poor area.

Counsellors and information can be influenced by a plethora of ideas and biases. The information that parents finally receive has often been altered by a variety of sources. Unfortunately, the influence does not end once the parents receive the information. Certain social situations also influence the parent's choice making process.

Social Issues

Most choices made have, to at least some degree, been shaped by a wide range of social influences, from the large scale such as mass media, or the smaller local culture such as communities and family. Society has a huge amount of influence over the daily decisions people make, from what they wear to what they believe (politics, religion, etc.).

Though many people are free to make choices regarding themselves and their situations, these decisions are not made without some consideration of people's social networks. "[I]ndividual choice, while it must be always defended, must be understood in the context of the society which structures the choices available to individuals" (Rotham 1984: 23). Rarely do people make choices that go against the norm of their community. If they do, social stigma is often a result. "Anticipated social disapproval and self-disapproval appear to be major deterrents to choosing an attractive course of action"

(Janis and Mann 1977: 140). Rewards and threats are both types of social pressures used to make people act a certain way, even if it is against their own beliefs and judgements (Janis and Mann 1977: 256).

Choices open and choices close. For those whose choices meet the social expectations, for those who want what the society wants them to want, the experience of choice is very real. Perhaps what we should realize is that human beings living in society have precious little choice ever. There may really be no such thing as individual choice in a social structure, not in any absolute way. The question is not whether choices are constructed, but how they are constructed. Society, in its ultimate meaning, may be nothing more and nothing less than the structuring of choices. (Rotham 1984: 32)

Many choices made by people with HIV/AIDS are influenced by the society they live in. In all corners of the world, in resource rich as in resource poor countries, there is social stigma associated with HIV/AIDS. Stigma is a powerful instrument of social control. It can be used to control the actions of a person or of a social group by making them react in a particular way during a certain situation. In the case of HIV/AIDS, the stigma surrounding the disease often makes people react with fright. People believe that those living with HIV/AIDS are low class, dirty, abusing drugs and promiscuous. Many people have lost their jobs, their homes, their friends and family after they revealed their status. Despite the HIV/AIDS education around the world, the stigma persists in many places. People living with the virus or with the disease still face discrimination based on their status. Consequently, many people are afraid of being tested for the virus, seeking medical treatment, or revealing their positive status. This fear has created an enormous obstacle in the fight against the HIV/AIDS pandemic. For some, a private death from AIDS is better than a public death.

Health workers are very aware of the stigma associated with HIV-positive people and with health clinics that test for HIV. While they do not want their patients to be stigmatised, they also do not want to perpetuate the negative social attitude towards the disease. This places health workers in a very precarious position. They must find a balance between the rights of the patient to privacy and choice, and increasing the awareness of HIV/AIDS.

Summary

This chapter examines three main themes that are, at least to a certain degree, apparent in the three training documents analysed in this thesis. Mother-to-child transmission issues introduce information concerning maternal nutrition, breast milk, non-human milk and breastfeeding. Procedural issues look at how vertical transmission information is provided to parents through counselling and how testing and antiretroviral drugs play a role in the MTCT of HIV/AIDS. Finally, this chapter examines how social issues also contribute to the way information about HIV/AIDS is altered and influences the actions of people. The common aspect within all of these themes is that information is malleable, yet is also a crucial component in making informed choices.

Without sufficient reliable information, framed accurately and objectively, and without some assurance that the terms we agree to today will be in force tomorrow, our choices run the risk of not being truly informed choices. Those who claim that we have made such choices, but who have manipulated the information in such a way as to force a certain decision, are operating well outside the bounds of ethics. (Vogt 2002: 2)

The next three chapters will introduce the three training documents and the organisations that created them. The chapters will examine the mandates, objectives and

structures of the organisations that produced the training documents, using various concepts. In addition, the chapters will make reference to the main themes discussed in the above section by looking more closely at how the organisations address these issues.

CHAPTER 5

WORLD HEALTH ORGANIZATION/UNITED NATIONS CHILDREN'S FUND/JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS

HIV and Infant Feeding Counselling: A training course

The previous chapters have provided information that is indispensable to the following analysis of the three HIV/AIDS and mother-to-child transmission training documents produced by WHO/UNICEF/UNAIDS, International Planned Parenthood Federation, and the Population Council. Bearing in mind the information provided in the previous chapter on various themes and issues (i.e., scientific positivism, power, discourse, liberalism and feminism, as well as on HIV/AIDS and MTCT, procedural and social issues), the aim of this chapter, and of Chapters 6 and 7, is to analyse the mandates and objectives of the organisations that produced the training documents, as well as the documents themselves.

This chapter introduces WHO/UNICEF/UNAIDS, and, using two levels of analysis, examines why and how certain mother-to-child transmission of HIV/AIDS information is provided by WHO/UNICEF/UNAIDS. The first section, under the heading *General Analysis*, examines the organisation's mandate, objectives and strategies. Highlighting this material demonstrates how various concepts, such as human rights, power and discourse are evident in WHO/UNICEF/UNAIDS' mandate, and, consequently the information they provide to the public. With this information in mind, the *Specific Analysis* section that follows examines why particular information is being taught to counsellors, and eventually the public, through the training document that WHO/UNICEF/UNAIDS produce. This second level of analysis provides examples of

how the concepts introduced in the General Analysis influence the information on three specific themes found in the training document.

Introduction to WHO/UNICEF/UNAIDS

The World Health Organization (WHO), the United Nations Children's Fund (UNICEF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) have collaborated on various projects, since the beginning of the HIV/AIDS pandemic, in the hope of preventing the spread of the virus. One of their major focuses is mother-to-child transmission of HIV. They believe that by eradicating this type of transmission, a whole generation of children can be born HIV negative and remain healthy, dramatically reducing the HIV/AIDS pandemic. In order to accomplish this, WHO/UNICEF/UNAIDS produced a training document, *HIV and Infant Feeding Counselling: A training course*, aimed at equipping health workers and counsellors with the information and the counselling skills necessary to communicate HIV/AIDS and MTCT information to people in resource poor countries. In order to understand the information WHO/UNICEF/UNAIDS chose to provide to the public, it is important to know what their mandate and objectives are, and how the organisations are structured.

World Health Organization

The World Health Organization (WHO), the world's first global health organisation, was created in 1948 by the United Nations in order to improve the health and well-being of humanity (WHO n.d.a). WHO is based in Geneva, Switzerland. Its primary mandate is the attainment by all peoples of the highest possible level of health, which is defined

“... as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO n.d.a⁵). To help fulfil this massive and complex mandate, WHO is governed by the World Health Assembly (WHA), which is comprised of representatives from each of the UN’s 192 Member States. The WHA’s primary task is to provide WHO with direction by approving programs, policies and budgets⁶. In order to accomplish this, the WHA appoints a 32 member executive board, all of which are doctors or people technically qualified in the health field, and a director-general who oversees the WHO’s 3,500 person secretariat (WHO n.d.b). WHO’s secretariat focuses its work on certain core functions, including advocating for ethical policies, assessing current trends and information, securing funding, stimulating new research, and developing new technologies, tools and guidelines (WHO n.d.d).

In order to strengthen their mandate, WHO has developed a Constitution, which, in conformity with the Charter of the United Nations and the Universal Declaration of Human Rights, has adopted principles they believe are the foundation to the well being of all people. Certain of these principles are relevant to this chapter:

- 1) “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition;
- 2) The extension to all people of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health;

⁵ This training document is co-produced by WHO/UNICEF/UNAIDS, but is published by WHO. For the sake of simplicity, the citation and reference of the document will be WHO 2000.

⁶ The WHO receives various types of funding, primarily assessed contributions from the UN member states and voluntary contributions from member states and other sources. For the 2002/03 year, assessed contributions (or membership fees) totalled \$850,000,000, while voluntary contributions amounted to \$1,380,000,000 (WHO n.d.a).

- 3) Informed opinion and active co-operation on the part of the public are of the most importance in the improvement of the health of the people” (WHO 1946: 1).

WHO’s mandate and activities can basically be summarised as gathering, analysing and disseminating information that will lead to the improvement of the health and well being of the world’s human population. All the work WHO does revolves around information regarding health care and illness prevention.

United Nations Children’s Fund

The United Nations Children’s Fund (UNICEF), another UN agency, is concerned with the well being of children. It was established in 1946 to help children suffering in post-war Europe and China (UNICEF n.d.c). It is headquartered in New York City, and works in over 160 countries world wide, employing over 7,000 people (UNICEF n.d.a). It is governed by a 36-member Executive Board comprised of government representatives elected by the UN⁷, who establish policies, approve programmes and administer budgets (UNICEF n.d.b). UNICEF gets the majority of its funding (63%) from voluntary governments and intergovernmental organisations and 33% of its funding from NGOs and public sector organisations. The United States is by far the largest donor, providing UNICEF with over 27% of its annual funding, while the second is Japan at just under 13% (UNICEF 2002a: 34).

UNICEF’s mandate is based on human rights, more specifically, on the rights of the child. Two important documents have been produced to promote and protect children’s rights to education, health care, shelter and nutrition: the Declaration of the Rights of the

⁷ Of the 36 members, 8 are from Africa, 7 from Asia, 4 from Central and Eastern Europe, 5 from Latin America and the Caribbean and 12 are from ‘other’ or ‘developed’ countries.

Child (1959) and the Convention on the Rights of the Child (adopted in 1989 and in force 1990) (UNICEF n.d.d). Both documents mirror the ideology of the Universal Declaration of Human Rights (UDHR) that was produced in 1948 by the United Nations. The UDHR proclaims "... that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status" (United Nations 1959). The Declaration of the Rights of the child specifically mentions that these rights against discrimination apply to the child, as well as his or her parents.

Principle 4, within the Declaration is particularly important for children in areas of high HIV prevalence. It states that: "The child shall enjoy the benefits of social security. He shall be entitled to grow and develop in health; to this end, special care and protection shall be provided to both him and to his mother, including adequate pre-natal and post-natal care. The child shall have the right to adequate nutrition, housing, recreation and medical services" (United Nations 1959). In order to promote and protect these rights during the HIV/AIDS pandemic, UNICEF has been particularly concerned with providing infant feeding and vertical transmission information to parents, as well as providing mothers with voluntary counselling and testing and, where it is financially possible, with antiretroviral drug treatment, all in the hopes of reducing the rate of MTCT.

One of UNICEF's major priorities within the next four years (2004-2008) is the fight against HIV/AIDS. Over 90% of children infected with HIV acquired the virus from their mother, thus, UNICEF is particularly focused on providing counselling and advice regarding infant feeding options that will help reduce MTCT. UNICEF, in collaboration

with WHO, has supported the training of more than 100 trainers in resource poor countries on breastfeeding and on HIV and infant feeding counselling. They, in turn, have trained more than 1000 counsellors, who have counselled thousands of mothers.

Joint United Nations Programme on HIV/AIDS

The Joint United Nations Programme on HIV/AIDS (UNAIDS), the newest of the three organisations, was created in the 1990s as the UN's official agency working to win the fight against HIV/AIDS. It pulls together the knowledge and experience of various UN related organisations such as UNICEF, UNDP, UNFPA, UNESCO, WHO, World Bank, UNDCP and the ILO (UNAIDS n.d.c). The secretariat is headquartered in Geneva and has offices in more than 60 countries. It is governed by a Programme Coordinating Board that is comprised of 22 government representatives from around the world⁸ (UNAIDS n.d.b). In 2002, UNAIDS received more than US \$92 million from 28 governments and philanthropic organisations. Again, the United States were the biggest donors (20%), followed by the Netherlands, the Scandinavian countries and Japan (UNAIDS n.d.a).

UNAIDS' mission statement is to be the " ... main advocate for global action on the epidemic. It leads, strengthens and supports an expanded response aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS, and alleviate the impact of the epidemic" (UNAIDS n.d.c).

⁸ Less than half of these representatives are from resource rich countries. The United States does not sit on this board.

With the three collaborating organisations introduced, the following section will examine more closely how human rights, and issues of power and discourse have influenced WHO/UNICEF/UNAIDS' mandate and the information they provide to the public.

General Analysis

In order to understand why certain information about HIV/AIDS and mother-to-child transmission is provided in the WHO/UNICEF/UNAIDS' counsellor training document, it is important to examine what concepts may have influenced their mandates and objectives. This section looks at how issues such as human rights, power, and discourse have influenced WHO/UNICEF/UNAIDS and the information they provide to people.

Human Rights Ideology

All three organisations involved in the production of *the HIV and Infant Feeding Counselling: A training course* (2000) document, are agencies of the United Nations. It is, therefore, not surprising that their mandates and objectives are strongly influenced by the United Nations and its human rights ideology, or more specifically, by the rights set out in the Universal Declaration of Human Rights (UDHR). The United Nations proclaimed the UDHR in 1948 in the hope of protecting humanity from barbarous acts committed by individuals, groups and governments. All aspects of life are protected under the UDHR.

Everyone is entitled to all the rights and freedoms set forth in this Declaration without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other

status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty. (United Nations 1948)

More specifically, the UDHR states that everyone has a right to proper nutrition, health care and social services (Article 25-1), as well as education (Article 26-1). In addition, the rights of mothers and children are especially safeguarded, as they require special care and assistance (Article 25-2) (United Nations 1948).

Following the UDHR's commitment to human rights, a joint HIV and Infant Feeding Policy Statement by WHO, UNICEF and UNAIDS declared that "All women and men, irrespective of their HIV status, have the right to determine the course of their reproductive life and health, and to have access to information and services that allow them to protect their own and their family's health" (WHO 2000: 9). These beliefs are reiterated in the principles set out by WHO's mandate, as well as UNICEF's Declaration of the Rights of the Child and the Convention of the Rights of the Child. While UNAIDS does not specifically mention human rights in its mandate, it acts primarily as a coordinating body for UN organisations fighting the war against HIV/AIDS, and works within the mandates of the other organisations.

Though WHO/UNICEF/UNAIDS adopt this universalistic approach to rights, they also recognise that all cultures are unique and require culturally specific information in order to make appropriate choices. "Equity in AIDS prevention requires that correct and culturally appropriate information be imparted, along with existing prevention tools, to those most at risk of HIV infection, wherever they live" (WHO 2003: 47).

Power and Discourse

For as long as language has existed, it has been controlled by those who hold power or control knowledge. As discussed in Chapter 2, knowledge is produced and manipulated by those who hold power - e.g., governments, researchers, big business, counsellors, etc. Those with power use language to convey desired knowledge to the public, influencing people to think or act in particular ways. They can also create social rules to make people conform to a certain standard, which reflects the knowledge they have produced (Escobar 1984: 379).

While WHO and UNICEF's mandates demand equal rights for all people, including equal access to education and accurate information, the information that they provide to the public does not completely respect this concept. They do provide people with information, but such information is not always impartial. For example, WHO/UNICEF/UNAIDS contend that breastfeeding is the best infant feeding practice and should be promoted in all situations: "In infancy, no gift is more precious than breastfeeding" (WHO n.d.e). Despite its mandate to provide accurate information to all people, WHO/UNICEF/UNAIDS' publications, documents and web sites fail to remain unbiased. Their approach is rooted in a belief in the superiority of western culture and scientific knowledge (scientific positivism), which allows them to justify their control over knowledge and information that is provided to people. WHO/UNICEF/UNAIDS are in a position of power, and this power gives them the ability to use language in such a way as to promote certain ideas and actions. By creating a certain discourse about the benefits of breastfeeding and the risks of not, WHO/UNICEF/UNAIDS are able to influence the infant feeding choices of parents living in areas of high HIV prevalence.

The high profile of these organisations means that they wield considerable influence over the thoughts and actions of the public, especially in resource poor countries where people do not have access to additional or alternative information.

WHO/UNICEF/UNAIDS betrays its bias towards breastfeeding by providing positive information on the physiological and psychological benefits of breastfeeding, for both the mother and the baby. They make statements such as “[e]veryone should have access to information about the benefits of breastfeeding ...” (UNICEF n.d.f), and “[b]reastmilk is the best food a young child can have. Animals’ milk, infant formula, powdered milk, teas, sugar drinks, water and cereal foods are inferior to breastmilk” (UNICEF n.d.e). While this may be true, such messages can create a false sense of security in parents who breastfeed their children if the realistic risks are not also provided or are not emphasised.

