

Reimagining death: A posthuman analysis of life support and the concept of death in the
intensive care unit

by

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ABSTRACT

Often assumed to be simply the opposite or absence of life, death is in truth a distinctively uncertain category which troubles assumptions about what it means to be alive, and what it means to be human. In this project, I explore what happens to understandings of bodily endings when the “normal human” is de-centered from the concept of death. I take a post-Enlightenment, post-humanist approach in the mode espoused by Rosi Braidotti (2006, 2019) which seeks to move beyond the elite and exclusive category of “human,” as well as to get outside of anthropocentric patterns of thought. This project focuses on shifting definitions and meanings of death in the midst of advanced life-sustaining technologies and against a backdrop of cultural fascination with immortality as represented by the modern intensive care unit. Employing ethnographic methods and concepts from feminist new materialism, and founded on an in-depth understanding of posthuman theory, this work contributes novel analyses of how death happens in technological spaces, and how our understandings of it could be approached differently. I contrast cases of patients sustained on life-support technologies seemingly beyond their desired limits with those of individuals declared to be dead against their beliefs to explore ontological, epistemological, and practical elements presently maintaining the appearance of universal definitions of death. A final analysis of media cases of people who continue to produce life through pregnancy despite being categorized as dead helps to reconfigure assumptions about life, death, and life sustaining technologies into a new understanding of how bodily endings, alongside perceptions of liveliness, are always a particular product of ongoing and unfolding social and technical

relations. Ultimately, I suggest that life sustaining technologies and their capacity to promote impressions of vitality allow us to better appreciate how death is already always a part of life, a perhaps unwanted “other” that we might learn to tolerate and accept, a personal ethical threshold of existence with the potential to transport us into different futures. This work expands the application of posthuman theory into the domain of clinical death and demonstrates the added value of posthuman analyses in medical spaces.

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CHAPTER 1 | Introduction

Why study death?

Locating the exact moment at which “alive” becomes “dead” is a concern which has preoccupied medical practice for centuries. Ascertaining time of death is necessary to assign or relieve blame in homicide cases, to permit legal release of assets and life insurance, to begin the transition to funeral and burial rites, and to facilitate medical practices such as deceased organ donation. The question of the exact moment at which human death occurs is especially relevant in contexts of modern scientific medicine. Minutes can make the difference between murder (procuring organs from someone who is still alive) and deceased donation success. Advanced life sustaining technologies such as breathing machines and drugs used to artificially maintain blood pressure blur the lines between life and death, as well as the limits of ethical responsibility with assigning human death. Sophisticated physiological monitoring has demonstrated the persistence of certain electrical signals in the heart long after the last breath has been drawn (Dhanani et al. 2014, 2021). And the success of deceased organ donation itself assures us that declared death of the body does not necessarily signify the end of organ activity. Often assumed to be simply the opposite of life, death is instead a distinctively uncertain category. The question of why one might be interested in exploring further its blurry boundaries are illustrated through the following paradoxes.

First – a statistical paradox. Surveys of people in Canada and the United States indicate that a large majority express a preference to die at home, without pain and

suffering, surrounded by friends and family (Wilson et al. 2013). In reality, this type of perceived “good death” is only possible when dying of certain diseases. Most people die following an accident, sudden illness, or very commonly, a long trajectory with a chronic illness that eventually results in a catastrophic terminal event such as a heart attack or stroke. In an increasing number of cases, this terminal event lands people in the intensive care unit, where they are sustained using life-support technologies until their heart stops or until their family makes the decision to remove life-sustaining therapies and allow death to occur. Intensive care units are the places in the hospital where most of the life-saving technology is concentrated, and a stay there costs about 3 times more than a stay in a general ward (Canadian Institute for Health Information 2016). Despite the concentration of life-saving technology and medical expertise, intensive care units are fairly common locations of death, with mortality rates in Canada around 10% and as high as 30% in some countries (Canadian Institute for Health Information 2016; Garland et al. 2013; Teno et al. 2015; Wunsch et al. 2011).¹ Why do we invest so much time, energy, and money into the production of technologically mediated deaths such as those that occur in the intensive care unit if these types of deaths are actually undesirable to most people? How much power should individuals have to shape the timing, location, and character of their bodily endings?

¹ These figures do not account for changes in mortality and intensive care use caused by the COVID-19 pandemic.

Of course, the intensive care unit is also a place for saving lives, and some may point out that technological deaths are simply an unfortunate by-product of the desire to save and sustain human life. This brings us to the next puzzle – what kinds of “life” or “lives” is the intensive care unit sustaining?



Figure 1. “The Immortal” (Cohen and van Balen 2012)

The Immortal, pictured above, is an art piece that I first came across in 2012, while I was writing a master’s thesis (Epidemiology) on the variations in clinical processes of how medical professionals withdraw life sustaining therapies (van Beinum et al. 2015, 2016). In this piece, artists Cohen and van Balen take five different life support machines from a neonatal intensive care unit and connect them using medical tubing and electrical circuits. Each machine supports the other through a pulsing,

whirring loop. Is this life? Note the absence of any human body here, though we could easily imagine one lying motionless on a bed in the centre. One of the characteristics of an intensive care unit is that life support machines usually vastly outnumber the patients. Does the presence of an inanimate human body make this non-human assemblage somehow more alive? Most patients in the intensive care unit are unconscious and do not make any purposeful movements; they are dependent on technical connections for their sustenance. Some might argue that intensive care unit patients represent some of the most disabled forms of human life currently possible given available medical technologies. The paradox remains, how do we negotiate, or locate, human death in contexts in which the living “human” does not fit traditional moulds? At what point can we permit death to occur in a situation where life-support machines can potentially self-sustain or help to sustain forms of bodily life forever, as the title *The Immortal* suggests? What kinds of bodies, and what types of subjects are permitted to die? How do we know when death has occurred if it was possible for life to continue?