In addition, the use of negative language to describe all infant feeding practices other than breastfeeding is quite evident. The World Health Assembly, the directorate of WHO, claims that “... every year as much as 55% of infant deaths from diarrhoeal disease and acute respiratory infections may be the result of inappropriate feeding practices, that less than 35% of infants worldwide are exclusively breastfed for even the first four months of life, and that complementary feeding practices are frequently ill-timed, inappropriate and unsafe” (Baby Milk Action n.d.). Instead of focusing on teaching parents how to prepare non-human milk properly to make it nutritionally adequate, they prefer to point out the risks associated with breast milk substitutes. Not only do they use ‘scientific’ arguments to promote breastfeeding, but they also use terms such as “[f]aulty feeding practices” (WHO n.d.e) to refer to non-human milk and formula. By making such statements, it becomes evident that WHO/UNICEF/UNAIDS

are biased towards breastfeeding, and that this bias may, in fact, influence all of the information that they provide to parents seeking infant feeding information.

Despite their mandate of providing all people with all relevant information necessary in making a health related choice (WHO n.d.a), WHO/UNICEF/UNAIDS continue to emphasise breastfeeding as the best form of infant feeding practice, and all other forms as inferior, if not dangerous. They use materials and knowledge, such as the WHO/UNICEF/UNAIDS training document (WHO 2000), to influence women into breastfeeding their babies. Regardless of the risks associated with HIV-positive women breastfeeding their babies, the training document uses particular language and recommendations to persuade women into choosing breastfeeding as their infant feeding practice, rather than providing them with all pertinent information and allowing parents to make informed decisions.

The following section, the Specific Analysis, provides specific examples of how human rights, power and discourse, have influenced the information provided in the three main themes of the WHO/UNICEF/UNAIDS training document.

Specific Analysis

WHO/UNICEF/UNAIDS have collaborated on the production of a counsellor training document in the hope of educating health care workers and counsellors about the risks and benefits of the infant feeding options available to parents in resource poor areas of high HIV prevalence. One of the most effective ways of curbing the rate of vertical transmission of HIV is to train health workers and counsellors who, in turn, can educate parents and parents-to-be about HIV, its transmission and infant feeding options. In

order to help counsellors and health care workers, WHO/UNICEF/UNAIDS developed a document in 2000 entitled *HIV and Infant Feeding Counselling: A training course*, primarily because "... it has been difficult for health workers to advise HIV-positive women how best to feed their infants. It is perhaps even more difficult for a mother and her family to decide what is best, and women need accurate information and counselling to enable them to decide" (WHO 2000: 1).

The WHO/UNICEF/UNAIDS training document has the potential to reach a very large number of people because of the UN's many alliances with governments, non-governmental organisations, multinational corporations, community based groups, and religious organisations, and their ability to diffuse it globally (UNAIDS n.d.c). Additionally, because it is co-produced by three international United Nations agencies, it can draw on their knowledge and experiences, allowing for a more comprehensive document.

The objectives of this training document are to provide health workers, who interact with mothers and babies, with the knowledge and skills necessary to counsel HIV positive women about infant feeding options. The document also aims to help all women feed their babies effectively and safely, and to reduce the spillover of artificial feeding to HIV negative or HIV unknown women by encouraging them to breastfeed (WHO 2000: 1). However, the document does provide a disclaimer stating that, "This course does NOT prepare people to conduct full voluntary confidential counselling and HIV testing - which includes pre-test & post-test counselling for HIV, and follow-up support for general living with HIV. This course covers only aspects specifically related to infant feeding" (WHO 2000: 1).

Despite this, the training document does contain some information on three major themes: mother-to-child transmission issues, procedural issues, and social issues. This section will look specifically at the information provided on these three themes, which WHO/UNICEF/UNAIDS promote through their training document, and provides concrete examples of how the concept of human rights, power and discourse have affected the information that WHO/UNICEF/UNAIDS to provide to people in resource poor, HIV prevalent areas.

Mother-to-child Transmission Issues

Little is said in the WHO/UNICEF/UNAIDS training document on proper nutrition for mothers because, as noted above, the document is generally intended to provide information on infant feeding options for women living in areas of high HIV/AIDS prevalence. However, nutritional elements, such as levels of vitamin A, may contribute significantly in the mother-to-child transmission of HIV. WHO is a strong believer that Vitamin A supplements are essential to the mother and to the baby's development *in utero*, as well as in the reduction of vertical transmission. It has supported studies that suggest that vitamin A supplements are an important part of maternal prenatal care (WHO n.d.g). WHO's research, web site and publications all encourage the use of vitamin A supplements in resource poor countries, despite the fact that other studies have shown contradictory information concerning MTCT and Vitamin A, such as an increased risk of MTCT of HIV (Fawzi et al. 2002) and the chances of birth defects (Rothman et al. 1995).

Interestingly, the WHO/UNICEF/UNAIDS training document only briefly discusses vitamin A and its affect on vertical transmission of HIV. The document only states that Vitamin A supplements should be given to women during antenatal care in order to reduce the risk of MTCT of HIV (WHO 2000: 18). However, the document does not even recommend a specific dose, nor does it mention the risks associated with taking vitamin A supplements⁹. WHO must be very confident in the accuracy of its studies if it does not bother to mention the possible risks of vitamin A supplements. This could be crucial information for parents trying to decide which infant feeding practice is best for them and their situation (i.e., should a mother take vitamin A supplements for her own health and give her baby non-human milk, or should she wait until after she has stopped breastfeeding to take the supplement?).

Like the scientific debate that takes place about vitamin A and its potential effects, a controversy also surrounds breast milk and mother-to-child transmission of HIV. There are obvious physiological and emotional benefits to feeding a baby breast milk, but the risks associated with breast milk are very real and cannot be ignored. From the start of the training document, it is obvious that WHO/UNICEF/UNAIDS strongly favour breast milk over all other forms of infant nutrition. The language used in the document easily reveals the bias towards breast milk. In order to promote breastfeeding over all other types of infant feeding, the training document frequently downplays any risk of MTCT associated with breastfeeding. It encourages counsellors to tell people seeking information that, despite what they may have heard, the transmission of HIV via breast milk “... only happens to a few babies, not all” (WHO 2000: 88) and that the risk of having a sick baby is greater if he/she is not breastfed. “There is a small risk of a baby

⁹ See Chapter 4 for more information on the risks associated with vitamin A deficiency and supplements.

getting the HIV infection through breastmilk but it is also important to remember that a baby may get ill and not grow well if he is not breastfed” (WHO 2000: 43). When the information is presented this way, it can influence parents into accepting breastfeeding as the only safe infant feeding option, despite the fact that the rate of transmission of HIV through breast milk can be as high as 45% (IPPF 2002c: 50).

Not only does the language reveal the training document’s bias towards breast milk, but so do its anecdotes and the way they are presented. For example, the document tells the story of a woman who began feeding her baby formula, which she obtained free from a charity organisation. After a few weeks, the woman returns to the charity to get more formula, but is informed that there is none left. The woman is very upset as her breast milk has dried up and she has no money to buy formula from the store (WHO 2000: 80). This story is added to the document to show what a bad choice formula feeding is, and that the only real option is to breastfeed.

In addition to using language to positively portray breastfeeding and negatively portray other infant feeding practices, WHO/UNICEF/UNAIDS may purposefully be omitting important information in the hope of influencing women to breastfeed. For example, the document does not mention the risks, and/or the benefits associated with a baby ingesting colostrum from an HIV-positive woman. It is interesting that a document dedicated to proper infant feeding practices fails to mention a potentially important component in the vertical transmission of HIV.

If, after all this ‘encouragement’ to give their babies breast milk, women still choose to feed their babies non-human milk, the training document does provide some information on breast milk substitutes, though it does so with reservations and warnings.

The training document goes into some detail on how to modify animal and artificial milks in order to make them nutritionally and metabolically adequate for babies by adding sugar, water and micronutrients (WHO 2000: 34, 35). However, the document repeatedly stresses the additional costs in time and money on preparing replacement feeding or modifying milk, perhaps in hopes of discouraging parents from adopting alternative infant feeding practices (WHO 2000: 36, 61, 73, 84). In fact, there is a whole section of the document entitled “Costs of Replacement Feeding” (WHO 2000: 84). The training document even has calculation and comparison tables in order to show the parents how costly replacement feeding is compared to breastfeeding (WHO 2000: 85). The document also suggests that the supply of non-human milk is rarely reliable, and, therefore, a risky choice (WHO 2000: 32).

In addition to using positive and negative language to describe breast milk and non-human milks, the document follows a similar pattern when discussing the benefits and risks associated with breastfeeding. It is evident throughout the whole training document, that WHO/UNICEF/UNAIDS favour breastfeeding over all other forms of infant feeding practices. The document gives information regarding the advantages of breastfeeding and the disadvantages of NOT breastfeeding, but does not mention the advantages of NOT breastfeeding or the disadvantages of breastfeeding (WHO 2000: 8, 24). It encourages breastfeeding by downplaying the risk of vertical transmission from mother to child, stating that the risk is low because only three of every 20 babies born to HIV-positive mothers will get the virus (WHO 2000: 5). However, as indicated above, some studies suggest that the rate of transmission may be as high as 45% (WHO 2001: 3; IPPF 2002c: 50).

The training document offers an abundance of information on proper breastfeeding techniques. It teaches health care workers how to assist mothers who are breastfeeding in order to assure that the baby is receiving an adequate supply of milk. It provides important information on the baby's attachment to the breast, the frequency of feedings, and the prevention and treatment of mastitis (WHO 2000: 25, 28). The document encourages exclusive breastfeeding, as well as its early, abrupt cessation in order to decrease the chance of mother-to-child transmission of HIV. "Stopping breastfeeding early reduces the risk of transmission of HIV by reducing the length of time the infant is exposed to the virus in the breastmilk"¹⁰ (WHO 2000: 28). Furthermore, the document briefly describes the maternal benefits of breastfeeding including amenorrhea (prolonging the interval between births), and protection against ovarian and breast cancers (WHO 2000: 9).

By concentrating primarily on the positive aspects of breastfeeding, the document fails to discuss the advantages of NOT breastfeeding or the disadvantages of breastfeeding (WHO 2000: 24). Medically, there are some risks associated with breastfeeding, such as the heavy metabolic burden on the HIV-positive mother and the acceleration of HIV to active AIDS (Nduati et al. 2001). Instead of presenting the counsellors or the health workers with all the facts (risks and benefits), the document deflects the attention away from the risks of breastfeeding and emphasises the risks of not breastfeeding. In order to do this, it uses statements such as "[o]nly about 1 baby in 7 is likely to get HIV through breastfeeding" (WHO 2000: 19), and, "[i]n many situations, the risk of illness and death

¹⁰ However, the document is not consistent in its recommendation of exclusive breastfeeding and abrupt cessation: One section recommends four months (WHO 2000: 44), while another recommends six months (WHO 2000: 7).

from not breastfeeding is greater than the risk of HIV infection through breastfeeding” (WHO 2000: 8). In addition to the chapter on, ‘The Risks of Not Breastfeeding’, the document makes the sweeping claim that babies who are not breastfed will not have enough social interaction and physical contact with its mother and members of its social network, which will affect them negatively in such ways as decreasing their social skills (WHO 2000: 49, 53). This implies that people who do not breastfeed their children will be depriving their children, and suggests that they will be lacking as parents. Using this kind of language on people seeking infant feeding information may influence some of them to breastfeed, even if this is not the safest option for them.

In order for parents to make the best infant feeding decision for them and their baby, it is important that they receive all the information possible, in a neutral language that does not try to influence them one way or another. In a sense, health care workers are instructed through the document to make choices for all women by presenting all information about breastfeeding and breast milk in a positive way, and all information about replacement feedings negatively.

Procedural Issues

Counselling is central to the WHO/UNICEF/UNAIDS training document (a full chapter is dedicated to counselling skills), and within counselling, issues of power and discourse become apparent. Women who are seeking infant feeding information rarely have the opportunity or the resources to conduct their own research into the risks and benefits associated with each feeding practice. Consequently, they are often at the

‘mercy’ of the counsellors or health care workers providing them with information. In order to be most effective, this information must be up to date, accurate and bias free.

Providing mothers with this information may be logistically difficult in resource poor countries, as it may take longer for the information to reach the clinics and counsellors or health workers, but it is possible. Unfortunately, it is almost impossible to provide bias free information, especially when training documents, such as this one, supply information that is manipulated by language and value judgements based on what WHO/UNICEF/UNAIDS deem to be ‘best’ infant feeding practice.

Officially, the document recommends that counsellors not push their own particular opinion onto people seeking information. “A counsellor does NOT make a decision for a woman, nor push her towards a particular course of action, nor enforce a health policy” (WHO 2000: 9). However, by using certain language, it becomes obvious that the document favours one infant feeding practice over another. For example, the document makes statements such as: “When you counsel a woman who does not know her HIV status about infant feeding, she may need reassurance that breastfeeding is the safest option for her baby” (WHO 2000: 14); and, “... if a mother does not know her HIV status, she should be encouraged to breastfeed” (WHO 2000: 5). Who has decided that breastfeeding is the safest option for this woman and her baby? What do they mean by ‘encouraged’? The training document also encourages counsellors to give practical help, provide some relevant information and “[m]ake one or two suggestions, not commands” (WHO 2000: 37). Because of the status of health workers and counsellors, a suggestion coming from a health worker might be enough to influence the parents’ choice if they are given information that pushes them in one direction, or another. People may not be given

enough information to make a vigilant choice, especially if they lack formal education or access to additional information or resources. This type of language clearly demonstrates that the document is not necessarily allowing women to make their own choices, but instead influencing them to make the particular one promoted by the clinic or the counsellor.

One of the objectives of the WHO/UNICEF/UNAIDS training document is the prevention of the spillover effect, which WHO/UNICEF/UNAIDS states will destroy good breastfeeding practices (WHO 2000: 1). "If formula is made easily available, there is a risk that women who are HIV-negative or who have not been tested will want to use it. They may lose confidence in breastfeeding, and decide to feed their babies artificially. This needless spread of artificial feeding is called *spillover*" (WHO 2002: 76). In order to prevent this spillover, the training document encourages health care workers to limit all information concerning replacement feeding to women who are HIV-positive. "General information sessions do not need to discuss the details of other ways of feeding. If a woman asks about other options, of course it is necessary to tell her what they are, including mentioning some of the difficulties. But details about how to use other options should preferably be discussed individually with those mothers to whom it is relevant" (WHO 2000: 19). WHO/UNICEF/UNAIDS suggests that women who witness HIV-positive mothers receiving counselling on infant formula preparation or non-human milk modification will be so strongly influenced that they will adopt these practices. "HIV-negative and untested women should not watch demonstrations of how to prepare formula. Doing so could undermine their confidence in their ability to breastfeed, and make them disbelieve the messages that promote breastfeeding as the best option for

them” (WHO 2000: 83). The document claims that this is for the protection of HIV-negative or HIV-unknown women. The training document states that this not only reduces spillover onto HIV-negative women and mothers with unknown status, but it also protects the confidentiality and dignity of HIV-positive mothers (WHO 2000: 83). However, it would stand to reason that placing HIV-positive women in a room away from all other women and giving them ‘privileged’ information not only reduces their privacy but may also increase the amount of stigma that they experience from other parents.

This type of information discrimination infringes on human rights as well as one of WHO’s principles, which states that the fullest attainment of health is only possible if people are accurately informed about issues that affect them and their families (WHO 1946). By segregating women based on status, WHO/UNICEF/UNAIDS fail to take into consideration that women who are HIV-negative when they are receiving infant feeding information may become positive at any time and may, consequently, need this information if they want to protect the health of their babies. By not informing these HIV negative or status unknown women, they are essentially treating them like children (i.e., paternalistic approach). This type of control over the information they choose to provide women is evident throughout the document.

The WHO/UNICEF/UNAIDS training document bases the information it provides to parents on the mother’s HIV status. This type of segregated counselling is only possible if mothers know their HIV status. HIV testing is rarely mentioned in the WHO/UNICEF/UNAIDS training document. The only recommendation given in the training document is that women should be tested before they receive information on

vertical transmission of HIV (WHO 2000: 11,14). It is interesting how the training document encourages women to be tested, and counsels them according to their status, but does not provide them with any information about the testing procedures. Where will women get information and counselling on HIV testing if not from their local health workers? It might be too presumptuous to assume that mothers will either choose to visit other clinics to get more information on HIV testing, or that the counsellors and health workers will be trained with numerous documents, including one that discusses the benefits of getting tested. A truly informed choice cannot be made if a woman does not know her HIV status, not if she is only counselled about the benefits of breastfeeding, and the risks of not breastfeeding, and not about the benefits of replacement feeding.