The third paradox continues this epistemological line of inquiry and draws attention to the close relationships between scientific medical objectivity and death as a clinically-determined boundary. Foucault’s well known concept of the “clinical gaze” (1973), through which an objective medical practice could see the “truth” about the body, was partly facilitated by death, dead bodies and the practice of autopsies. Throughout the Enlightenment, the humanist practice of scientific medicine became focused on locating abnormalities by using signs and symptoms directly observed on the

body. The knowledge and tools of medical science were then employed to correct irregularities and return bodies to an ideal state of “normal,” in a pattern which Clare (2017) refers to as the violence of cure. Death, in this context, was mostly experienced as a failure. It was either a failure to correctly identify the problem with the body or a failure to implement the appropriate solution. Once it occurred, death became another tool used to uncover the truth about what happened to the body and what went wrong with the course of scientific medicine that was supposed to fix it. In this way, medicine primarily related to death as a means of understanding *life*, rather than a state deserving of focus in and of itself. Paradoxically, after many years of poking around in dead bodies, scientific medicine doesn’t actually know that much about death and the natural processes of death in the human body. It has only been more recently that we’ve seen the development of scientific medical practices used to “objectively” locate and diagnose death in the human body. The development of the concept of a neurological determination of death or “brain death” in the 1960s is one example (Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death 1968; Lock 2002; Powner, Ackerman, and Grenvik 1996).

Although brain death has been widely accepted in North American medical practice, resistance to the concept of the declaration of death using neurological criteria has been growing over the past several years, both in published literature and in clinical cases. “Requests for accommodation” (A Lewis et al. 2016), as challenges at the bedside are legally called, help to highlight a final paradox regarding the blurry boundaries of

death – how much power should scientific medicine have to determine how and when death has occurred? And how do we handle the inevitable exceptions? Three widely publicized cases in Canada and the United States involved situations in which doctors had declared a patient to be brain dead, but where the patients’ families disagreed and pursued legal action to prevent removal of life sustaining therapies (Janus 2018; Luce 2015; McGillivray 2018; Ontario Superior Court of Justice 2018a; Truog 2018). These cases are framed in the media as being about “religious” or “cultural” differences in how death should be declared, but a critical sociological lens indicates the potential presence of a deeper tension. From my position, I don’t think it’s a coincidence that two of the three most widely publicized recent cases involve the deaths of young Black women, and that all three involve patients from communities with long histories of oppression and social exclusion, especially within medical practice. Not all bodies are the same, and not all bodies have traditionally been considered by scientific medical standards to fit in the category of the normal or prototypical human. This point again highlights the importance of taking seriously the question of what death looks like and for whom, alongside the knowledge practices involved in discerning when and how it has occurred. A critical position might suggest that not all deaths are the same, and that we should pay closer attention to who, or what, gets lost as a result of dominant medical and social practices of deciding the moment of death amidst life-sustaining technologies.

Why study death? The slippery nature of this presumedly universal and often taken-for-granted boundary makes a rich site for critical sociological analysis. The

practical, technical, and medically relevant question of *when* death has occurred is revealed to be undergirded by conceptual questions about *what* death is (an ontological concern), and also *how* we understand this to be true (an epistemological concern). These questions bring up accompanying moral and ethical concerns regarding the nature of individual subjective limits to life and how and when we can discern whether these limits have been reached. Finally, there are political issues about how to accommodate unusual exceptions, such as posthumous motherhood, and how to make space for future challenges and opportunities, such as the possibility that dead brains could one day be revived. This last concern links back to the immediate technical realities of the practical world of the intensive care unit, where new strategies for saving and sustaining life are regularly invented. Studying death and how it comes to be determined, decided, and denied, seems increasingly relevant in a world where technological advancements are oriented on the one hand towards making death an impossibility, while simultaneously producing its structural inevitability for underserved and socially oppressed others. Attending to the technical, social, and material mechanisms of death permits a deeper ethical reflection on the types of futures produced through particular endings.

Project overview

In this project, I grapple with some of the paradoxes involving the shifting definitions and meanings of death in the contexts of scientific medicine. Rather than aiming to provide substantive or universal answers, I instead focus on generating space for new creative lines of questioning. Using the intensive care unit as a rich sociological

site in which to critically explore the puzzles of modern technological dying, I aim to break from established patterns of thinking about death and to “think the unthinkable,”² in order to develop new modes of inquiry about how bodily endings occur against a backdrop of a cultural fascination with immortality.

This dissertation begins with an in-depth consideration of questions related to the epistemology and ontology of death. In Chapter 2, I undertake a critical interdisciplinary reflection on the questions, what is death, and how do we know? At the conclusion of this investigation, I introduce posthuman theoretical perspectives as new modes for thinking about the epistemology of death and dying. Chapter 3 situates the site of this work in the intensive care unit, including providing a brief history of intensive care medicine and a description of the field site in which I collected data. In Chapter 4 I describe in more detail how and why I chose to employ a posthuman, feminist, and new materialist methodology for analyzing death in technological contexts. I consider the possible strengths of new materialist methods, such as approaching data through modes of diffraction, and I introduce the analytical concept of agential cuts. I then outline the specific practical steps I took to produce this work. In Chapter 5, I present vignettes from my fieldwork and explore the technological and ideological background of the intensive care unit in detail. I consider how medical technologies combine with underlying orientations towards particular forms of life to influence the possibilities for death permitted in the intensive care unit. In Chapter 6, I draw from interviews with Canadian

² “Thinking is trying to think the unthinkable: thinking the thinkable is not worth the effort” (Cixous 1993:83 as quoted in Davies, 2018).

critical care physicians and a recent publicized case of contested brain death to consider the entwined and unequal relationships between knowing and making death against a backdrop of life-sustaining technologies. Chapter 7 returns to a theoretical consideration of where and how “life” and “the human” can be located within intensive care, and then proposes new angles for thinking about and understanding the relationality between individual bodily endings and collective understandings of death. Lastly, Chapter 8 offers a final reflection and conclusion to this work, including imagining how perspectives about death might impact the creation of future worlds.

This project brings into relief the inextricable relationships between life-sustaining technologies and the production of new forms of life and death. The intensive care unit operates as a space for life saving and, in the process, facilitates new forms of life as patients are connected to invasive, yet supportive, machines. An ethical tension is thus produced in which intensive care is both responsible for producing new and creative forms of life, and yet, at the same time, is responsible for negotiating and facilitating the conditions in which these lives end. A power imbalance exists between the authority of medical knowledge about the ideal human body and how human life ends, and the bodies and subjective experiences of patients and families, most of whom do not fit the definition of the ideal, rational, conscious human by the time they are seen in the intensive care unit. In order to make space for the posthuman possibilities of new forms of living and dying, I argue throughout that improved modes of ethically understanding the critically ill, disabled, dying patient on their own terms are needed, including

understanding the complexities that occur when the technological capacities for sustaining life and patients' subjective desires for death are in conflict.

CHAPTER 2 | Making and knowing death: practices of death and dying

When is dead, really dead? This question, though seemingly unthinkable, has persistently troubled human societies (Green 2008:46–47). The idea that there can be more than one way to be dead, and that some types of deaths might be somehow less-than or not-quite as dead as others can produce considerable anxiety. Fears of accidentally causing or inappropriately establishing death, historically evident in practices such as death bells and safety coffins (Bondeson 2002), are compounded in new ways in the now common practices of deceased organ donation, withdrawal of life sustaining therapies (“pulling the plug”), and medical assistance in dying (i.e., medically assisted suicide) (Lock 2002). In Canada, a growing number of legal challenges contesting the declaration of death and the maintenance or denial of specific life-support therapies indicate the challenges faced by current legal and medical practices in establishing acceptable and universal limits to human life. Legal and medical tensions inherent in the definition of death are amplified by a political climate of liberal capitalism, where individual rights to determine the limits to one’s own life are often pitted against the common good (Scheper-Hughes 2008). These tensions are exacerbated in the context of publicly funded healthcare; many people are vehemently opposed to spending public funds on the expensive physiologic maintenance of bodies that have been classified as dead. In contrast, in the private sphere, those with enormous financial capital have been investing in technologies of immortality such as cryopreservation and strategies for halting

telomere degradation (Alcor 2020; Warner 2018). On a smaller scale, and as explored in great detail through the ethnographic work of Nancy Scheper-Hughes, only moderate amounts of wealth are required to purchase life-sustaining organs on the black market (Scheper-Hughes 2007, 2008; Scheper-Hughes and Wacquant 2002). Finally, continual and widespread advances in technology and medical practice continue to blur the boundaries of nature and culture, what it means to be human, and how and when it is possible for death to occur. The lifesaving and life-sustaining technologies of the intensive care unit are now capable of sustaining human bodies far beyond what were once established “natural” limits. Cutting-edge research in brain resuscitation technology and techniques suggests that these limits will be continually surpassed (Vrselja et al. 2019). Expanding possibilities for sustaining bodies and lives continue to dissolve the idea of a nature/culture divide and foreground the necessity of making active ethical choices when determining limits to human life. Asking, simply, “*When is dead, really dead?*” subtly invokes these broader, underlying tensions within current practices of medicine, law, politics, and philosophy.

There is a rich tradition of work in sociology and anthropology about these social aspects of death and dying (Green 2008; Kaufman 2005; Lock 2002; Robben 2004; Seale 1998). Social scientists have identified and described the many ways in which death is a social and cultural event, from elaborate funeral rites to Facebook memorials (Fearon 2011; Suzuki 2004). However, most work carried out to date on social aspects of death tends to accept unquestioningly the anthropocentric position that death equates to

cessation of what it means to be human, the end of the human subject. In this chapter I attempt to think through an adequate answer about what death is and how it is understood within the social contexts of bio-technical, scientific medical practices from a position which does not privilege a humanist conception of death. Here I am mainly concerned with thinking about the embodied practice of material dying, the social and technical process through which an alive body becomes understood as a dead body, without taking for granted that bodies are always human in the traditional sense. Focusing on how the fact of death is established by large social institutions (e.g., medical, legal, religious) is imperative to understanding how the practical exercise of establishing death is carried out in techno-medical spaces such as the intensive care unit. Producing a workable position on the material question of, “*When is dead, really dead?*” builds directly into my broader concerns with how understandings of life and death are practically established amidst contexts of lifesaving and life-sustaining technologies in the intensive care unit. It also provides a better account of the openings and possibilities for grasping how technological dying might be a site for learning how to imagine life and death differently. Using a critical feminist, posthuman perspective that is grounded in a politics of locations, I have organized my inquiry around who (or what) has been privileged to ask questions about death and to contribute to its practice(s) of declaration, and how these questions have been pursued within the contexts of scientific medicine.

I begin with a brief overview of classical humanist understandings of death as a social ritual, reflecting on collective community practices used to establish death. I then

consider major critiques of this position that may cause conclusions about the social enactments of death to be questionable. In the next section, I trace understandings of death as a scientific fact, as asserted through ideals of rational positivism. I reflect on the central and yet unspoken role of death in the practice of modern techno-scientific medicine, along with its relationship to exclusions of marginalized others. The splintering of confidence about a universal scientific death has been furthered by the growing volume of traditionally excluded voices and has become more prominent as medical technologies enable new trajectories of dying. Pinpointing the moment of death has always been a difficult cultural task (Green 2008:46–47). In this analysis, I consider how the contexts in which technologically mediated death commonly occurs in the intensive care unit involve novel complexities and uncertainties against which questions about what and how death occurs become increasingly challenging. I conclude this chapter by introducing a posthuman theory of death, one that is, “accountable for our times” (Braidotti 2013, 2019). Finally, I discuss how this new way of understanding the death of the human may help to build from the strengths and move beyond the shortcomings of past notions in order to approach our technologically mediated future deaths in an ethical manner.

It is my goal in this chapter to make clear how the answer to the question, “*When is dead, really dead?*” cannot be located in the human body or in any non-human body assemblage. Instead, an answer to this question requires renewed critical attention to ongoing changes in political and subjective positions made possible through evolving

medical technologies. Creating the tools with which we can adequately, practically, and ethically seek to understand and address the changing character and meaning of clinical death is the overall aim of my work.