While little information is given about HIV testing, even less is given about antiretroviral drugs. This is surprising because WHO/UNICEF/UNAIDS are very strong advocates of ARV therapy. By limiting the document to information strictly about infant feeding, they may miss an opportunity to promote the use of ARVs by pregnant women. As WHO/UNICEF/UNAIDS concentrate more and more on ARV treatment, future revisions of the training document will probably include more information about the benefits, and also (hopefully) the risks, of antiretroviral drugs. This information should be mentioned in the WHO/UNICEF/UNAIDS training documents because it could influence the choices made by parents regarding infant feeding practices.

Social Issues

The WHO/UNICEF/UNAIDS training document does not make any direct references to the stigma associated with HIV/AIDS. However, it does perpetuate the cycle of

stigmatisation by treating HIV-positive and HIV-negative/unknown women differently. The document claims that by separating HIV-positive and HIV-negative/unknown women, the chances of the spillover effect will be decreased. In the guise of protecting women from negative social stigma, the course states that, "HIV-positive women should be taught how to use formula privately, and not by a demonstration in front of other mothers. This both protects their own confidentiality and dignity, and avoids influencing other mothers" (WHO 2000: 83). However, this could have the opposite effect. If certain women are singled out and counselled privately about infant feeding options, this could make the other parents suspicious of them, potentially causing some stigma. Bringing all women together and providing them all with the same information may actually reduce the stigma as no one is singled out.

What little information is provided about social issues involves mothers who choose not to breastfeed, especially in countries where the practice is prevalent.

Explaining why they are not breastfeeding can create real difficulties. In some situations, women can say that they are not breastfeeding because they are ill, but they do not say what illness. If her husband or other family member knows that she is HIV-positive and supports her, they can say that she is a good mother even if she does not breastfeed. In some situations, where a number of mothers allow their HIV status to be disclosed, or they belong to support groups who know about each other, this can help to overcome the problem of stigma. (WHO 2000: 35)

The WHO/UNICEF/UNAIDS training document focuses on the potential stigma associated with not breastfeeding, possibly as a means of influencing women to adopt this practice by making them afraid to reveal their status to others through their chosen infant feeding practices.

Summary and Conclusion

The WHO/UNICEF/UNAIDS training document offers useful information on such things as mother-to-child transmission, HIV, and counselling skills. It promotes breastfeeding over any other type of infant feeding practice, but does prepare the health workers or counsellors to answer basic questions about the use and the modification of non-human milk. However, it repeatedly mentions the disadvantages (in terms of costs, time, suitability, etc.) of all replacement feeding and uses language that may influence the choices of parents. In addition, the document limits information on replacement feeding to HIV-positive women. While the mandates of WHO/UNICEF/UNAIDS are heavily influenced by human rights, these beliefs are not truly respected in the information they provide to counsellors, and, consequently, to parents, through their HIV and infant feeding training document. Instead, by encouraging the counsellors to provide certain information that may steer parents into adopting breastfeeding as the infant feeding option that WHO/UNICEF/UNAIDS considers to be best, these organisations are influencing the decision making process simply through the discourse they employ. In essence, by deciding who receives what information, WHO/UNICEF/UNAIDS is using knowledge and information selectively, thereby inhibiting parents from making a fully informed choice. Infant feeding options should be open to ALL women, not just those who are HIV-positive, primarily because women who are HIV-negative today, may very well be HIV-positive tomorrow. This prior understanding of mother-to-child transmission will allow such women to make choices, or to change their choice, depending on what their present situation is, because information empowers people.

CHAPTER 6

INTERNATIONAL PLANNED PARENTHOOD FEDERATION - Programme Guidance and Counselling For STI/HIV Prevention in Sexual and Reproductive Health Settings: For Counsellors, Health Workers, Educators and All Those Working in STI/HIV/AIDS

This chapter introduces the International Planned Parenthood Federation, and examines its structure, mandate and objectives in order to understand which concepts influence the information IPPF provides to the public about mother-to-child transmission of HIV. The general analysis looks at how human rights and liberal feminist perspectives have influenced IPPF's mandate and objectives, while the specific analysis examines how these concepts have influenced the information IPPF provides on MTCT issues, procedural issues, and social issues in its *Programme Guidance on Counselling For STI/HIV Prevention in Sexual and Reproductive Health Setting: For Counsellors, Health Workers, Educators and All Those Working in STI/HIV/AIDS* training document.

Introduction to International Planned Parenthood Federation

The International Planned Parenthood Federation (IPPF) was created in 1952 by volunteer members of national family planning associations in eight countries - Germany, Hong Kong, India, the Netherlands, Singapore, Sweden, the UK and the USA. Today, having established itself in over 182 countries through Family Planning Associations (FPA), IPPF is the world's largest sexual and reproductive health care organisation dealing primarily with rights and choices. IPPF has a central office in London and five regional offices in Brussels, Kuala Lumpur, Nairobi, New York and Tunis (IPPF 1999b: 4).

The Governing Council of IPPF, consisting of 30 elected members¹¹, five each from its six offices, is the chief decision-making body of the IPPF. The Governing Council is also responsible for appointing a Director-General, who implements the policy decisions made by the Governing Council, and also manages the Secretariat, which coordinates the day to day tasks of the various policies and projects (IPPF 1999b: 4).

The majority of IPPF's budget comes from various governments (\$60 million in 2002) as well as from private donations (\$31 million in 2002) (IPPF 2002a: 18, 22)¹².

The IPPF has achieved consultative status with several UN organisations and works closely with voluntary, inter-governmental and UN agencies that are also concerned with sexual and reproductive health, and with the well-being of women and children (i.e.: UNICEF, WHO, United Nations Population Fund (UNFPA), etc). In addition, IPPF often collaborates with academic institutions, governments, governmental organisations and non-governmental organisations (NGOs) (IPPF 1999b: 5).

IPPF's mandate "... is to advance the basic human right of all women, men, and young people to make free and informed choices regarding their sexual and reproductive health: this rights-based approach is the cornerstone of IPPF's work throughout the world" (IPPF 1999b: 11). IPPF acknowledges the fact that the only way this mandate can be achieved is if three important goals are met: 1) women are empowered to be in control of all aspects of their lives; 2) authoritative information on sexual and

¹¹ According to IPPF bylaws, at least 50% of the members elected to the Governing Council must be women, as well as at least one elected member from each regional office must be under the age of 25 (IPPF 1999b: 4).

¹² The majority of these governments represent western or developed countries. This amount does not include grants from the United States of America, under the presidency of George W. Bush, who have cut all funding to family planning organisations who engage directly or indirectly to abortion-related activities (IPPF 2002a: 10).

reproductive health, including family planning, is provided to those who seek it; and, if 3) resources are mobilised in order meet these needs (IPPF 1999b: 9).

IPPF strives to reach these goals by establishing numerous objectives, which are outlined in its Strategic Plan. The Strategic Plan emphasises IPPF commitment to all aspects of sexual and reproductive health (SRH): researching, collecting and disseminating (through media, NGO networks and other means) accurate information concerning sexual and reproductive health to all people in order to provide them with the tools they need to make informed choices; establishing equal rights for women to enable them to exercise control over their own reproductive and sexual health choices; influencing trends, policies and services that will support its primary goal of freedom to SRH information and services; attracting and securing diversified funding base from governments, NGOs and donors, and maintain accountability in all aspects of IPPF's work; and, recruiting and training volunteers who, by always staying informed, will help educate people of the issues of SRH (IPPF n.d.d).

In addition to the objectives set out in the Strategic Plan, IPPF's Governing Council established a legal Charter on Sexual and Reproductive Rights in 1995 based on various bills of rights and international human rights documents¹³ (IPPF n.d.b: 5). This Charter

... sets out the human rights context within which IPPF carries out its mandate in the field of sexual and reproductive health and rights. ... The Charter sets out what the Federation considers sexual and reproductive rights to be; it also makes the connection plain between human rights language and service delivery realities in the field of sexual and reproductive health. (IPPF n.d.b: 4)

¹³ These documents include the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the Convention on the Elimination of All Forms of Discrimination Against Women and the Convention on the Rights of the Child (IPPF n.d.b: 7).

The Charter identifies twelve rights from within international human rights agreements, which IPPF claims are essential to sexual and reproductive health (IPPF n.d.b: 9):

1. The Right to Life
2. The Right to Liberty and Security of the Person
3. **The Right to Equality, and to be Free from all Forms of Discrimination**¹⁴
4. **The Right to Privacy**
5. The Right to Freedom of Thought
6. **The Right to Information and Education**
7. The Right to Choose Whether or Not to Marry and to Found and Plan a Family
8. The Right to Decide Whether or When to Have Children
9. **The Right to Health Care and Health Protection**
10. **The Right to the Benefits of Scientific Progress**
11. The Right to Freedom of Assembly and Political Participation
12. The Right to be Free from Torture and Ill Treatment

These rights have influenced IPPF's mandate, and consequently all of the information and services that IPPF provides to people around the world. An analysis of IPPF's mandate and rights will clearly show what this influence has been. With this introduction to the organisation, a more general analysis can be done to determine which concepts influence its mandates and objectives, as well as the information IPPF provides in its training document.

General Analysis

In order to understand why certain information about HIV/AIDS and mother-to-child transmission IPPF provides in its counsellor's training document, it is important to first examine how certain concepts have shaped its mandate and objectives. It is evident that IPPF has been strongly influenced by human rights and by feminist ideology, specifically

¹⁴ The Rights that will be examined more closely have been emphasized.

liberal feminism. This section examines IPPF to show exactly how these concepts have influenced the information IPPF provides to the public.

Human Rights

It is obvious that the International Planned Parenthood Federation is highly influenced by human rights ideology. A Human Rights perspective permeates throughout their mandate, objectives, strategies and documentation. The rights that IPPF set out in their Charter on Sexual and Reproductive Rights are based on international human rights documents such as the Universal Declaration of Human Rights, the Convention on the Elimination of All Forms of Discrimination and the Convention on the Rights of the Child (IPPF n.d.b: 7). IPPF has amalgamated and edited these documents to form a charter that protects people's rights to freedom and choice, especially in terms of sexuality and reproduction. For the scope of this analysis, five of the twelve rights outlined in IPPF's Charter on Sexual and Reproductive Rights are examined more closely, in order determine if IPPF does indeed address or respect these rights within its mandate and objectives, and within the counsellor training document it produced. These five rights have been chosen because they are particularly relevant to the HIV/AIDS and mother-to-child transmission crisis.

a) The Right to Equality and to be Free from all Forms of Discrimination

The first right to be examined, the Right to Equality and to be Free from all Forms of Discrimination, ensures that

All persons have the right to equal access to education and information to ensure their health and well-being, including

access to information, advice and services related to their sexual and reproductive health and rights irrespective of race, colour, poverty, sex, sexual orientation, marital status, family position, age, language, religion, political or other opinion, national or social origin, property or other status. (IPPF n.d.b: 14)

In addition, this right guarantees that all females (young and old) have good nutrition, appropriate health care and access to education and information throughout their lives, and that they be free from any prejudicial customs and practices based on the ideology that they are inferior to men (IPPF n.d.b: 15). This right defends women who are often marginalised simply because of their gender. It allows women access to sexual and reproductive health information and services, even in countries or areas where women typically would not have this right.

As a result of this right to equality, IPPF emphasises maternal and child health, particularly in the face of the HIV/AIDS pandemic. Maternal and child health issues¹⁵ make up over 39% of the services offered by IPPF clinics, second only to family planning counselling (IPPF 1999b: 30). IPPF firmly believes that maternal and child health care is substandard in many resource poor countries because women are often uneducated, poor and have low social status, and, consequently, have very little opportunity to make important choices for them and their babies (IPPF 1999b: 15). The only real solution is if women have gender and social equity. "... [W]omen's empowerment and their full participation on the basis of equality in all spheres of society, including participation in the decision-making process and access to power, are fundamental for the achievement of

¹⁵ Maternal and child health care services include pre-natal and antenatal counselling, access to family planning methods and safe abortions.

development” (IPPF n.d.b: 10), and crucial for women’s ability to fully participate in the decision-making processes which affect them and their babies’ lives.

In addition to its focus on gender issues, IPPF states through this right that no one shall be discriminated against on the grounds of religious, social or political status. When the Charter was produced, this implied social, religious or political status. As the HIV/AIDS epidemic continues, the definition of status can now include a person’s HIV status. IPPF makes it clear that all people, regardless of HIV status, are equally entitled to health services and information. IPPF respects this right as, in its promotional and educational material, it does not make a distinction between the information it provides to HIV-negative and HIV-positive women. It aims at providing all people with the most comprehensive and accurate information it can.

b) The Right to Privacy

The second right to be analysed, the Right to Privacy, states that all people, individuals, couples, young and old, have access to SRH information and services, all the while maintaining their privacy and confidentiality for fear of discrimination or reproach (IPPF n.d.b: 16). In providing people with sexual and reproductive health information, IPPF strives to protect people’s privacy. Privacy is a major concern to IPPF, particularly in countries or areas where sexuality is not openly discussed or encouraged by society. For example, in areas where abortion is illegal, women who choose to have the procedure done rely on IPPF’s ability to protect their privacy in fear of being severely reprimanded by their social network and the authorities. A similar stigma might be associated with sexual orientation in conservative areas. If a man, for example, wishes to receive

HIV/AIDS information because he has engaged in unsafe homosexual practices, IPPF must take all precautions necessary to ensure that his sexual orientation will not be disclosed to the public.

Another poignant example is testing for HIV. A person's HIV status must be kept confidential until that person decides who and when to tell. "Confidentiality must be guaranteed and adequate pre and post test counselling should be provided" (IPPF 2001:

4). Because of the stigma associated with HIV/AIDS, this right must be enforced before people can feel safe enough to be tested.

c) The Right to Information and Education

The third right, the Right to Information and Education, IPPF "... recognizes and believes that all persons have the right to education and, in particular, to specific education information to ensure the health and well-being of persons and families including information and advice on sexual and reproductive health and rights..." (IPPF n.d.b: 18). Through this right, IPPF stresses the importance of objective, critical and accurate information in order to ensure that decisions related to sexual and reproductive health are made with "... full, free and informed consent" (IPPF n.d.b: 18). As stated above, under the right to equality, IPPF aims to provide as many people with information as they can. One of IPPF's objectives is "To provide an authoritative source of information on family planning and sexual health issues, trends, policies and services" (IPPF n.d.d: 8). The IPPF promotional material suggests that their clinics are open to all people, young and old, married and single, of any religious affiliation, and of any cultural group.

This right basically represents IPPF's mandate of providing sexual and reproductive health information and care to all people. In order to further this right, IPPF has made a concerted effort to increase society's knowledge of HIV/AIDS prevention and care. Since the mid 1980s, IPPF has extended its primary family planning mandate to include sexually transmitted infections (STIs), in particular HIV/AIDS (IPPF 1999b: 16). IPPF strives to provide up to date, accurate information about HIV/AIDS and vertical transmission prevention, care and support programs worldwide (IPPF n.d.c). If more people are educated about how to prevent the transmission of the virus, there is hope that the pandemic can be slowed and eventually eradicated. However, IPPF understands that even though they dispense condoms and promote them as an effective barrier against HIV, they must encourage behavioural education and change if the war against HIV/AIDS is going to be won (IPPF 2002b: 4). IPPF's mandate suggests that it is in a good position to combat the spread of HIV/AIDS because "[i]n many countries where AIDS is most severe, IPPF is one of the few organizations that are actually delivering services at the community level" (IPPF 2002c: 5).

One of the reasons IPPF is effective in producing and distributing accurate information on HIV/AIDS and MTCT is that its counsellors have a unique relationship with the people who visit their clinics. IPPF counsellors working with people are "... accustomed to dealing with the most personal aspects of people's lives – their sexual and reproductive health – which puts them in a favourable position to help in the prevention and control of sexual transmitted infections including HIV" (IPPF 1999b: 16). At IPPF or family planning association (FPA) clinics, people are looked at in a holistic way, not just "contraceptive acceptors" (IPPF 2002c: 6). They are provided with a wide range of

information on health and psychological issues surrounding all aspects sexual and reproductive health. IPPF believes that this approach helps to reduce the stigma associated with, not only SRH and HIV/AIDS, but also with IPPF or family planning association clinics (IPPF 2002c: 6).

d) *The Right to Health Care and Health Protection*

The fourth right, the Right to Health Care and Health Protection, states that all people “... have a right to the enjoyment of the highest attainable standard of physical and mental health” including SRH care, adequate nutrition, and antenatal, delivery and post-natal care for women and babies (IPPF n.d.b: 21). This care should be comprehensive and accessible, both geographically and financially (IPPF n.d.b: 21). For example, IPPF is a founding member of the global Safe Motherhood Initiative which brings together various United Nations agencies as well as the International Federation of Gynecology and Obstetrics and the International Council of Midwives. These agencies work together “... to reduce the risks of pregnancies through effective, affordable, accessible and acceptable maternity care for all women” (IPPF 1999a: 3).

e) *The Right to the Benefits of Scientific Progress*

Finally, the fifth right, the Right to the Benefits of Scientific Progress, endeavours to ensure that everyone has information about, and access to, the latest reproductive health care technology such as contraception, infertility treatments or HIV information and care. This includes any and all information on potentially harmful effects caused by the lack of, or the use of, reproductive health care technology (IPPF n.d.b: 23).