Death as embodied socio-cultural practice

One way to investigate the question about when death occurs involves framing the concern as having to do with social practices that establish human death, rather than with the presumed universal biological and physical changes that make up the material death of the body. Considering death to be an embodied social practice means understanding the aliveness or deadness of a person as determined through specific social practices. As mentioned, there is a wealth of social science research in this tradition. Some has evolved from the study of religion and religious ritual as guardian of social practices involving the establishment of death, but a great deal has also sprung from more secular Enlightenment concerns involving the assumed rational human fear of death (Bauman 2013; Becker 2004; Lifton and Olson 1974). Many social scientists trained within humanist schools of thought set out to explore various cultural practices of determining death under the assumption that anxiety about death was a universal human experience.

Within this tradition, research into the specific social processes through which death is declared has tended to be fixated on the production and description of mutually exclusive, hierarchical, and dichotomous categories (e.g., alive/dead, sacred/profane) and the theorization of transitions between separate categories. For scholars using this method of inquiry, the question, “*When is dead, really dead?*” can be answered by first

determining cultural context and then referring to a specific time and space in a socially determined, ritual categorical transition.

Durkheim and Mauss' essay on *Primitive Classification* (1963 [1903]) and Durkheim's continuation of themes of classification in *The Elementary Forms of the Religious Life* (1915 [1912]) helped to create a foundation for thinking through the production of the social categories of alive and dead. Durkheim described how categorizations and classifications within religions, and by his extension in societies, were organized around the fundamental dichotomous categories of "sacred" and "profane." According to Durkheim, religious practices all involved beliefs and rites to isolate and mythologize the "sacred," while simultaneously emphasizing the pollution of the non-sacred, or the "profane." Part of his thesis was that things, people, and places were not inherently "sacred," but rather were categorized as such through social and cultural practices of beliefs and rites. In other words, categorical work, the social act of producing a specific, situated category, is necessary in order to identify sacredness.

Durkheim's graduate student Robert Hertz (1960 [1907]) went on to apply his mentor's connections about proscribed social categories to the study of death. His comparative ethnographic work on funeral and burial practices in pre-industrial societies demonstrated the social and cultural elements involved in determining the category of death. In the societies studied by Hertz, persons were not categorized as dead until the community had performed a series of rites, often involving a double-burial. Hertz theorized that these rites were part of a collective need to ritually separate the impure

dead from the community of the living, and then to subsequently re-integrate the dead into a meaningful afterlife. Hertz's work showed how the social categorization of a person as alive or dead is more complex than the experiential recognition of material signs from the body. For example, he demonstrated how in some communities the affective response to dead bodies was not predicted by the fact that they were physically dead, but rather by which stage of the ritual transition they were in. Bodies that had been ritually separated and re-incorporated into the afterlife were no longer deemed awful or dangerous. This finding is still interesting to frame reactions and relations to death in today's world. For example, noticing a dead body on the adjacent hospital bed or on the sidewalk is likely to be more disturbing, and provoke a different reaction, than encountering the identical dead body during an open-casket funeral. The ritual framing and containment provided by the funeral home causes our affective reaction to a dead body to be different than if we encountered it in other locations. Hertz's work demonstrated that the categorization of death is a transitive social process with implications for the organization of social relations in the surrounding community. Similar to how Durkheim demonstrated that "sacred" objects can only be recognized as such through the social acts of rites and beliefs, Hertz's work established how socially acceptable categorizations of death could be orchestrated through ritual processes of appropriate burial, re-burial, and mourning.

Hertz's work on funerary rites pre-empted the influential findings of Arnold van Gennep (1960 [1909]) on of rites of transition. While Hertz surveyed common social

ritual processes of death and funerary practices, van Gennep was interested in describing more broadly the commonalities of collective rituals surrounding changing categorizations of social status, which he termed, “rites of passage.” In his survey of the rites of passage of pre-industrial societies, van Gennep observed that all transition rituals in which community members changed social categories (e.g., from girl to woman, alive to dead) that shared symbolic separation of “sacred” (or pure) and “profane” (or polluting) did so across three stages: rites of separation, rites of transition, and rites of incorporation. These categories of social status change and their basis for the concept of social practices of death determination continue to be important for present-day studies of clinical dying (e.g. see Timmermans 1999), thus are worth describing in more detail here.

Rites of passage begin first with rites of separation, during which members undergoing transition are stripped of their individuality (sometimes literally through removing clothing), expelled from their regular social group, and are made to enter some new place, space, or “in-between” status. During rites of separation, the transitioning individual may be deemed “sacred” and thus requiring ritual separation from “profane” society, or they may become polluting to the group (as in some cases of death) and thus in need of ritual separation to prevent contamination.

Van Gennep described the next stage as rites of transition. These ritual practices are performed while the individual under transition exists in an undefined social status. In this stage, the transitioning individual is not recognized as properly belonging to any defined social category, and thus is positioned as a threat to the stability of society. This

state, also called the “liminal state,” was observed to exist for variable lengths of time and may or may not have specific associated symbols. Van Gennep observed that individuals in this state were often subject to special rules of social engagement and were both feared and respected in the non-liminal society.

The final stage of rites of passage involves rites of incorporation. These ritual practices help to ensure the individual’s re-integration into existing social structures, and simultaneously to re-establish existing social structures as complete. These rituals help to reverse the original sacred/profane symbolism enacted during the rites of separation. Neither society nor the individual are the same after completion of the three stages of the rites of passage, but both are once again in stable status categorizations following rites of incorporation.