However, IPPF should be careful to ensure that this right offers unbiased information. The medical and scientific information that IPPF disseminates is recommended to them by their International Medical Advisory Panel (IMAP). IMAP consists of eight medical scientists or technical experts (in the fields of contraceptive technology, obstetrics and gynaecology, public health, epidemiology and endocrinology) who recommend policies and procedures based on their own experiences and the latest research findings (IPPF n.d.a). “The Panel currently consists of eight members appointed by the IPPF Governing Council and representatives from the World Health Organization and the United Nations Population Fund” (IPPF n.d.a).

A closer look at the potential biases of the members of the IMAP (country of origin, political and religious beliefs, employer, etc.) could help determine if or how the information recommended for dissemination to the public is predisposed towards a particular opinion.

It is very clear that IPPF’s mandate and strategies are influenced by a human rights perspective. They aim to acknowledge and uphold human rights, and inform people about their right to information, care and choice. In addition to this human rights perspective, IPPF is also influenced by liberalism and feminist ideology, in particular, liberal feminism, which is addressed below.

Liberalism and Liberal Feminism

It is obvious from its mandate that IPPF favours a liberal ideology. As noted previously, liberalism is the doctrine that gives all people, irrespective of gender, ethnicity or beliefs, freedom from coercion and the ability to make choices (Hayek 1982:

1 - 2). Liberal feminism begins with this ideology and applies it to the situation women generally find themselves in. It identifies that women have not been accorded the same rights and freedoms as men, and that society has constructed artificial barriers that have confined women to the private sphere of wife and motherhood (Beasley 1999: 51). As the previous section on human rights discussed, IPPF adamantly promotes sexual and reproductive rights, especially access and use of contraception, and safe abortions. The freedom to control her reproduction, and all issues surrounding it, will greatly empower a woman's position in society by allowing her the opportunity to make choices regarding her participation in the public and private spheres. In addition, in order to achieve good maternal health, which is often lacking in resources poor countries, IPPF also promotes gender equity (IPPF n.d.c: 1). It is only once women have equal access to education, health care, and social and economic opportunities, will they have the ability to make informed choice surrounding their sexual and reproductive rights, including infant feeding practices.

As a result of the unequal treatment, liberal feminists demand social reform that will grant them rights and privileges, public and private, equal to men (Beasley 1999: 52). Liberal feminists believe that this will only occur with government intervention, as it is the tendency of society to be unequal (Beasley 1999: 53). Consequently, organisations that deal specifically with women, such as IPPF, have adopted a liberal approach to their mandate and policies. Unfortunately, not all groups or people are open to liberal beliefs.

Paradoxically, the biggest obstacle to IPPF's ability to offer all-encompassing SRH services in all countries is perhaps its liberal approach. "Opposition from various sources ranged from the rational to the rabid, bringing in religion, tradition, culture, politics,

economics and sheer aversion to change” (IPPF 2002b: 2). Undoubtedly, its belief that all women should have access to safe abortions, and that all couples should have access to contraception, has limited IPPF’s ability to offer its services to countries with opposing laws. Because of some countries’ strict social customs or religious beliefs, people might be prevented from visiting IPPF clinics. As a result, the information available from IPPF might not reach enough of the intended audience. IPPF acknowledges the fact that this could potentially be problematic to their dissemination of information.

Some religions do not accept the use of contraceptives, including condoms and harass or stigmatise those who distribute them or use them. Organisations need to agree on policies to address these legal and ethical issues and disseminate them throughout the organisation. These might include advocacy for new laws and policies to prevent discrimination; educating people about laws and human rights agreements already in place and education aimed at changing negative attitudes. (IPPF 2002c: 9)

By focusing some of its attention on advocacy for new policies that addresses people’s sexual and reproductive rights, IPPF clearly demonstrates how its mandate is strongly influenced by a liberalist and liberal feminist’s perspective on universal freedoms and liberties. All people, no matter where they live, what their gender is, and what they believe in, have the same right to education and information concerning their sexual and reproductive health. Laws and customs that do not accept this should be changed (IPPF 2002c: 10). Therefore, although IPPF claim to be respectful of local cultures and social norms, they can never fully support this cultural relativist position because their belief is that an individual’s rights supersede collective rights.

As a result of its liberal leanings, and its push to change policies and influence laws, IPPF has been financially punished by governments and organisations that do not support

their beliefs. IPPF's stance on certain issues such as abortion has made it more difficult for them to secure funding in order to continue their work in international sexual and reproductive health. Certain governments, such as the United States of America, have withdrawn their funding because they do not agree with IPPF's pro-choice agenda. As a result, IPPF is under funded and this impedes their ability to offer information to people across the world (IPPF 2002a: 10).

In order to increase their funding, IPPF has had to request grants (totalling more than US\$20 million last year) from multilateral organisations such as the WHO and UNAIDS (IPPF 2002a: 8). This may seem like a reasonable alternative to a lack of public funding, however, depending on the funding source, it may compromise IPPF's ability to maintain its dedication to its mandate, maybe even making it susceptible to third donor biases. For example, a multinational organisation may offer financial support on condition that some of their products or services be predominantly offered to clients who attend IPPF or family planning association clinics. A perfect example of this type of financial influence is the Nestlé conflict of the 1970s¹⁶. Many aid organisations and health clinics were financially supported by Nestlé in exchange for the promotion of its infant formula. This led to a massive international outcry when it was reported that mothers using infant formula rarely had the resources to safely feed their babies artificial milk, which led to the death of millions of babies from malnutrition or dehydration. This is not to suggest that IPPF will easily fall under the influence of a large multinational organisation, but history often repeats itself, especially where money is involved.

¹⁶ Though the Nestlé story broke in the 1970s, there are still many reports of abuses by Nestlé and other multinational corporations.

For the moment, IPPF appears more influenced by its roots in family planning advocacy than by multinational corporations that produce infant formula as noted above. In its promotion of smaller, well planned families, created out of informed decisions, IPPF will continue to recommend breastfeeding, not only as a superior infant feeding practice, but also as a natural form of birth control (IPPF 2002b: 2). If fewer women breastfed, there would be more unplanned pregnancies and IPPF would have failed to achieve part of its mandate (IPPF 2002b: 2). IPPF must protect itself from external influences as much as possible or it may eventually become difficult for them to respect their mandate and objectives if they accept support from MNCs and organisations with, for example, vested interests in a particular drug or product.

It has been shown how human rights, liberalism, and liberal feminist perspectives have influenced the mandate and objectives of IPPF. The following section will examine how these concepts have specifically influenced the information that IPPF provides in its counsellor training document.

Specific Analysis

The second document used in this analysis was produced in 2002 by IPPF. *Programme Guidance an Counselling For STI/HIV Prevention in Sexual and Reproductive Health Settings: For Counsellors, Health Workers, Educators and All Those Working in STI/HIV/AIDS* was created during a three-day workshop by a group of experienced counsellors from various Family Planning offices and AIDS organisations.

The IPPF training document is designed to give health workers appropriate counselling skills in the area of Sexually Transmitted Infections (STIs) and HIV (IPPF 2002c: 3). Since there is often a lack of professionally trained health workers in resource poor areas, the document is geared towards 'lay' health workers. "This guide aims to provide information, ideas, and suggestions for those who work with clients (young people, male and female clients, individuals and couples) and who want to improve their knowledge and skills in counselling in STI/HIV prevention, safer sex, pre and post HIV antibody testing and other issues related to the subject" (IPPF 2002c: 3). In addition, it aims to help mothers and families weigh the benefits and risks of different infant feeding options (IPPF 2002c: 50). Though it is not strictly a document for HIV and infant feeding counselling, it deals with many of the important issues involved. The document is general enough to contain information useful to a wide range of situations, and can be adapted to conform to local needs and culture (IPPF 2002c: 3). However, being a general document focused on sexual and reproductive health as opposed to only HIV and vertical transmission, there may be some concern that there is not enough information to help parents make informed infant feeding decisions.

From its mandate, it is clear that IPPF is concerned with access to information and education about sexual and reproductive health issues. Human rights, liberalism, and liberal feminism play a big role in determining what kind of information IPPF provides to the public. They strongly believe that strong sexual and reproductive knowledge is not only a right, but is also necessary in order to achieve good health.

This section examines some of the information presented in the training document while keeping in mind IPPF's mandate and the concepts that have influenced it. The

following analysis will show direct examples of how human rights, liberalism, and liberal feminism have influenced the information IPPF provides by looking at three main themes found in its counsellor training document: MTCT issues, procedural issues, and social issues.

Mother-to-child Transmission Issues

The IPPF training document offers surprisingly detailed information on vertical transmission of HIV, despite the fact that it is primarily used as an STI/HIV counsellor training document. Though it contains useful and important information, very little information is given about the influence of nutrition on mother-to-child transmission of HIV. In order to have good prenatal health, the training document does stress the importance of eating a balanced diet of cereals and tubers, oils, fruits and vegetables, meats, fish and dairy (IFFP 2002c: 42). It also briefly mentions that vitamin A deficiency in pregnant women may increase the risk of MTCT and that women should be given a supplement or advised about which local foods are rich in it (IPPF 2002c: 53). It is not astonishing that the IPPF document would make such a claim as it relies on the scientific and medical research conducted and promoted by the members of its International Medical Advisory Panel. This panel includes a representative from WHO (IPPF n.d.a), and, as noted in the previous section, WHO is a strong supporter of vitamin A supplements. However, unlike the WHO document, the IPPF training document provides women a choice of options when discussing the treatment for vitamin A deficiency. The IPPF document encourages counsellors to tell women that they can receive vitamin A supplements or they can learn how to get vitamin A by consuming specific local foods

(IPPF 2002c: 53). By offering women information on natural and synthetic sources of vitamin A, IPPF is providing women with information that they can use to make choices in reducing the risk of vertical transmission of HIV.

Possibly the biggest choice a mother in resource poor areas with a high HIV prevalence must make is whether or not she should feed her baby human or non-human milk. The IPPF training document agrees that breast milk is best for babies, but it also explains that there are risks associated with its ingestion directly from the breast if a woman is HIV-positive (MTCT of HIV, effect of antiretroviral drugs, etc.). However, it does not compare the value of breast milk to that of other types of milk. The document gives some of the factors that increase the rate of vertical transmission of HIV through breast milk, as well as some of the risks associated with replacement feedings (IPPF 2002c: 53). It aims to provide impartial information to women who must make choices themselves. IPPF stresses that babies must receive milk (human, animal or artificial) and a woman must weigh the risks and benefits associated with all types of feeding before she makes a decision that is best for both her and the baby. By using a human rights perspective to support their mandate and the information it produces, IPPF tries to remove, as much as possible, the value judgement placed on various types of infant feeding practices, allowing parents to make an infant feeding choice based on what they feel is safest option for all of them.

If the parents feel strongly about their baby being fed breast milk, but are afraid of transmitting the virus, the document does briefly mention some alternative methods of breastfeeding or infant feeding including heat treating breast milk, breast milk banks, and wet-nursing (IPPF 2002c: 54). Unfortunately, it fails to give many details about these

practices, other than some of the possible negative aspects associated with each, such as the risk and the costs in time and money (IPPF 2002c: 54). A brief, one paragraph explanation on Holder's pasteurisation¹⁷ would offer enough information to health workers and parents, and possibly save many young lives in the process.

If, however, the parents decide that the risk of giving their baby breast milk is too great, they need to be properly informed on alternative infant feeding practices. Even though IPPF believes in the superiority of human milk, its training document provides information on non-human feeding practices because IPPF firmly believes that any type of milk is beneficial to babies. "From birth to six months, milk in some form is essential for an infant" (IPPF 2002c: 54). While the IPPF document does offer non-human infant feeding information, it does not teach health workers how to properly modify animal milk with sugar, water and micronutrients in order to make it a suitable food for the baby. It also warns about the costs and the risks associated with non-human milk feeding practices, such as malnutrition, infection, loss of child spacing, loss of mother to child bonding and stigmatisation from people in the community (IPPF 2002c: 53).

In order to reduce some of the risks of transmitting HIV via breast milk, the document encourages exclusive breastfeeding for the first six months, with a complete cessation once the baby begins to receive food or milk substitutes (IPPF 2002c: 53). This practice may reduce the risk of transmission. In addition, the document strongly recommends that mothers who are receiving antiretroviral drugs do not give their breast milk to babies as the drugs are passed through the breast milk and could harm the baby (IPPF 2002c: 53).

¹⁷ Holder's Pasteurisation refers to the act of heating breast milk at least 62.5 degrees Celsius for at least 30 minutes (Chantry 2000).

The IPPF training document not only provides warnings about non-human milk alternatives, but also warns about the risks of breastfeeding. First, it cautions about the increased risk of mother-to-child transmission of HIV if a mother contracts HIV or other sexually transmitted infections during the time she breastfeeds. As described in Chapter 3, the virus in a newly infected body rapidly replicates itself and, consequently, a person's viral load becomes extremely high, making them more infectious. In order to reduce the risk of transmission, and in keeping with its family planning roots, the document teaches health workers and counsellors about the importance of practising safe sex, especially during pregnancy and lactation (IPPF 2002c: 51). The second warning the IPPF document provides concerns the type of breastfeeding mothers should practice if they so choose. If parents choose to breastfeed, the training document advocates doing so exclusively (IPPF 2002c: 53). Exclusive breastfeeding is extremely important for the health of the baby, as any other liquid or food given at the same time as infected breast milk might irritate the gut, allowing the virus to easily infiltrate the body. If an HIV-positive mother decides to breastfeed her baby, IPPF recommends that the baby be exclusively breastfed for six months, without a drop of other liquid (milk, water, juice, etc). As soon as other foods or liquids are introduced to the baby's diet, breastfeeding should stop immediately and completely (IPPF 2002c: 54).

Apart from these two warnings, very little is said about breastfeeding in general. There are no sections about proper infant-breast attachment or prevention of mastitis in order to reduce the rate of HIV transmission. If mothers decide that breastfeeding is the best choice, they need to receive counselling on proper breastfeeding techniques. However, the IPPF training document does not give much information about the

technicalities of breastfeeding. The IPPF training document offers more information on procedural issues than it does on MTCT issues.

Procedural Issues

Counsellors are an extremely important part of the fight against HIV/AIDS. Professionally trained counsellors are, however, hard to find in resource poor countries. IPPF realises that the majority of the people being trained with its document are not professional counsellors, but lay people from within the community who are willing to help educate people on sexual and reproductive rights (IPPF 2002c: 7). IPPF's training document indicates that an effective counsellor should be impartial, objective and not impose his or her own opinion on the people seeking counselling. However, lay counsellors or health workers may have the same attitudes towards HIV/AIDS as the rest of the community, but not the education or the experience to identify and control their biases when providing counselling. Consequently, counsellors need time and support to explore their own attitudes towards sexual issues and how these may affect their skills. Identifying and understanding their own biases would help to improve their impartial counselling skills (IPPF 2002c: 8). The document therefore cautions counsellors to be aware of their own attitudes and try to keep them to themselves in order to provide, as much as it is possible, value-free information to those they counsel.

When offering their services, it is important that counsellors are aware of their biases, but it is also important that they find a common language in which to disseminate the information to people. In an effort to provide all people with useful information, the IPPF document encourages the counsellors to use a language that the clients can

understand easily (IPPF 2002c: 39). Furthermore, to allow for cultural sensitivity, the document remains culturally neutral. It allows counsellors the liberty to tailor the presentation of the information depending on the religious and political atmosphere of a given country. For example, a section of the document "... provides some pointers on common issues for counsellors working with different groups in various cultures. You need to learn about your local situation by listening to clients and learning from groups in the community as well as through reading, the Internet and collaboration with specialist agencies" (IPPF 2002c: 10). It encourages counsellors to be aware of the various cultures they may be working with and to educate themselves about their differences (IPPF 2002c: 14). In addition to culture, the training document encourages counsellors to learn about the groups of people they might service, such as adolescents, homosexuals, sex-workers, etc. (IPPF 2002c: 10).