Throughout each of the three stages described above, ritual practices involve specific, symbolic actions and aspects of world building such as establishing certain conditions for sacredness and profanity. Who and what is ritually classified as sacred or profane, dead or alive, changes depending on social context and transition stage. What is most interesting about thinking through transitions from life to death using van Gennep’s model of rites of passage, and indeed one of his major contributions to the study of ritual, is the spatial element introduced by theorizing category and status changes as a ritualized continuum. Instead of “either/or,” there is a “both/and” category introduced at each transition between rites of separation, rites of transition, and rites of incorporation. In particular, the liminal period introduced by the concept of rites of transition highlights the

possibilities for socially recognized existence in the spaces *between* established social classifications. Van Gennepe's rites of transition introduced a plausible framework for theorizing the socially sanctioned and ritually important state that exists between alive and dead.

British anthropologist Victor Turner (1969, 1977) became interested in van Gennepe's rites of passage framework, though he concluded that modern society no longer subscribed to the type of all-encompassing, collective ritual practiced by van Gennepe's "semi-civilized societies" (van Gennepe 1960). For this reason, Turner created the concept of the "liminoid" space to explain persistent states of ambiguity observable in modern social worlds despite a relative lack of collective transition rituals. As positions-in-between, both liminal and liminoid spaces share the properties of ambiguity, mystery, and danger. Both involve spaces where the juxtaposition of dichotomous categories (both/and) is made visible. In this stage of social transition, individuals are held in a space that is at the same time within and outside of society, a place that affords a novel, and potentially destabilizing perspective on social structures and norms. Liminoid spaces, according to Turner, are places where "the curtains may part" and reveal the truth of what we otherwise perceive to be distinct states (1969). Compared to the liminal space of van Gennepe's traditional and collective rites of passage, Turner theorized the liminal-like "liminoid" space as a result of the voluntary transitions more common in post-industrial society. Turner added an important emphasis to van Gennepe's work on rites of social state transition by insisting on the potentially generative nature of this transition space.

The significance of liminal spaces in categorizations of states of existence remains a prominent topic of discussion in the social science literature (Kaufman and Morgan 2005).

Writing around the same time as Turner, British anthropologist Mary Douglas also made substantial contributions to social science thinking about social processes of categorization and raised some important critiques of the social study of rituals. In *Purity and Danger* (2002 [1966]), Douglas was concerned with the relationship between pollution (i.e. Durkheim's original idea of "profanity") and ritual, especially as they occurred in religious practices. Douglas took issue with assumptions of religious anthropology that framed certain societies as "primitive" and "backwards" for their extensive social rites surrounding pollution and impurity. Through careful analysis, Douglas demonstrated how the ritual framing of certain objects, acts, people, or places as "dirty" is more often about enforcing a socially acceptable categorization of "clean" or "pure" than about a fetishized focus on dirt. Thus, social rituals that establish a category of death also do the work of reinforcing what it means to be alive, or at least, what it means to *not* be dead. In some contexts, this reinforcement of the alternative (e.g., life) is more important than the establishment of the social category (e.g., death).

While drawing conclusions about the societies and rituals under study, Douglas also drafted a pointed critique about the assumptions of European social scientists and ethnographers. She outlined how claims about the "primitiveness" of cultures under study mainly served to reinforce Eurocentric ideas about civilization and humanity. In their

focus on establishing hierarchical difference, many studies using methods of structural analysis failed to grasp a complete and accurate account of the phenomena under study.

In the essay, *Grief and a Headhunter's Rage*, American anthropologist Renato Rosaldo (2004) outlines how he came up against the restricting limits of Eurocentric/Western worldviews. He describes how he initially interpreted the violent practices of Ilongot grief (locally enacted through activities of opportunistic assassinations) as being irrational and rage-filled, and thus markedly different from acceptable forms of grieving in American contexts. However, the sudden, accidental death of his wife during fieldwork caused Rosaldo to rethink his Eurocentric conclusions when he, too, was consumed with a violent rage as part of his grief. Rosaldo used his experiences to reflect on the process of ethnographic fieldwork and subjective cultural interpretation (1993). He noted that focusing on observed ritual processes as a detached observer may cause ethnographers to see only those "self-contained" spheres of culture enacted through ritual. This limited perspective prevents the ethnographer from experiencing and exploring culture as many interrelated, always unfinished and expanding processes. He points out that ritual has different meanings for different participants, and that it is often only one small part of a much larger, ongoing process. Rosaldo insists on describing rituals as more of a "busy intersection" or a "crossroads" where "distinct trajectories can traverse" rather than as a microcosm or window through which a smaller snapshot or version of the larger culture can be viewed (Rosaldo 2004:174).

Douglas' critique of Eurocentric perspectives on "other" societies and Rosaldo's conclusions about social ritual as unfinished process help to underscore the potential pitfalls of thinking about the material process of dying solely from the perspective of an embodied social ritual. First, it is important to recognize that theories about the role of social transitions and the polluting nature of death are in some ways born of a Western humanist assumption that to be human is to fear and thus seek to overcome death (Becker 2004). A result of this assumption is that much traditional research on rituals tends to position "cultural death" as a special rite that certain "other" social groups practice, while the inevitable and inherently fearful "natural" biological processes of death and dying remain unquestioned in the background. In addition, claims (such as those made by Turner) about the inability to locate rituals in present-day societies serve to simultaneously construct ideas about the complexity of the "modern Western world" as in opposition to the simplicity and "culture" of more primitive, historical Others. These Eurocentric ideas fail to fully grasp the complexity that has always been present at important moments of transition such as death, and the potentially meaningful and useful role of ritual in making sense of this complexity.

Nevertheless, investigations into ritual transitions of death and dying and cultural rites of passage have helped to identify spatial components of dying, along with some elements of the socially contingent aspects, particularly surrounding affect. The concept of a socially mediated material death highlights how death cannot be located as an instant in time, but rather appears as a more complex process facilitated by the interactions of the

surrounding community. In a final analysis, however, research about death and dying from the perspective of death as a social-cultural ritual overlooks the contingent material reality of death itself by almost always assuming some “natural” underlying fact of biologic death that occurs outside of the ritual social transition.

Stefan Timmermans’ (1999) work on sudden death in North America provides one important example of recent work on modern rituals of death and dying. In this work, Timmermans attempts to challenge the assumed nature-culture divide while still attending to social and cultural practices. In his exploration of the history of sudden death and the life-saving technology of cardio-pulmonary resuscitation (CPR) in North America, Timmermans demonstrates how the practice of CPR has simultaneously become a form of ritual to permit death while also changing the material nature of death itself. By undertaking an exposition of the history of CPR combined with a detailed ethnography of the practice of CPR at a large American hospital, Timmermans demonstrates how the bio-physical concept of a “sudden death” has been all but eliminated. Instead, life-saving technologies such as defibrillators, ambulances, and mandatory CRP training work to insert space and time into the dying trajectory. In the presence of emergency medicine and trained first responders, the absence of breath and pulse no longer signifies a body that is dead but rather a person who is in need of immediate resuscitation and transport to a hospital. Only after resuscitation has been conducted for an appropriate amount of time is death declared. The “lingering death” timeline produced as a result of the stretched dying trajectory from accident location to

hospital bed allows time for rituals such as the final family visit and the kiss goodbye.

Similarly, maintaining a state of life in the body may allow the medical team to continue to investigate abnormalities and maintain the premise of a possible recovery.³

Timmermans' analysis foregrounds the role of the technology of CPR in blurring the nature-culture distinction between perceptions and realities of death. His creative use of the concepts of rites of passage and social ritual also allowed him to investigate the bigger picture of why life-saving interventions are desired and sometimes mandated for people who might otherwise be considered dead.

The concept of ritual social transitions surrounding death and dying continues to be an important tool for thinking about when dead is really dead. A consideration of the social and cultural aspects that help to shape interactions around death and dying is necessary to produce an adequate understanding of the material process through which death occurs. To be most useful, analyses must take into account the multiple complexities and exceptions inherent in all social processes. In addition, one must remain aware that the concept of ritual can carry assumptions about Otherness in opposition to some privileged and unspoken Eurocentric norm. Social and cultural ritual practices do not occur against an assumed and unquestioned backdrop of what is truly happening to the body in some ideal human nature. Instead, they are themselves involved in the ongoing process of shaping and being shaped by material physical processes. To fully

³ An additional and more recent consequence of the stretched dying timeline, not touched on by Timmermans, is the increasing potential for deceased organ donation from people who die after attempted CPR (Ortega-Deballon, Hornby, and Shemie 2015).

understand how this is the case and before applying this lens to some present-day contexts of death and dying, a more detailed examination of the assumed “nature” of human death is warranted.

Death as rational scientific fact

When early anthropologists encountered the death rituals of non-European peoples, their observations of “primitive” rites were framed in comparison to modern “scientific” understandings of death established during the Enlightenment era. In Europe, the scientific revolution of the 17th century saw a shift in understanding of the external world from an ethereal truth created by God in an already perfect form to a rational, objective reality which could be systematically observed and manipulated. Methodical observations about differences between people encountered through colonial exploits resulted in scientific assertions of both a prototypical Man and the subsequent exclusion of non-white, non-male gendered, and non-European others from the exclusive category of human (Willinsky 1998).

Many critical thinkers and scientists working during the period of modernity focused on describing and understanding the fundamental nature of humankind. For example, the psychoanalytic theories of Sigmund Freud provided a starting point for many subsequent scholars interested in the workings of the human mind. Freud’s conception of the human subject as assembled from a rational, conscious mind (the ego) and an irrational, unconscious mind (the id) expanded possibilities for thinking about human behaviors and social tendencies, including death. In his later work, Freud (1963)

proposed that all humans possessed a “death drive,” the desire for death and destruction, which is held in opposition to and as part of a “pleasure drive” within the unconscious mind. Freud proposed that the ego, with its narcissistic aims of self-preservation and control, worked to manage and repress pleasure and death drives, permitting them to emerge only in ways that are socially acceptable.

Freud’s idea of the death drive as a constitutive part of the rational human psyche inspired new ways of thinking about the modern social and biological fact of human death (Akhtar and O’Neil 2011). Anthropologist Ernest Becker (2004) considered in further detail the social aspects of how the death drive, as a fear of death, became a defining aspect of human nature. In line with Freud, Becker (2004) proposed that children come to learn about and then immediately repress understandings of their mortality from a young age. Absence of such repression, proposed Becker, would lead to mental paralysis resulting from fear of inevitable death (Robben 2004:2–3). To escape the paralysis of knowing and thinking about death, Becker suggested that humans seek to evade their deaths through cultural projects of immortality such as leaving behind a legacy (Green 2008:4–5), a theory further developed by Lifton and Olson (1974) with their concept of symbolic immortality.

Much later, Zygmunt Bauman (2013) again re-worked theories about the inherent human fear of death and its social and cultural responses by positing mortality as a “defining feature of humanity,” and the consequent quest to evade death as a major

motivating force behind long-lasting cultural projects.⁴ In his analysis of cultural strategies for eluding death, Bauman argues that the period of modernity is defined by an obsession with mortality in which denying death becomes a routine part of everyday life, accomplished through actions such as exercising, dieting, and public health initiatives like the prevention of accidents (2013:10; Lock 2002:201). In contrast, a postmodern strategy involves an obsession with immortality in which death and rebirth, enacted through risky and “near death” experiences such as skydiving and drug use, promise an endless life of the everyday (Bauman 2013:10). Bauman argues that a combination of both strategies are employed as part of a modern cultural impetus to postpone individual human death as long as possible (Lock 2002:201).

In philosophy and psychology, a focus on describing the rational individual human mind inspired social scientific focus on the terror and denial of death as a core feature of the human condition. At the same time, a modern emphasis on measurable scientific rationality triggered transformations in the practice of Western medicine and resulting biological conceptions of bodily death. In *The Birth of the Clinic*, Foucault (1973) explains how the concept of scientific objectivity as applied to the study of the human body transformed the role of the physician from healer to diagnostician. Instead of treating the subjective needs of patients, physicians became more concerned with identifying abnormalities and aberrations of the assumed normal and natural human body. Where doctors had once sought to assuage physical and mental suffering, they now used

⁴ As pointed out by Lock (2002:202), Tierney (1997) has suggested that this argument is similar to Heidegger’s theory of “being-towards-death.”

medical technology to search for “objective” signs of diseases. Foucault famously titled this searching behavior as the “clinical gaze” (1973:143–46).