Finally, in order to be aware of discriminatory practices that may affect the distribution of information, the IPPF training document encourages counsellors to become informed about the specific gender 'situation' in the geographical area in which they are working.

National laws may promote greater equity between men and women and positive sexual and reproductive health practices. These laws may be different from local norms related to culture, religion and class. The law may state that girls should not marry until they are 18 years old but local culture promotes marrying girls after puberty to avoid premarital sex. Universal human rights and sexual and reproductive rights include the right to life and to bodily integrity and making our own decisions about sexual activity, marriage and having children. (IPPF 2002c: 20)

Once counsellors are aware of their biases, local language(s), cultures and groups of people, they are in an excellent position to provide information to people. However, it is extremely important that, in order for it to be influential, the information that counsellors are providing is accurate and up to date (IPPF 2002c: 8). IPPF is very aware of how quickly information is changing on issues related to sexual and reproductive health, especially HIV/AIDS, and it tries to respect the Right to the Benefits of Scientific Progress (IPPF n.d.b: 23) by keeping its counsellors updated with new and accurate HIV information as often as possible, but this can be difficult in resource poor countries where access to information is limited.

By offering people a chance to receive counselling, IPPF encourages the right to informed decision making. Generally, people living in resource poor countries do not have the time, opportunity or money to seek information from various sources. Clinics such as family planning associations allow people to get the information they need to make decisions about their sexual and reproductive lives, including issues related to vertical transmission of HIV.

HIV/AIDS education and counselling is a top priority of IPPF. They firmly believe that sexual and reproductive health counselling should not only include discussions about the disease and treatment, but should also include a recommendation for HIV testing (IPPF 2002c: 34). As a result, the training document offers considerable information on HIV testing, including how the tests work (antibody versus antigen testing) and which tests are used (ELISA versus Western blot versus rapid testing) (IPPF 2002c: 34). However, the document offers very little information on false negative and false positive results, other than to concede that this does happen, and when it does, could lead to

unnecessary worry (IPPF 2002c: 35). The document even stresses the importance of offering this information in a language that the clients will understand (local language as opposed to scientific language) (IPPF 2002c: 39). This supports IPPF's human rights view that all people should have the right to accurate information, including it being provided in a language that they can understand. "Find language which makes the meaning of the test clear to clients. If they are not from a scientific background explain HIV and antibodies in a local way" (IPPF n.d.b: 18).

In addition, IPPF stresses that testing is voluntary and no one should be forced to take an HIV test or to get its results (IPPF 2002c: 9). The document states that counsellors should "Never persuade or pressure clients to have an HIV antibody test. For any individual, the disadvantages of doing this may outweigh the advantages, particularly if testing facilities are poor or they are not in a powerful position in the family" (IPPF 2002c: 36). Getting tested for HIV is a choice, and IPPF believes that the ability to make an informed choice can only come once the right to information and education is provided to all people.

Unfortunately, a choice to get tested for HIV is sometimes not realistic in resource poor countries. Though HIV testing has become a lot simpler and less expensive, it is not available everywhere. The same fiscal and logistical problem applies to the use of antiretroviral drugs. This may explain why the IPPF training document does not provide much information about the use of ARVs to reduce the risk of mother-to-child transmission. The IPPF training document states that ARVs can be used relatively safely by HIV-positive women who are pregnant and by newborn babies (IPPF 2002c: 50, 52). According to IPPF, a short course of antiretroviral drugs may reduce the rate of vertical

transmission during pregnancy and labour to 10% (IPPF 2002c: 52). However, the training document heavily cautions about using ARVs by breastfeeding women.

“Mothers who have ARV treatment should not breast-feed their infants because the drug goes into her breast milk and may harm the baby. The feasibility and safety of alternative infant feeding in the mother’s particular circumstances may determine whether she decides to have ARV treatment” (IFFP 2002c: 52). Unfortunately, the document does not make it clear why it is safe for a pregnant woman and her newborn baby to receive ARVs, but it is not safe for a breastfeeding woman or a breastfed child.

Regardless of whether or not a pregnant woman or a new mother chooses to get tested for HIV, use ARVs, breastfeed or use replacement feeding, the IPPF document stresses the importance that choices can only be made once a woman receives all possible information regarding MTCT of HIV. However, even with all the information at her disposal, a woman may not, because of social pressures, have the freedom to put into action the choice that she prefers.

Social Issues

The social stigma associated with HIV/AIDS is a very real and a serious concern for those who know or suspect that they are HIV-positive. “People with a positive result may lose their marriage, children, home and job if others get to hear about it. Women are very vulnerable, they may be isolated, beaten and stigmatised, with severe long-term effect on their well-being and family lives” (IFFP 2002c 35). The counsellors who created the IPPF training document are aware of the potential risks associated with divulging this information to family and community. In order to protect their patients, health workers

are encouraged to counsel them about the problems that could arise from informing others about their positive HIV status, and stress that "It is very important that they do not tell anyone without thinking about it carefully because of stigma" (IPPF 2002c: 36). The document even recommends that HIV-positive women should consider breastfeeding if the anticipated stigmatisation is too severe (IPPF 2002c: 54).

By offering a variety of health services, IPPF may help to prevent HIV/AIDS stigma (IPPF 2002c: 6), and, consequently, protect a client's privacy (IPPF 2002c: 9), and, thereby, securing peoples' Right to Privacy (IPPF n.d.b: 16). If clinics only offered HIV/AIDS information and care, all people going into the clinic would be potential targets for discrimination. Offering a package of different health services might prevent stigma (IPPF 2002: 6). People seeking any type of sexual and reproductive information may be more comfortable entering a clinic that offers a holistic approach to sexual health care. In addition, IPPF counsellors are used to dealing with more sensitive, intimate issues as they counsel people on issues surrounding sexuality, and may be better suited than other health workers in gaining the trust and respect of people who need their help.

IPPF also believes that privacy or confidentiality issues are ethical issues and should be taken very seriously by counsellors working with people in areas of high HIV/AIDS prevalence (IPPF 2002c: 9). Counsellors need to discuss with clients all aspects of the social ramifications involved with divulging their HIV status. The negative aspect of encouraging privacy and confidentiality is that the longer people conceal their HIV-positive status, the longer the stigma associated with it is perpetuated. There is also the likelihood of further transmission of HIV as people deny or ignore their positive status.

Unfortunately, the HIV/AIDS stigma is generally directed towards women, who are often blamed for bringing the disease into the family, regardless of whether they did or not. In the hope of combating the stigma of HIV as a woman's disease, IPPF suggests that HIV testing not be conducted at antenatal clinics. The testing should be performed at IPPF/FPA or health clinics (IPPF 2002c: 52). HIV testing at antenatal clinics might contribute to the idea that HIV/AIDS is a woman's disease, which could lead to further negative stigma associated with women and with the disease. IPPF's fight against the HIV/AIDS stigma reflects its belief in the Right to Equality, and to be free from all Forms of Discrimination (IPPF n.d.b: 14). It hopes to reduce the stigma surrounding HIV/AIDS and any form of discrimination, regardless of gender or HIV-status, by providing all people with all the same information, and at the same location.

Summary and Conclusion

International Planned Parenthood Federation's mandate is based on both human rights and liberal ideologies. It demands access to information and the right of all people to enjoy good sexual and reproductive health. By combining their mandate and Charter with various human rights documents, IPPF promotes its liberal views in countries that have ratified human rights documents and are legally bound to respect them. "Many provisions in international conventions quoted in the Charter are obligations that governments have entered into and to which they can be held accountable" (IPPF n.d.b: 9). By working within this framework, IPPF can guarantee acceptance of their mandate and continue to inform people about their sexual and reproductive rights. In countries that have not signed human rights documents or continue to deny/abuse human rights,

IPPF liberal ideology encourages family planning associations and people in the community to lobby for change that would allow people to have access to information and be made aware of choices.

The IPPF training document truly respects its human rights perspective. An examination of the social issues surrounding vertical transmission clearly demonstrates how human rights are promoted in IPPF's training document. For example, the Right to Information and Education, states that all people are entitled to be adequately and accurately informed on matters that affect their health, as well as their families (IPPF n.d.b: 18). The IPPF training document respects that right by not making a distinction between the information it provides to HIV-negative, HIV-positive parents, and those whose HIV status is unknown. It provides all people with the most comprehensive and accurate information it can. IPPF is not concerned about the spill-over effect of providing HIV-negative or HIV-unknown women with information regarding infant feeding methods alternative to breastfeeding because they understand that an HIV-negative woman seeking information on infant feeding options, today, may become infected with the virus tomorrow. If a mother already has all the information on infant feeding options and the risks and benefits associated with them, she will be able to make a decision if her HIV status or her current situation changes.

Throughout the document, IPPF emphasises the fact that infant feeding practices are a woman's choice, and she should be supported in her choice. While it does mention that breast milk has more nutritional value than other forms of milk, it does not ascribe negative associations to them, staying true to its liberal leanings and strong belief that all

people should have the right to make any decisions regarding themselves and their families.

While some of the chapters within the document do not make reference to mother-to-child transmission, the whole of the document still provides useful information on HIV/AIDS, breast milk and HIV testing. However, the document might be more useful if additional information was given, for example, on nutrition, how to modify non-human milk, and the use of antiretroviral drugs. Given the limited time and financial resources of the vast majority of people in resource poor countries, IPPF cannot assume that people will have the opportunity to visit both antenatal and reproductive health/family planning clinics. A training document should, therefore, be as comprehensive as possible. People need to be aware of how the foods and medicines (drugs, supplements) they ingest might affect them; especially mothers who choose to breastfeed their babies.

The next chapter will introduce and analyse the mother-to-child transmission of HIV training document produced by the Population Council. The structure of the chapter will mirror both this and the preceding chapter.

CHAPTER 7

POPULATION COUNCIL

Prevention of mother-to-child transmission of HIV: A short course for health workers providing PMTCT services in areas with limited resources and high HIV prevalence

The final organisation to be examined is the Population Council. This chapter introduces the Population Council, as well as its mandate, structure and objectives. Using a General Analysis, this chapter examines which concepts have influenced the Population Council. The next part of this chapter, the Specific Analysis, examines how these concepts have directly influenced the information that the Population Council provides to parents in resource poor countries on mother-to-child transmission of HIV.

Introduction to the Population Council

The Population Council was established in 1952 by John Rockefeller III. It is an international, not for profit organisation that strives to "... improve the well-being and reproductive health of current and future generations and to help achieve a humane, equitable, and sustainable balance between people and resources" (Population Council n.d.a). In order to help meet this broad mission, the Population Council has been conducting research in the areas of biomedical, social science and public health for the past 50 years.

The Council is unique in combining excellence in demographic studies, operations research, technical assistance, basic research on reproductive physiology, and the development of new contraceptives. In addition, the Council helps to improve the research capacity of reproductive and population scientists in developing countries, through grants, fellowships, and support of research centers. (Population Council n.d.a)

The Population Council hopes that the information produced by this type of research will encourage people to reflect upon and improve various situations or problems related to reproductive health and population growth (Population Council n.d.a).

The Population Council, and its Centre for Biomedical Research, is headquartered in New York City. It also has an office in Washington, D.C., which manages the STI/HIV prevention programs. In addition, the Population Council does work in over 70 countries (most of them resource poor) and employs 600 staff members. It is governed by a board of trustees comprised of leaders in research, policy development and business from various countries¹⁸ (Population Council n.d.a).

In 2002, the Population Council's expenditures totalled US \$74.2 million (Population Council 2002a: 37). Fifty-one percent of its budget was received by the USA government; 5% from other governments (Canada, Denmark, the Netherlands, New Zealand, Norway, United Kingdom); 4% from multilateral organisations (European Union, UNAIDS, UNICEF, UNFPA, World Bank, WHO); 24% from foundations, corporations, NGOs (such as International Planned Parenthood Federation) and individuals; and 16% from internal funds (Population Council 2002a: 38). These funds were mostly used for program services (84%). The remainder was used for administration, investments and fundraising (Population Council 2002a: 38).

The majority of the funding that the Population Council, and its various programs, receives is from the USA government, or more specifically, the United States Agency for International Development (USAID). USAID is the government department which provides global economic development and humanitarian assistance to other countries

based on US foreign policy goals¹⁹. “U.S. foreign assistance has always had the twofold purpose of furthering America’s foreign policy interests in expanding democracy and free markets while improving the lives of the citizens of the developing world” (USAID n.d.a). It partners primarily with NGOs, other governments, universities, international agencies, and with over 3,500 American companies (USAID n.d.a).

USAID’s commitment to improving global health includes confronting global health challenges through improving the quality, availability, and use of essential health services. USAID’s strategy for global health seeks to stabilize world population and protect human health through programs in maternal and child health, HIV/AIDS, family planning and reproductive health, infectious diseases, environmental health, nutrition and other life-saving areas. Global health issues have global consequences that not only affect the people of developing nations, but also directly affect the interests of American citizens. (USAID n.d.b)

USAID suggests that HIV/AIDS is not only a humanitarian issue, but also one that threatens global economic growth and stability (USAID n.d.b). Consequently, it has committed over \$ 3.2 billion since 1986 towards HIV/AIDS prevention and care (USAID n.d.c). As a result of this generous undertaking, USAID believes itself to be “... the world leader in responding to the HIV/AIDS crisis in the developing world. USAID and its partners implement prevention, care and support, and research activities in more than 50 of the hardest hit countries and in a number of technical areas, such as behavior change, communications, voluntary counselling and testing, and children affected by AIDS” (USAID n.d.d).

¹⁸ Of the 17 members of the board of trustees, 10 are from the USA, 2 from Europe, 2 from Africa, 1 from Asia, 1 from the Middle East and 1 from Mexico.

¹⁹ USAID receives its foreign policy direction from the Secretary of State (USAID n.d.d).

One of USAID's primary focuses is the treatment of HIV/AIDS patients with antiretroviral drugs (USAID n.d.c). USAID is confident that new developments in ARV research (i.e., simpler dosage) and a dramatic reduction in the price of the drugs will allow them to provide drug treatment to millions of people infected with HIV/AIDS, especially women of child bearing age. Though USAID claims its aim is the prevention and treatment of HIV/AIDS, there is a sense that economic factors also play a big role in their focus on ARVs. Because of USAID's interest in the use of antiretroviral drugs for the prevention of HIV infection, and the potential success of using ARVs to reduce the rate of vertical transmission, it is logical that USAID has an interest in vertical transmission programs. Supporting such programs may give USAID the opportunity to promote the use of certain antiretroviral drugs by pregnant women. This may be the case for the Population Council's Horizons Program, which produced the Kenya Prevention of Mother-to-Child Transmission (PMCT²⁰) Project counsellor training document used in this study.

Horizons Program

In 1997, the Population Council's International Programs Division implemented the Horizons Program to help in the fight against HIV/AIDS, and, its effects in and on resource poor countries, by producing documents and administering projects geared at reducing the rate of transmission. To accomplish this, Horizons has partnered with other international organisations, as well as with national and local groups around the world. This collaboration has enabled Horizons to develop more than 60 AIDS related research

²⁰ The acronym for the Horizons Program Kenya Prevention of Mother-to-Child Transmission (PMCT) Project does not include two Ts, such as MTCT.

projects to improve HIV/AIDS service delivery in resource poor countries (Population Council n.d.f).

Among Horizons' response to the HIV/AIDS pandemic is its commitment to "... identify, support and enhance sustainable and cost-effective responses that ... work toward the prevention of mother-to-child transmission of HIV" (Population Council n.d.f). One of the tools created to help reduce vertical transmission is the Kenya PMCT Project, which is a training document for health workers providing prevention of mother-to-child transmission information to counsellors in resource poor areas with a high HIV prevalence. This particular kind of training document was produced because:

A needs assessment was carried out among health workers and communities at the beginning of the Kenya PMTCT project. It identified gaps in health workers' knowledge and practice related to preventing mother-to-child transmission of HIV, maternal and infant nutrition, counseling and health education. In April 1999, a team of experts from eastern and southern Africa developed the curriculum for a course designed to fill these gaps. The team included experts on MTCT of HIV, nutritionists, counselors, adult educators and policy-makers. (Population Council 2002b: viii)

The Population Council training document is very useful for the discourse analysis of this study, which examines the mother-to-child transmission of HIV information given to parents in resource poor areas. Unlike WHO/UNICEF/UNAIDS and the International Planned Parenthood Federation training documents, which were produced more generically, the Population Council training document was produced specifically for Kenya. The Specific Analysis of this chapter will provide more information on the Population Council's training document and the information it provides.

Following the model used in the two previous chapters, this next section shows, using a General and Specific Analysis, which concepts have influenced the Population Council's mandate and objectives, and the information they provide in their counsellor training document.

General Analysis

The Population Council's is heavily influenced by western concepts. The first section of the General Analysis examines how the liberal feminist ideology has influenced the Population Council's mandates and objectives. This is followed by a section on scientific positivism, which demonstrates how the belief in the superiority of western-based scientific knowledge has also influenced the mandate of the Population Council. Finally, the last section of the General Analysis shows how economic factors have also influenced the mandate and objectives of the Population Council.

Liberal Feminism

It is not surprising that feminist ideology has influenced the Population Council's mandate and objectives, as the Population Council conducts research on a wide variety of gender and reproductive issues, in the hope of improving the status of women and the quality of family planning in resource poor countries (Population Council n.d.g). It is evident that liberal feminist ideology influences the Population Council's mandate and objectives.

There is possibly no greater liberal feminist concept than birth control. Birth control is about choice: the freedom to decide if and when to have children. Birth control is also

about women having control over their reproductive abilities. Liberal feminists believe that women have long been oppressed because of their reproductive abilities, and have been 'banished' to the private realm, where their role is to have babies and take care of the home. Birth control enhances women's opportunities to become part of the public sphere, the private sphere or both.

Since its inception, the Population Council has conducted considerable research into the development of contraceptives and other products that would improve the reproductive health of people in resource poor countries (Population Council n.d.a). In addition, "...the Population Council's Gender, Family, and Development (GFD) program has fostered exploration of how gender and power imbalances between men and women affect reproductive and sexual decision making behavior, care seeking, safety, and well-being" (Population Council n.d.d). The Population Council acknowledges the fact that gender discrimination severely affects women, especially in resource poor countries. By offering women choices and services, the Population Council hopes to improve the position of women within the private and public spheres, and create a more equal society.

By offering examples of the liberal feminism found within the Population Council's mandates and objectives, it is clear that they are influenced by feminism. However, this is not the only western concept that influences them. Scientific positivism is also apparent within the information provided by the Population Council.

Scientific Positivism

The concept of scientific positivism was introduced in Chapter 2. This concept assumes that western scientific knowledge is superior to all other knowledge, because it

is based on observed phenomena, and should, therefore, be universally promoted. Many societies accept science as 'truth' and base their practices on scientific information.

There are, however, two major problems with science, and both are related to power: Scientific data and language are exclusionary, and scientific data can easily be manipulated in order to support a particular theory or a desired outcome.

Scientific knowledge is exclusionary primarily because it uses complex, scientific language to control knowledge. Consequently, scientific information is generally only accessible to those trained within a western model of education. Power polarisation occurs, or is re-enforced, as a result of this disequilibrium of knowledge. The power created by controlling scientific discourse effectively keeps all who are not scientists at the dependence of those who are. Science also follows a universalistic view by assuming that the knowledge it produces is relevant to everyone, regardless of cultural situation or gender. This may create a situation where people who are receiving the information are not able to comprehend it within their local framework.

The approach used by the Population Council is based on biomedical research and on scientific discoveries. As a result, the documents and training information it produces are extremely scientific, most likely making it difficult to comprehend for anyone who is not scientifically (or western) educated. For example, the Population Council website offers an abundance of biomedical information concerning contraceptives, microbicides, reproductive biology, immunology, etc. The Population Council unnecessarily complicates the transfer of knowledge it produces with the result that it limits those who can gain easy access to the information.

The question is why would the Population Council/Horizons Program produce information that is so exclusive? Perhaps it hopes to steer people towards adopting certain actions, such as breastfeeding. This may be why it promotes breastfeeding by using positive language to describe the benefits, while using negative language to inform mothers on alternative infant feeding practices. If the information presented is too complex, there is a significant chance that counsellors will misinterpret the information or only provide certain basic facts to those who seek it. This will inevitably influence the decisions people make. For example, a recent Horizons project survey indicated that 28% of women who sought information regarding infant feeding options, felt that breastfeeding was being promoted by the counsellors (Population Council n.d.f). This means that almost a third of women could tell that they were being provided with biased information. Many may not even realise that this is happening. While most counsellors are probably providing biased information unconsciously, some may be doing it intentionally.

Those with money and power have the ability to reflect positively on some results or information and negatively on others, thereby promoting their own interests, be they monetary or other. Scientific knowledge and data can easily be manipulated by those who control such information. Thus scientific knowledge should never be accepted without first examining who produced it, and why. When the task of producing information is left to a select few, there is concern that what is being produced is not necessarily what is best for all people, but what is best for whoever is producing it.

Those who fund scientific research often have an economic interest in the results it produces. "In 1956, the Population Council obtained a grant to establish its own

biomedical research laboratory at the Rockefeller University. In this way the Council could help *influence* research in fertility regulation by providing facilities where young people could be trained and collaborative work carried out with established investigators” (italics added, Population Council n.d.c). The use of the word ‘influence’ may raise some concerns about how, why and to what degree the Population Council wishes to influence research conducted in its facilities. It is a safe assumption that the Population Council is fiscally concerned with the type of research and products it develops. “Biomedical researchers at the Population Council also conduct fundamental research on reproductive and immunological processes. This provides the knowledge base upon which applied research and successful product development are built” (Population Council n.d.b). By researching and gathering particular information, the Population Council can determine which area of study or which product development will be the most financially rewarding for them. And even though the Population Council is technically a not-for-profit organisation, it is heavily involved with companies and government departments who are for profit. By helping them make money, the Population Council can count on continued funding from them.

Economic Factors

Economic factors influence the information provided in the Population Council’s Kenya prevention of mother-to-child transmission of HIV training document. For the Population Council, it appears that health care and research is, to some degree, more about money for their funding partners than about people. A prime example of how

focused the Population Council is on the financial aspects of research is how they compare the health care crisis with the marketing of a new product.

Introducing a new idea or product is a challenging task for industries all over the world. Companies invest large amounts of money to ensure that their product hits the market and is purchased to recover both production and marketing cost before they can even think of a profit. In the health arena, new disease and challenges hit society all the time. Scientists and health care providers are expected to inform communities of the new problems and the solutions and ensure that these are adopted to reduce loss of lives. Unlike in industry, where the purchaser can see immediate benefits, health professionals have to convince communities that a problem exists and ensure that the community adopts preventive and curative practices. (Population Council 2002b: module 5 – 5)

In order to keep up with current fiscally beneficial trends, it appears that the Population Council may be shifting away from its interest in contraceptive research and production towards a focus on the prevention of HIV/AIDS transmission through use of antiretroviral drugs. “The Council strongly believes that access to ARVs is critical in the prevention of HIV/AIDS” (Population Council n.d.e). As noted above, the Population Council is funded in part by USAID, which receives its funding from the Global HIV/AIDS Strategy. The USA government released the objectives of this strategy, which is based on USA foreign policy of economic development, in March 2004, confirming the trend in research and development of antiretroviral drugs. The strategy lays out how the USA will spend \$15 billion within the next five years on HIV/AIDS prevention and care (CHANGE 2004: 3). The document specifies that fifty-five percent of the total Global Strategy budget will be dedicated to HIV/AIDS prevention and care through antiretroviral treatment (CHANGE 2004: 11).

However, this focus on HIV/AIDS prevention and drug treatment raises questions as to whether or not these American policies have in mind the best interest of people living with HIV/AIDS, or that of the pharmaceutical companies and MNCs. Critics have raised concerns about the USA government's dedication of over \$7 billion to the use of antiretroviral therapy, and whether this is the best way to spend the money.

[D]espite the appropriation by Congress of funding for ARVs, huge gaps will remain between the number who need treatment to live, and those who will have access to treatment in a timely manner. Therefore, the expansion of treatment access with U.S. funding also raises critical questions about efficiency and equity in the delivery of ARV therapy including questions about how and under what conditions access will be determined, and how efficiently available funds are spent. (CHANGE 2004: 11)

There is also concern that the USA government is filling the coffers of big companies, especially since they are only approving the purchase of brand-name antiretroviral drugs from large pharmaceutical companies, and not the generic drugs which are as effective, and much cheaper (CHANGE 2004: 12). Not only is USA policy strongly encouraging the use of brand name ARVs, but they are also trying to discredit generic drugs (CHANGE 2004: 11). The Administrator of the Global HIV/AIDS Strategy, Randall Tobias, has publicly stated that the safety of generic ARVs cannot be assured, and that the USA would not purchase them (CHANGE 2004: 12). This statement was made despite the fact that the generic drugs have been approved by the WHO and donor organisations (CHANGE 2004: 12). "By raising doubts about the 'standards by which to judge efficacy and safety' the United States appears to be trying to deflect the real issues of generic versus branded drugs and of protectionism towards the U.S. pharmaceutical industry..." (CHANGE 2004: 12).

Though the costs of brand-name ARV drugs have decreased in the last few years, they are still much more expensive than generic drugs (CHANGE 2004: 11). As a result, fewer drugs can be bought and made accessible to people living with HIV/AIDS (CHANGE 2004: 13). What worries critics is that, if fewer ARV drugs are available, who decides who will receive them?

With limited resources, choices will inevitably be made about who will be treated and when, raising the issues of equity in access to treatment for sub-groups of those infected. Given that stigma and discrimination already pervades all aspects of prevention, treatment and care there is a need for efforts to ensure that treatment programs reach vulnerable groups ... which, due to social, economic, and cultural discrimination and lack of access to health care, already face a disproportionately higher risk of infection. (CHANGE 2004: 14)

While, helping people in resource poor countries may have no apparent monetary value to the USA government, supporting MNCs has huge monetary rewards. By concentrating mostly on a capitalist economy, the USA government is more concerned with making money for its pharmaceutical industry, than it is with lives of millions of people who could benefit from generic ARV drugs.

While the Global Strategy, calling for the use of antiretroviral drugs, did not influence the Population Council training document, which was produced in 2002, it confirms the fact that the USA government, as well as many American based multinational corporations, have a particular interest in the research and development of ARV drugs. From the studies it produces or supports, the Population Council is already recommending the use of Nevirapine as an effective way to reduce the rate of vertical

transmission. Nevirapine is produced in the United States by Roxane Laboratories (Boehringer Ingelheim n.d.).

The training document, which will be further examined in the Specific Analysis, may indicate the beginning of the influence USA antiretroviral drug policies have on the Population Council. Now that the Global Strategy has official announced the USA government's focus on ARV drugs, it is to be expected that the Population Council will continue to increase its work in this area.

The General Analysis above reveals that the Population Council is influenced by feminist ideology, scientific positivism and economic factors. The following section looks more closely at specific examples within the Population Council training document that reflects these concepts, influencing the information it provides to counsellors and parents.

Specific Analysis

The last of the three training documents analysed in this study is the *Prevention of mother-to-child transmission of HIV: A short course for health workers providing PMTCT services in areas with limited resources and high HIV prevalence*. It was produced by the Population Council, and supported by the Horizons Program, in order to help health workers prevent vertical transmission of HIV.

The document was developed following an assessment of needs, pilot tested and then revised based on the feedback given by the trainers who implemented it. Over 500 health workers throughout Kenya have been trained using this document from January 2000 to the end of 2001 (Population Council 2002b: viii). Though the document is primarily

aimed at certified health workers (nurses, mid-wives, doctors, clinical officers) it recognises that these people are rare in resource poor countries, and that a lot of clinics employ lay counsellors and health workers instead.

From the beginning, the document acknowledges the fact that the volatile nature of HIV will pose a problem in providing up to date information to people. “The area of [prevention of mother-to-child transmission] is changing very fast, and this course will certainly change in structure, content and duration. The intent is that this first edition, published in 2002, will be revised periodically” (Population Council 2002b: ix). As it stands now, the Population Council training document provides important information on the vertical transmission of HIV, and the various themes that surround it, specifically mother-to-child transmission issues, procedural issues, and social issues. The following section will look at the information provided within these themes, and demonstrate how the liberal feminism, scientific positivism and economism concepts, which were discussed above, have influenced the information the Population Council provides in its prevention of mother-to-child training document.

Mother-to-child Transmission Issues

The Population Council’s prevention of mother-to-child transmission document is highly specific. It provides a plethora of information on almost everything related to MTCT of HIV. In particular, it goes into great detail about maternal nutrition and HIV/AIDS (Population Council 2002b: module 2). Extensive scientific information is given on *all* micronutrients necessary for a well-balanced diet (calcium, magnesium, phosphorous, iodine, etc.) as well as *all* the vitamins (A, B, C, D, E, K), which play a role

in maternal nutrition. A background in biochemistry would be useful to decipher all of the information presented in this document. The quantity and degree of information presented is far too complex for a lay counsellor or other non-medically trained staff to comprehend. As presented, the scientific information seems to exclude the very people that would benefit from a better understanding of HIV and vertical transmission, such as law counsellors and parents making infant feeding decisions.

Interestingly, and perhaps due to the volume of information, the training document contradicts itself at times. For example, varying information concerning vitamin A deficiency and mother-to-child transmission is provided. One section of the document claims that vitamin A deficiency increases the rate of MTCT (Population Council 2002b: module 1, 11²¹), and that supplements of not more than 20,000 IU should be part of routine antenatal care (Population Council 2002b: module 1, 40). Another section of the document claims that studies have shown that vitamin A supplements have failed to reduce vertical transmission (Population Council 2002b: module 2, 39). Still another unit states that vitamin A supplements may actually increase the rate of transmission of HIV and cause birth defects if more than 10,000 IU are given (Population Council 2002b: module 2, 22). Its final recommendation is that vitamin A supplements for pregnant or lactating women should not exceed 5,000 IU (Population Council 2002b: module 2, 22). Such contradictions may not only confuse health workers, but also the parents relying on information to make choices regarding vitamin supplements and infant feeding. This particular information is extremely important to HIV-positive mothers who are deciding if they should feed their baby's breast milk.

²¹ The Population Council training document is separated into 5 modules, each beginning pagination at 1. For example, the citation "module 1, 15" refers to module 1, page 15.

The training document also provides a very detailed and complex module on the biochemical composition of breast milk (Population Council 2002b: module 3). Such detailed scientific information unnecessarily complicates the training document, and, thus, the diffusion of important information. There is a whole section of the document dedicated to the composition of breast milk (Population Council 2002b: module 3, 5) and the immunology of breast milk (Population Council 2002b: module 3, 25). Topics such as water, lipids, cholesterol and sugar content of various milks are discussed (Population Council 2002b: module 3, 5 - 24). Not only that, but each component of breast milk is further analysed. The document teaches the concept of fatty acids such as linoleic, linolenic, arachidonic and docohexanoic acids, as well as their functions (Population Council 2002b: module 3, 11). Again, a background in science would help to understand the information presented. Despite the use of complicated scientific terminology and concepts, the Population Council remains optimistic that “[b]y the end of this unit the learner should be able to discuss the immunology of breast milk” (Population Council 2002b: module 3:31). The health workers or counsellors might be able to discuss some of the information regarding breast milk, such as the basic immunological benefits of breastfeeding, but will probably not be able to discuss all the details at length, especially if they are ‘lay’ counsellors.

Despite the fact that there is an abundance of information on breast milk, it is critical to recognise that the training document provides little information about colostrum, other than how it is beneficial to the baby and how breastfeeding should begin as soon as possible after the birth (Population Council 2002b: module 2, 53). There is no direct mention of the potentially harmful effects of colostrum on a baby if it is produced by an

HIV-positive mother. However, the training document does note that “[m]ost transmission takes place in the first 6 weeks of the infant’s life” (Population Council 2002b: module 1, 12). It is possible that women who know this may choose not to give their baby’s colostrum, or any breast milk at all.

If an HIV-positive woman chooses to breastfeed her baby, the document mentions the possibility of heat-treating breast milk in order to kill the virus either by bringing the milk to a boil and then cooling it precipitously or by using Holder’s pasteurisation, in which breast milk is heated to at least 56C for 30 minutes (Population Council 2002b: module 3, 40). Though this temperature has been shown to kill HIV, the accepted procedure states that the breast milk should be heated at 62.5C for 30 minutes (Chantry 2000).

For HIV-positive women who choose not to give their baby’s breast milk, the document offers a considerable amount of information about other types of non-human milk supplements appropriate for a baby’s consumption (Kenya 2002: module 3). Though the document clearly supports breastfeeding as the ideal infant feeding practice, it also acknowledges that it is not best in all situations. It gives details about the risks and benefits associated with various infant feeding options, including modified animal milk and infant formula. The document stresses the importance of modifying non-human milk in order to protect the baby from metabolic distress caused by the disproportion of proteins, sugars and fats (Population Council 2002b: module 3, 17). “Use of non-human milk, especially unmodified cow’s milk, leads to metabolic stress in the baby because the baby cannot metabolize the high content of protein” (Population Council 2002b: module 3, 17). In order to educate parents on how to modify non-human milk properly, the course provides many details on how much water, sugar and micronutrients must be

added to the milk, depending on various stages of the baby's growth. The drawbacks of replacement feeding are also given in detail: the costs, the utensils needed, the accessibility, the preparation time, etc. (Population Council 2002b: module 3, 37).