Death and technology are closely linked to the clinical gaze because of their ability to facilitate ever more detailed investigations into the interior structures of the body. The practice of dissecting dead human bodies, instead of the animal corpses which had previously been used, allowed clinical scientists to “see” with their own eyes the insides of the body and the abnormalities caused by disease. The process of death provided the materials through which modern medicine could empirically uncover its desired objects of study. In keeping with Enlightenment ideals in which the findings of empirical science and rationality gradually acquired greater cultural importance than the religious ideology of the church, autopsies also performed an important political statement of allegiance with humanist progress.⁵ In this paradigm of bodily objectivity, death is an endpoint of one human life, but also the moment at which “truth” about the body is finally revealed (Foucault 1973:143).⁶ The epistemic shift in medical thought which began in the 17th century saw the concept of disease morph from that of an accident or a curse into a physiologic process which could be precipitated, controlled, and prevented through human means (Foucault 1973:155–56). Death, as the moment at which

⁵ Members of Paris’ 19th century Mutual Autopsy Society, a private club in which members donated their bodies to be objectively examined after death, were at least as likely to be vehemently against the church as they were in support of scientific progress (Green 2008:40–45).

⁶ Interestingly, this approach located all “truths” about the alive body in the *dead* body, highlighting the strange relationship between death and modern medicine since its inception.

truth about disease processes could be revealed, also became less important in itself and more relevant as a tool for exploring what went wrong.

Rather than gaining importance as a focus for specific investigation, the role of death as a perspective for understanding the intricacies of the human body caused it to be quite literally overlooked as a result of its being looked through. From this medical perspective, death is not a moment of transcendence or transition to a new social state but rather the moment at which the power of medicine can no longer control disease and has thus failed in its role. With the shift in epistemological understanding of disease, scientific medicine became focused intensely on characterizing diseases, how they can be diagnosed, their course in the body, and their potential treatments. This “objective” perspective ensured that patients’ personal experiences of their conditions took a secondary role to the technologically-mediated investigations of body structures and organ function. The modern physician sought the demonstrable “seat” of disease in order to apply a diagnosis and afterwards, a treatment (Foucault 1973:140). This form of rational scientific medicine, which underlies current practices of what I continue to refer to as “scientific medicine,” assumes the presence of a universal natural human form at the core of each idiosyncratic individual. The practitioner’s goal is to identify the specifics of each patient’s deviations (i.e. diseases, disabilities) and to apply forms of treatment or “cure” that return patients to the ideal, the normal (Clare 2017). Death itself has no real role within this medical paradigm other than to signify the failure of treatment or diagnosis. It is no surprise then that despite widespread enthusiasm for the new post-

mortem investigations of scientific medicine and a modern approach to death which seeks to integrate awareness of mortality into everyday life, few direct explorations of the nature and form of bodily death itself were conducted.

On a population level, the 17th century also saw the convergence of medicine and state control. An “avalanche of printed numbers” in the form of reliable public records and an understanding of disease as caused by controllable, natural structures combined to form the field of public health (Foucault 1973; Hacking 1982). Armed with the technologies of vaccination and scientific knowledge linking certain exposures to disease, state officials could work to control the growth, life, and death of populations. Rather than using power to repress and oppress populations, Foucault (1978) theorizes through his well-known concept of biopower that the authority of the modern state is used to enhance the conditions under which life can flourish. In his analysis of the role of state-controlled public health, Foucault emphasizes the pervasive focus on life as the centre of power, so much so that death is all but forgotten. The flip-side of this position is that large swaths of the population are (at times strategically and deliberately) left to die or considered as-good-as dead due to their lack of power or desirability (Agamben 1998; Butler 2009; Mbembe 2003). Historically, this trend has also been visible through eugenic policies of sterilization and forced institutionalization of disabled, racialized, queer, gendered, and otherwise “abnormal” bodies supposedly in need of medical correction or cure (Clare 2017; Ordover 2003). Today, although overtly eugenic policies are uncommon, an underlying necropolitical force remains present and hidden within

different language. For example, while plans are made for expensive improvements to emergency room medicine for urban centres, many remote Indigenous communities continue to live without clean drinking water (Ontario PC Party 2018; Schlote 2019). This is an insidious form of necropolitics that locates the value of urban, economically productive life and makes peace with allowing the untimely and preventable deaths of “othered” communities. The many, many similar examples provide evidence of how government management of resources is not necessarily centred around cost-effective maximization of life itself, but rather seeks to sustain and further some life and some forms of life at the expense or neglect of others. The insidiousness of this dynamic is that death and dying remain relatively unspoken, unrecognized events. There is no active killing in a necropolitical approach, and thus no moral quandary (Bauman 1988). Rather, certain populations considered less valuable are left to die “naturally,” allowed to die through their own means and decisions which can rarely be directly pinpointed or blamed on government inaction. With necropolitics, as with biopolitics, death as a concept in itself remains missing in action and undertheorized.

Just as the death of the patient in the clinic is considered a failure of the medical practitioner, death at the population level represents a loss of power of the state, and an economic failure (Bayatrizi 2010). This is the motivation behind large-scale public health measures such as requirements for seatbelts, sanctions against drunk driving, and anti-smoking legislation - these political actions aim to reduce untimely deaths in young people and thus maintain a higher level of power and productivity. Power, the potential to

act, interact, and to build a future, rests only with life and more so with some lives and forms of life than others. Thus, in the setting of Western scientific medicine and its associated public health practices, death is something to be controlled and limited, allowable only for certain undesirable populations in specific contexts, such as those deemed as no longer economically productive. At the same time, it is something to be mostly avoided and not actively inflicted. Given these theoretical premises about biological death, when is dead, really dead? Within the setting of Western scientific medicine, death is an objectively measurable event that occurs “naturally” inside of a normal human body. In contrast to earlier religious and ritual theorizations, the moment of death from the viewpoint of rational scientific medicine is not necessarily recognized as an imperative or socially important event affecting a collective social body. Instead, clinical death occurs in the individual human body against contexts of failure, absolute loss, and/or exclusion within scientific medicine. After centuries of medical practice, the objective “nature” of bodily death has been barely characterized and poorly theorized due to its associations with disappointment and loss and its location as an endpoint of disease and bodily power, rather than an event-in-itself. However, this pattern of the unexamined clinical death has been gradually changing, as advances in medical technologies and critical theory about the production of scientific knowledge meet to apply new pressure on old, unexamined assumptions.