It is critical to notice that, the guidelines state that this information should only be given to HIV-positive women, in fear of negatively influencing those that are HIV-negative and HIV-unknown. Unlike the Population Council's feminist mandate, this training document does not promote choice and liberalism. It uses its ability to withhold information to manipulate the knowledge it provides, thereby limiting, if not controlling, women's choices concerning infant feeding practices.

For example, the Population Council training document recommends breastfeeding in most situations, and praises the benefits of breast milk and breastfeeding for both the mother and the baby. "Breastfeeding is the optimum form of infant nutrition and should continue to be protected, promoted and supported" (Population Council 2002b: module 1, 23). It clearly states one of its main objectives is to instruct health workers on how to plan and implement antenatal programs that will encourage mothers to breastfeed (Population Council 2002b: module 2, unit 2) - as opposed to encouraging mothers to make appropriate choices for themselves and their families. According to the document, prenatal education should not include information on formula feeding or animal milk modification, but does list the risks associated with these types of feedings. "What should prenatal education include? It should emphasize the importance of exclusive breastfeeding. It should explain the risks of artificial feeding and use of bottles and pacifiers, soothers, teats, nipples. It should *not* include group education on formula preparation" (Population Council 2002b: module 2, 53).

Despite the document's breastfeeding bias, it does state the fact that HIV can be transmitted through breastfeeding (Population Council 2002b: module 1, 23).

Furthermore, credit must be given to this document for acknowledging, on more than one occasion, the potentially detrimental effects of breastfeeding on an HIV-positive mother.

Breastfeeding is a metabolically active process. Women require the equivalent of a whole extra meal per day to accommodate lactation. Under normal circumstances, the energy needs of lactation are accommodated by improved metabolic efficiency, increased nutrient intake, and breakdown of subcutaneous fat. If nutritional intake during pregnancy and lactation is inadequate, foetal growth and milk production go on at the expense of the woman's own nutritional status. (Population Council 2002b: module 2, 8)

A woman who is breastfeeding requires an additional 600-700 calories per day in order to maintain adequate energy levels (Population Council 2002b: module 2, 14).

Very few women in resource poor countries are able to meet these additional nutritional needs. Consequently, the mother becomes malnourished, which affects the quantity of milk production (Population Council 2002b: module 2, 15). In addition to being malnourished and having low energy levels, "[p]reliminary observations indicate that breastfeeding increases the likelihood of dying for HIV-infected women with advanced disease. It is thought that this could be due to nutritional depletion by breastfeeding and from the HIV disease" (Population Council 2002b: module 2, 15).

There are many complex issues surrounding mother-to-child transmission of HIV. Those who are HIV-positive or are at risk of becoming positive need counselling in order to receive information and make choices that best suit their situation. Counsellors play an extremely important role in providing mothers or parents with information on vertical transmission.

This next section will examine the procedures used in the fight against HIV/AIDS: counselling, HIV testing and use of antiretroviral drugs. However, it is important to remember that the success of counselling depends, in part, on the quality of information given to people, and the skills and competencies of the counsellors who rely on the training document for support.

Procedural Issues

The Population Council training document is used to teach health workers and counsellors how to provide information to parents in resource poor areas about HIV/AIDS and mother-to-child transmission. The document states that mothers and fathers need counselling in order to become aware of the risks and benefits associated with various infant feeding practices (Population Council 2002b: module 2, 83). Like the other sections of this document, the Population Council indicates that, after the completion of the unit on counselling skills, the counsellor will be effectively trained: “By the end of this module, participants will have basic knowledge of counselling skills and knowledge needed for voluntary counselling and testing for prevention of MTCT of HIV and will be able to supervise and support other staff” (Population Council 2002b: module 4, 5).

According to the document, counselling “... is a skilled system of helping individuals to explore personal issues for them to make decisions and put plans into action” (Population Council 2002b: module 4, 21). Basically the mother, or the parents, seeks information from the counsellors, who in turn teach them different decision making strategies and problem solving techniques (Population Council 2002b: module 4). People

must be given the information they need to be able to make informed decisions, and, in the case of HIV/AIDS, this information must be constantly up to date in order to be effective (Population Council 2002b: module 4, 54).

The training document recommends that parents making infant feeding decisions base their choice of which practice has the lowest risk for them and the baby. “Ideally the risk of giving replacement feeding should be less than the risk of HIV transmission. Priority should be given to the mother’s or the couple’s choice” (Population Council 2002b: module 3, 41). It is interesting that the Population Council chooses to include the latter sentence. Should infant feeding not always be the mother’s or couples choice?

Information and choice must be provided to all people. According to the document, “All parents irrespective of their HIV status have a right to choose the type of feeding for their child. Preferably they make this choice after they receive adequate information from health workers - that is, their choice should be an informed one” (Population Council 2002b: module 3, 37). However, in the very next paragraph, the document states that “[h]ealth workers should understand and be able to counsel on the different feeding options for HIV-infected women. They should be able to state the advantages and disadvantages and the costs while at the same time *not giving* this same information to HIV-negative women” (italics added, Population Council 2002b: module 3, 37). It claims that there is a strong possibility of a spillover effect. As discussed in relation to the WHO/UNICEF/UNAIDS training document above, the Population Council also suggests that if HIV-negative or women of unknown HIV status see HIV-positive women feeding their babies modified animal milk or infant formula, they will be influenced to do

the same. However, in one of its own evaluation documents, the Horizons Program states that this is a not an issue.

Some observers have expressed concern that PMTCT programs that discuss replacement feeding for HIV-positive mothers may inadvertently cause other mothers who do not know their HIV status to avoid breastfeeding. This evaluation found little evidence of this 'spillover' effect. In Kenya, less than 2 percent of women of unknown status ... report exclusive use of infant formula or other replacement feeds. This is similar to the very low proportion (less than 1 percent) of HIV-negative women at both sites who use replacement feeds. Thus, women of unknown HIV status living in areas with a PMTCT program are not disproportionately using replacement feeds. (Population Council n.d.e)

If spillover is not actually a reality, then the document should not encourage the segregation of information. Basically, the document teaches counsellors to be selective in the information they provide. HIV-positive mothers are to receive certain information, while HIV-negative and HIV-unknown mothers are to receive different information. How can this segregation of information possibly allow all mothers, or all parents to make informed decisions?

From the outset, it is understood that this course is *primarily* for the use of certified health professionals, such as nurses and midwives. The document claims that is why the information is presented in a very scientific manner. "Counsellors must be adequately trained to provide HIV counselling, given the sensitive and challenging nature of their work. The health workers selected for VTC for MTCT intervention course should either undergo or have undergone a counselling course of at least certificate level" (Population Council 2002b: module 4, 9). Additionally, the course states "Counsellors are trained in the theories of counselling and are perceived by both recipient and themselves as the

recipient's counsellor" (Population Council 2002b: module 4, 21). However, the course also states that a counsellor "... is anyone who intentionally takes on the role of HIV counsellor" (Population Council 2002b: module 4, 25) and that the majority of lay people who provide counselling have received only 20-30 hours of basic counselling skills and HIV awareness (Population Council 2002b: module 4, 26).

The Population Council document also recommends that regardless of whom the counsellor is, he or she needs to remain neutral and should not influence parents into making particular decision about infant feeding.

Counselors are first of all people and secondly they are counselors. They have their own weaknesses, strengths, fears, anxieties, doubts and certainties. All these can either hinder or facilitate their work with clients. Counselors must therefore continuously engage themselves in self-exploration to be aware of themselves, how others affect them, and the effect they have on others. (Population Council 2002b: module 4, 10).

Counsellors and health workers need to explore their own values, attitudes, fears and prejudices in order to avoid passing those on (Population Council 2002b: module 4, 84). Once they are aware of their values and opinions, they will be in a better position to offer unbiased information concerning vertical transmission of HIV.

There is a plethora of information on counselling and counsellors in the Population Council training document. The document teaches counsellors to provide the information using a western style of counselling. It encourages counsellors to sit close to the client, facing them and making constant eye contact (Population Council 2002b: module 4, 41). This type of counselling might be effective in some western countries, however, it may not respect the traditions of people from other cultures, who may not feel comfortable with such an approach.

The Population Council training discourse presents various infant feeding practices in positive and negative lights. While the document encourages counsellors to withhold some information on non-human milk preparations, it also uses negative language to describe non-human milk feeding practices. The training document uses positive discourse to promote breastfeeding. It provides information about artificial infant feeding practices in a negative language. For example, it states that “dreaded issues”, referring to the risks associated with non-human milk feeding practices, need to be raised with mothers who choose not to breastfeed (Population Council 2002b: module 4, 60). In another section, one of the module units is entitled “Management of the mother who chooses not to breastfeed” (Population Council 2002b: module 3: 48). The word ‘management’ carries a negative connotation, i.e., difficult people are ‘managed’ and controlled. Words such as ‘support’ or ‘assistance’ may have been a better choice.

Finally, the document raises the issue of the importance of accurate and up to date HIV information: Counsellors can suffer from inadequate expertise and a major source of stress is having to give information that is incomplete or that may later prove to be incorrect because of the rapidly increasing and changing knowledge about HIV/AIDS (Population Council 2002b: module 4, 79). The more accurate and up to date the information is, the more informed counsellors and those having to make critical decisions regarding infant feeding practices will be.

Despite all the information the document provides on breast milk components, proper breastfeeding techniques, counselling skills, etc., very little is said about HIV testing. The document only offers basic information about HIV testing. It briefly mentions that ELISA and Western Blot tests for antibodies, not virus, and that positive results are re-

tested using a second test if it is available. It cautions that false positive or false negatives occur (Population Council 2002b: module 4, 56). It also encourages mothers to be tested for the virus in order to be fully informed about their situation and, consequently, better able to make decisions that are best for them and their babies. It describes the advantages and disadvantages of being tested and of knowing the result (Population Council 2002b: module 4, 54). The training document also acknowledges the testing/treatment conundrum that occurs when testing is available but treatment, such as antiretroviral drugs, is not (Population Council 2002b: module 1, 43).

The use of antiretroviral drugs is an important issue within the training document. "It has been demonstrated that using antiretroviral drugs during pregnancy, delivery and early neonatal life is effective in preventing MTCT transmission of HIV" (Population Council 2002b: module 1, vii). The document also mentions, however, that there are limitations and risks associated with the use of ARVs. Most women of childbearing age in resource poor countries do not have access to, or the money needed to purchase, the drugs (Population Council 2002b: module 1, 43). The document also cautions about the volatile nature of antiretroviral drugs and the importance of remaining informed. It warns that more research and studies need to be conducted before ARVs are provided to all HIV-positive pregnant women as a drug resistance might occur in both mother and baby, making the control of HIV/AIDS symptoms more difficult. "Drug resistance has been reported in some women exposed to short-course antiretroviral regimens used for preventing MTCT. The implications of such resistance are uncertain and need to be considered in the context of increasing access to ARV treatment for patients in developing countries" (Population Council 2002b: module 2, 78). The training document

states that the recommendations for the use of antiretroviral drugs will continue to change as more information about its use and effects continue to be researched. As a result, the document emphasises that health workers and counsellors stay informed in order to provide parents with accurate and up-to-date information (Population Council 2002b: module 1, 23). However, these warnings may be replaced by a recommendation for the use of specific antiretroviral drugs if economic factors continue to influence the Population Council and their programs.

Social Issues

Very little information is provided in the Population Council's Kenya PMCT training document on the psycho-social aspects of HIV/AIDS and vertical transmission. The document concentrates on the physiological and medical dimensions of the disease and its transmission, consequently, little is said in this document about the social stigma associated with HIV. The document does not address the possible negative social effects of having HIV testing done at antenatal clinics, alongside other prenatal care. Rather, it encourages HIV testing and counselling at antenatal clinics (Population Council 2002b: module 1, 37) because mothers are already there for other health services. "Maternal and child health services are an entry point for [voluntary counselling and testing]" (Population Council 2002b: module 1, 33). It suggests that women may feel more comfortable getting HIV/AIDS information and counselling in a setting that focuses on them, and not on men. The document does not take into consideration the possible negative effects of providing women with mother-to-child transmission of HIV information and HIV testing in antenatal clinics. It fails to mention the stigma this might

create against women who are HIV-positive, despite the fact that one of the studies it supported showed that “[t]he pilot experience highlights how antenatal clinics are generally regarded as women’s spaces where men do not feel comfortable” (Rutenberg et al 2003: 28).

Summary and Conclusion

The Population Council’s training document offers an abundance of very specific, highly scientific information on most issues surrounding mother-to-child transmission of HIV. Though the document is primarily geared at certified health workers, it acknowledges the fact that in many cases, lay people are the primary counsellors at local clinics. Vital information is missing, however, and this might have an impact on the infant feeding decisions that parents make. For example, there is little said about colostrum, the harmful effects of breastfeeding, HIV testing, and about the social stigma associated with being HIV-positive.

The Population Council training document shows how liberal feminism, scientific positivism and economism have influenced the Population Council’s mandate and objectives, as well as the information it provides to the public through documents such as the training document. Liberal feminist thought influences the focus the Population Council has on contraception, gender issues and counselling. In addition, the Population Council’s belief in scientific positivism clearly comes through in the training document. The document has a massive amount of scientific information, and while it is geared towards trained counsellors, it does acknowledge the fact that it will generally be lay counsellors working within the community. Finally, the Population Council’s economic

interests are examined in terms of its research, development and distribution of antiretroviral drugs.

Chapters 5, 6 and 7 analyses the mandate and objectives of WHO/UNICEF/UNAIDS, IPPF, and the Population Council, as well as their training documents. These chapters bring together the information provided in Chapters 2 (concepts), 3 (HIV/AIDS and mother-to-child transmission), and 4 (key issues related to mother-to-child transmission of HIV) to produce a discourse analysis of the mother-to-child transmission of HIV information parents in resource poor countries regarding infant feeding options. The following chapter summarises the information provided in this study and answers the questions raised in the introduction: *What information is given to women about mother-to-child transmission of HIV? How does the conceptual approach to mother-to-child transmission, adopted by various organisations, affect the information that they provide to parents? Why is the mother-to-child transmission of HIV information in the three documents different?*

CHAPTER 8

SUMMARY AND CONCLUSION

Summary

This thesis examines the mother-to-child transmission of HIV information presented to parents in resource poor countries, and considers how various concepts influence the organisations that produce the information, and ultimately the choices people make regarding infant feeding practices.

While this thesis offers evidence that an informed choice may not be possible under certain circumstances, it does not aim to prove that all parents in resource poor countries are unable to make informed decisions regarding infant feeding, as this question is much more difficult to answer. Instead, the thesis endeavours to answer a question that becomes obvious when three counsellor training documents are analysed and compared: *Why is the mother-to-child transmission of HIV information in the three documents different?* Before this question can be answered two other questions must to be examined: *What information is given to women about mother-to-child transmission of HIV? How does the conceptual approach to mother-to-child transmission, adopted by various organisations, affect the information that they provide to parents?* Once these questions are answered it becomes evident why the information differs within the three training documents.

What information is given to women about mother-to-child transmission of HIV?

The three documents, *HIV and Infant Feeding Counselling: A training course*, (WHO/UNICEF/UNAIDS, 2000), *Programme Guidance and Counselling For STI/HIV Prevention in Sexual and Reproductive Health Settings: For Counsellors, Health Workers, Educators and All Those Working in STI/HIV/AIDS*, (IPPF, 2002), and *Prevention of mother-to-child transmission of HIV: A short course for health workers providing PMTCT services in areas with limited resources and high HIV prevalence*, (Population Council, 2002), were created in order to train health care workers with counselling skills and specific information related to the mother-to-child transmission of HIV.

All three documents offer some of the same, basic HIV/AIDS and mother-to-child transmission information, such as how the virus is transmitted, how breast milk is superior to replacement milks in most situations, how counselling is important prior to choice making, etc. However, not all documents provide the same amount or type of information. Chapters 5, 6 and 7 examine the information found in the three training documents regarding specific issues surrounding mother-to-child transmission of HIV: maternal nutrition, breast milk, other milks, breastfeeding, counselling, HIV testing, antiretroviral drugs, and social stigma. This information can be brought together under three broader themes, mother-to-child transmission issues, procedural issues, and social issues. These chapters clearly show how some of the organisations provide certain information about vertical transmission of HIV, while omitting other information. For example, all three documents state that breast milk is generally superior to other types of milk, but it is only the IPPF training document that emphasises a baby's need for milk of

any kind. Ironically, it also only the IPPF document which does not provide information on non-human milk modification.

HIV testing is another example of where information is lacking. Both the Population Council and the IPPF documents discuss the importance being tested for the virus before any infant feeding decisions are made. These two documents also provide some information about the various tests and the risks of getting false results.

WHO/UNICEF/UNAIDS's document does not discuss HIV testing.

Throughout the information analysis, these inconsistencies are evident. None of the three documents provided exactly the same information about issues surrounding mother-to-child transmission of HIV to counsellors, and, eventually, parents.

The Specific Analysis sections in the preceding chapters show what information is being provided to parents through the training documents and concludes that the information is inconsistent. The next logical question is: Why are there inconsistencies? The General Analysis sections of Chapter 5, 6, and 7 examine the various concepts that influence the organisations that produced these counsellor training documents in order to answer this question.

How does the conceptual approach to mother-to-child transmission, adopted by various organisations, affect the information that they provide to parents?

Chapter 2 introduces various theoretical concepts: scientific positivism, power, discourse, liberalism, and liberal feminism. These concepts have influenced, in varying degrees, the mandate of, and the information provided by WHO/UNICEF/UNAIDS, IPPF, and the Population Council. In addition, the thesis shows that human rights and economic factors have also influenced the organisations and the way they structure their

training documents. Chapters 5, 6 and 7 examine how these concepts and influences have determined the mandate of the organisations, as well as the information they provide to parents in resource poor countries regarding mother-to-child transmission of HIV.

This section summarises these concepts and shows how they have, in addition to human rights and economic factors, and in various combinations, influenced

WHO/UNICEF/UNAIDS, IPPF, and the Population Council and the information they produce.

It is obvious from all the information collected on WHO/UNICEF/UNAIDS that a belief in human rights has played a major role in the work these organisations have done around the world. Being part of the United Nations, they are expected to support and enforce the Universal Declaration of Human Rights, the Declaration of the Rights of the Child, and the Convention of the Rights of the Child. For example, WHO's Constitution states that all people have the right to the highest attainable standard of health, as well as the "... benefits of medical, psychological and related knowledge" (WHO 1946). In addition, a joint statement by WHO/UNICEF/UNAIDS clearly states that all people, irrespective of their HIV status, have the right to information and the ability to make their own choices (WHO 2000: 9).

What is interesting about the WHO/UNICEF/UNAIDS training document is that it fails to comply with some of the human rights articles, as well as some of the principles set out in the WHO's Constitution regarding access to information. For example, WHO/UNICEF/UNAIDS promote breastfeeding as the best option for all babies, unless a mother is severely ill, and she has access to safe replacement milk(s). As a result of this belief, WHO/UNICEF/UNAIDS purposefully limit the information they provide to HIV-

negative or HIV-unknown women, violating human rights articles concerning the access to education and equal treatment for all people. These women are only provided with counselling on the benefits of breastfeeding, and are not educated on alternative infant feeding practices, because WHO/UNICEF/UNAIDS claim that the chance of a spillover effect is too great, and HIV-negative or status unknown women will be influenced by information regarding non-human breast milk alternatives and will stop breastfeeding their babies. This type of counselling definitely limits the information some women are receiving, and, in a real sense, controls the infant feeding choice they will make.

In addition, in order to encourage women to breastfeed, WHO/UNICEF/UNAIDS uses its international reputation and the control they have over knowledge and language to accentuate the benefits of breastfeeding and risks of using non-human milks. WHO/UNICEF/UNAIDS have at their disposal the infrastructure to produce, and control, research and knowledge, and the ability to control people's access to the information. WHO/UNICEF/UNAIDS' doctrine of scientific positivism - the belief in the superiority of science - allows them to justify their control over knowledge and its production. This scientific positivism is clearly evident in the WHO/UNICEF/UNAIDS training document. The document focuses on the benefits of breastfeeding, and downplays the risks associated with it. It also discusses, at length, the risks associated with all other forms of infant feeding practices. WHO/UNICEF/UNAIDS' bias towards breastfeeding seems to supersede their support of human rights, or more specifically, rights to education, information, and informed choice concerning health. As a result, women who do not have access to other information, or who trust fully in the recommendations of WHO/UNICEF/UNAIDS, are not being given all the information about breastfeeding

and mother-to-child transmission of HIV, and, consequently, are not able to make an informed choice about infant feeding options that are best for them and their babies.

Like WHO/UNICEF/UNAIDS, the International Planned Parenthood Federation is also influenced by a human rights perspective. However, as reflected in its training document, IPPF is actively supporting these rights. IPPF's Charter of Rights promotes and protects rights such as the Right to Equality, the Right to Privacy, the Right to Information and Education, the Right to Health Care and the Right to the Benefits of Scientific Progress (IPPF n.d.b: 9). By providing all people with the same information, by providing sexual and reproductive health services, and by aiming to keep its counsellors up to date on new information, IPPF respects the rights set out in its Charter.

In addition to a human rights perspective, IPPF is also influenced by liberalism and liberal feminism. Liberalism demands that all people have the ability to make choices they believe are best for themselves. Liberal feminism takes the liberal doctrine and focuses on the condition of women. Liberal feminists call for social reform, which will allow women to make real choices about their public and private lives. IPPF believes that all people have the right to make appropriate choices for themselves. This right includes having access to birth control, abortion, and any other service that may help improve their sexual and reproductive health. IPPF also works with governments and policy makers in the hope of increasing all people's access to sexual and reproductive health services. IPPF does not believe that the spillover effect will erode breastfeeding practices around the world, and, therefore, allows people to make infant feeding choices based on all the information available to them.

Unlike WHO/UNICEF/UNAIDS and IPPF, the Population Council's mandate, objectives, and training document are not obviously influenced by human rights. However, they are influenced by liberalism, liberal feminism, scientific positivism, power, discourse, and economic factors. The Population Council's dedication to the research and development of birth control clearly demonstrates their acceptance of a liberal feminist perspective. They strive to give people, especially women, the freedom to make choices about their reproductive rights. However, this organisational perspective is not apparent in the Population Council's training document. The fact that the Population Council is not only concerned about the spillover effect, but takes measures to prevent it, shows that they do not support a completely liberal perspective. It is interesting to note that although the Population Council's main financial supporter, the USA government, has signed the Universal Declaration of Human Rights, it has not ratified the Convention of the Rights of the Child, nor the Convention of the Elimination of all Forms of Discrimination against Women (Shah 2002). Perhaps the Population Council does not believe that it is violating human rights by withholding certain information from some women. By keeping information from mothers about *all* the risks and benefits surrounding *all* infant feeding practices, the Population Council is reducing the possibility that a mother will make an informed choice about how she will feed her baby.

The issue of scientific positivism, and the power and control over the dissemination of knowledge is further evident in the Population Council training document. The Population Council may use its ability to produce, select and disseminate scientific information to control or influence the choices mothers make about infant feeding

practices. The Population Council has the power to control knowledge by either withholding information, or presenting it in a positive or negative language. The scientific complexity of the training document inhibits many counsellors from learning, understanding and counselling parents in areas of high HIV prevalence. Most counsellors in resource poor areas do not have formal medical training and may lack the ability to provide parents with all the information provided in the training document. Instead, the counsellors may simply regurgitate some of the more basic, positively presented information found in the training document, which in this case is breastfeeding.

The Population Council not only limits the transfer of knowledge to counsellors and parents, but it also has the power to manipulate the knowledge it provides. This control is very important financially for the Population Council. The Population Council receives the majority of its funding from the United States government, and, as a result, some of the research that the Population Council supports is influenced by the USA government's priorities. In this case, the USA government is strongly pushing for the use of brand name antiretroviral drugs. By researching and developing ARVs, the Population Council helps the USA government promote the use, and control, of brand name antiretroviral drugs. Though the Population Council counsellor training document currently recommends cautious use of ARVs in order to reduce the risk of mother-to-child transmission of HIV, it will be interesting to see if future versions of the document contain a more prominent push for the use of antiretroviral drugs.

By showing that information is subject to organisational perspectives, it becomes clear that not all women are given the same information about mother-to-child transmission of HIV. Some women may receive information on all infant feeding practices, while other

women may only receive information on breastfeeding. The organisations, especially WHO/UNICEF/UNAIDS and the Population Council make it extremely difficult for parents to make truly informed decisions about their infant feeding practices.

The previous section considered the secondary questions related this study: What information is given to women about mother-to-child transmission of HIV? How does the conceptual approach to mother-to-child transmission, adopted by various organisations, affect the information that they provide to parents? Keeping this analysis in mind, the primary question can now be addressed.

Conclusion

Why is the mother-to-child transmission of HIV information in the three training documents different?

Throughout the previous chapters, it has been shown that the information in the three training documents is inconsistent, and that various concepts have influenced the mandate and objectives of the World Health Organization/United Nations Children's Fund/Joint United Nations Programme on HIV/AIDS, International Planned Parenthood Federation, and the Population Council, as well as the information they provide to the public. The analysis of this information has been sufficient to answer the primary question posed in this thesis: *Why is the information concerning mother-to-child transmission of HIV different in the three training documents?*

For such a complicated topic, the answer is quite simple. Each organisation that produced the training documents has a point of view, or an overarching philosophy, that it wishes to impress upon people. This point of view is inseparable from the concepts that have influenced the organisations. WHO/UNICEF/UNAIDS uses its power to control medical research and the information the public is receiving, and discourse on mother-to-child transmission of HIV, to discourage women from adopting any infant feeding practice other than breastfeeding. Despite its support of various human rights documents, WHO/UNICEF/UNAIDS are so confident in the benefits of breastfeeding that they purposefully deny some women information simply because of their HIV status. WHO/UNICEF/UNAIDS fail to take into consideration that HIV-negative and HIV-unknown women are at risk of contracting the virus and need to be equipped with all the information possible in order to protect themselves and their families.

On the other hand, the International Planned Parenthood Federation training document does exactly what its mandate decrees: It offers information and choices to all people, no matter what their HIV status, their gender, or their social status is. IPPF succeeds in respecting human rights, liberalism, and liberal feminism. IPPF aims to provide people with information and support that will allow them to make choices that they feel are best for them and their families. In its training document, IPPF states that milk, any kind of milk, is essential to the good health of babies, and it therefore explains the various infant feeding options to parents, as well as some of the risks and benefits associated with them. IPPF provides all of its information in a neutral, culturally specific way that seems to be conducive to making an informed decision.

Finally, the Population Council relies on notions of scientific progress, or scientific positivism, and uses its ability to select and promote specific information to influence women to breastfeed. It uses language to positively portray breastfeeding, and negatively portray all other forms of infant feeding. It also uses highly scientific knowledge, which has the effect of overwhelming the lay counsellor, who in turn may simply recommend breastfeeding as the best infant feeding option, because it is the only one discussed in a positive manner. Despite the Population Council having some liberal feminist leanings, its control over knowledge and information inhibits parents' ability to make an informed choice regarding infant feeding practices. In addition, it is important to keep in mind that future counsellor training documents may also recommend the use of specific antiretroviral drugs, as the Population Council is heavily financed by the USA government and multinational corporations, who are interested in the financial rewards of researching and developing ARVs.

Regardless of which concepts influence the three training documents, a woman's ability to make an informed choice about infant feeding practices is extremely important in a situation as serious as the vertical transmission of HIV. All parents must make a choice on how they will feed their babies, and this choice becomes more important and more difficult to make in resource poor areas where HIV/AIDS is prevalent. The consequences of an infant feeding choice may be the difference between sickness and health, or life and death, not only for the baby but also for the mother. In order to make informed choices, parents need to be equipped with two necessary tools: information regarding the various infant feeding choices available, and what their risks and benefits are; and, the freedom to make any choice they want. If both information and freedom are

available, then an 'informed' choice can be made. To make an informed choice, parents must also have access to accurate and up to date information about each option available, and this should be provided in a language they understand (EngenderHealth 2003: 27). Parents must be able to fully understand the risks and benefits associated with each option, and what the consequences of the choice will be. Unfortunately, the ability to make a free, informed choice is often not possible.

Despite advances in support of informed and voluntary decision making in SRH, a wide gap still exists between the rhetoric and the reality at the service-delivery level. Barriers to informed and voluntary decision making persist ... as a result of social factors, laws, policies, service-delivery practices, resource constraints, and service provider's attitudes. These barriers will remain until policymakers, program managers, and service providers are better informed about clients' rights and what they mean in terms of service delivery, and until the implications of the broader social and cultural context for individuals' ability to obtain information, make decisions, and seek services are considered. (EngenderHealth 2003: 1)

Only once parents are provided with all the information on the mother-to-child of HIV, and only once this information is provided without being influenced by a particular concept, will people have the opportunity to make truly informed choices in regard to infant feeding practices.

In order to accomplish this goal, certain steps must be taken. First, counsellors and parents need to be provided with updated and accurate information. One of the biggest problems in providing women with accurate information is the rate at which one scientific 'truth' about HIV/AIDS and vertical transmission is replaced with another. Although, in the past, this access to new information has been problematic, with the spread of the Internet, new information is becoming increasingly available in resource

poor countries. While a large majority of health clinics in these countries do not have access to information, there is an increasing chance that someone associated with the clinic will have at least some access to a computer, and, hence, new or updated information and training documents. All three of the training documents used in the analysis of this study were retrieved from the Internet. Revised and updated versions of the documents could easily be made accessible to people around the world.

In addition to access to information, "... mothers need culturally appropriate information to enable them to make better feeding choices. Clearer understanding of the forces that influence mothers is needed to begin to design such information" (Winnikoff 1988:1). Language is a very important component of counselling. Training documents must take extra care in ensuring that the information it provides to health workers and counsellors is in a language that parents can understand. Language used in counselling training documents does not necessarily reflect the language used within the targeted society. This does not simply imply local dialects, and medical language such as retrovirus and immune system, but also words like virus, transmission, colostrum, and sterilisation. Many societies do not have equivalent translations. In order to effectively convey neutral and beneficial information to parents regarding vertical transmission and infant feeding practices, organisations must take the local culture into consideration when developing training documents. Indigenous theories of contagion and local language(s) should be used to help parents understand issues surrounding mother-to-child transmission of HIV.

Organisations should also research local environments when producing culturally specific training documents. "[Prevention of mother-to-child transmission] programs

should establish national infant feeding guidelines which include recommendations for HIV-infected women, based on an assessment of local feasibility, acceptability, affordability, safety and sustainability of various feeding options” (Rutenberg et al 2003: 9). Counsellors should not automatically recommend breastfeeding to HIV-positive women, especially if there are safe, local alternatives.

Finally, for many parents, health workers and counsellors at local community clinics are their only connection to information on HIV/AIDS. Consequently, the burden of dispensing appropriate information falls heavily on the shoulders of these workers. Counsellors can have considerable influence over women’s choices because they are seen as the experts. This makes the role of the counsellor that much more critical because “... so often times women rely on the recommendations of the health experts and their health care providers. They do not act in accordance with their own judgement and discernment, adopting instead the opinions of those they respect” (Liles 2001: 3). Because counsellors hold an important position within many societies, they often have the ‘power’ to influence their clients. Their advice is trusted by parents who seek information about a particular situation. This is why it is very crucial that counsellors be properly trained and well informed. Counsellors and health workers can only be truly beneficial if they are able to provide parents with unbiased, accurate and up to date information about mother-to-child transmission of HIV. The organisations that produce training documents should be very aware of this and do all that they can to provide counsellors and, ultimately, parents with the critical and necessary information that will permit parents in resource poor countries to make informed choices regarding infant feeding practices.

Future research is needed on mother-to-child transmission of HIV, and on how information can be effectively disseminated to parents, especially in resource poor countries where HIV is highly prevalent. Research should be conducted on how information can be stripped of organisational perspectives, and how counsellors can be trained to identify and control their own personal biases, thereby allowing them to provide neutral information to parents regarding mother-to-child transmission of HIV and infant feeding practices. In addition, research should also be conducted on how new, updated information on vertical transmission can be quickly and accurately be provided to health clinics in resource poor countries. Unfortunately, because of the nature of the virus and the disease, and because of the constantly changing information, or paradigms, this may prove to be very difficult.

However, if such research is successful, and parents are eventually provided with accurate, updated, unbiased information, and the freedom to make decisions they feel are best for them and their families, then people will be able to make truly informed choices about infant feeding practices.

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