Challenges to rational scientific death

In September of 2017, a young Black woman named Taquisha McKitty was found unresponsive on a sidewalk in a suburban community of Toronto. An ambulance

was called, and Taquisha was rushed to hospital where she was stabilized on life support therapies consisting of drugs used to maintain her blood pressure and heart rate, and a breathing machine. After 6 days of active, life-sustaining treatment in hospital, physicians announced to the McKitty family that their daughter had sustained unrecoverable neurologic injuries from a likely drug overdose and that she met criteria for the neurological determination of death (Howorun 2017). Similar to many brain dead patients, the young woman continued to be warm and well perfused, to move when touched, and according to her family, to occasionally shed tears (Janus 2018). The McKitty family insisted that Taquisha was still alive and pursued a court injunction to prohibit the hospital from removing life support therapies despite the medical declaration of death using neurologic criteria. While the court case was ongoing, Taquisha remained in the intensive care unit supported by drugs, machines, and healthcare personnel. Her family, including her young daughter, visited daily. When the case was tried at the Ontario Superior Court of Justice, the judge determined that accepted medical practice in Ontario had been followed and that Taquisha was indeed dead (Ontario Superior Court of Justice 2018a). The McKitty family appealed this decision and maintained that their daughter had a right to be determined dead based on religious beliefs about when and how life ended. More than a year after her initial admission to hospital and while the case was being considered in the Ontario Court of Appeal, Taquisha McKitty's heart stopped beating and she was permitted to "die naturally" (Gibson 2018).

This recent, highly publicized case, to which I return in more detail in Chapter 6, is just one example of an increasing number of challenges being made to the prevailing rational scientific definition of death. Instances of challenged determinations of death call into question the assumption that death is an event that can be universally located inside of human bodies and described and characterized using the “objective” tools of scientific medicine. It is not a coincidence that the most recent publicized cases of families contesting medical determinations of brain death have all involved bodies historically excluded from the category of the “normal human” in scientific medical practice: young Black and Latina women, and Orthodox Jewish men (Gostin 2014; McGillivray 2018; Paris, Cummings, and Moore 2014). Western scientific medicine, with its assumption of a white, male, European universal human, has historically treated racialized bodies as less-than human and prone to disease, with resulting inequalities and unfair treatment (Chen 2012; Clare 2017; Snorton 2017). Racist assumptions about the physiology of bodies have a long history in medical knowledge production (the Tuskegee Syphilis Study experiment provides one well-known example (Brandt 1978; Reverby 2009)), and systemic racism present in everyday interactions and institutional structures of medical practice continues to be documented (Crawford-Roberts et al. 2020; Hoffman et al. 2016). Similar examples can be easily located regarding exclusions of women and gender-non-confirming persons, sexual minorities, persons with disabilities, poor people, religious minorities, and all other peoples who in some way do not fit into the white, male, European universal “human” norm. The not-so-distant history of the eugenics

movement sometimes unwittingly and other times overtly supported by scientific medicine, and associated practices of allowing certain marked bodies to die makes clear the relationship between racism and the declaration of death (Larson 1995; Ordover 2003; Pernick 1996). It is not surprising, then, that bodies historically excluded and most likely to be marked “as good as dead,” should be the first sites of public contestation about the power of scientific medicine to determine the moment of individual death.

So far, public scientific and political debates inspired by recent cases of contested determinations of brain death tend to focus on the ethical and philosophical questions of whether religious beliefs should be permitted to determine the moment of death. Left out is a critical, historical analysis of the role that social inequalities may play in shaping these individual cases. Linking histories of social exclusions to recent contestations of the declaration of death unearths larger challenges to the power of scientific medical knowledge to determine the boundaries and limits of certain physical bodies, and to exclude potentially disruptive alternate worldviews. The possibility that death could be fragmented into multiple understandings and the consequent requirements for consent to declare death produces uneasiness in some medical practitioners and bioethicists (Antommara, Sveen, and Stalets 2020; Bertino and Potter 2020; Lewis and Pope 2017; Paris et al. 2014).

An additional unspoken tension that underlies the anxiety surrounding contested declarations of death has to do with the medical technologies used to facilitate bodies in the supposed absence of life. Without breathing machines and the powerful drugs used to

maintain heart rate and blood pressure, it is next to impossible that the woman described in the case above would have been maintained as she was in a hospital bed for over a year. Indeed it is only the quiet success of life-supporting technologies that permit a person who has sustained devastating neurological damage to continue to exhibit “signs of life” (Macdonald et al. 2008). The blurring of the boundaries between bodily and technical life has helped to open up spaces of possibility for families to contest declarations of death and to put pressure on the epistemic assumptions of scientific medicine. Despite their role in facilitating challenges to the authority of scientific medicine, life-sustaining technologies themselves (e.g., who produces them and who has access, where, and at what cost) remain relatively unquestioned, unchallenged, and undertheorized.

Challenges to the authority of scientific medical definitions of death have also emerged from within scientific medical practice itself. Physicians and transplant surgeons introduced a major split in the definition of death with the introduction of the concept of neurologically determined death in 1968 (Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death 1968). Prior to this publication, clinical death was established through the absence of heartbeat and circulation, visibly and tangibly assessed through the classic “flatline” on the bedside electrocardiogram (ECG) monitor and a lack of palpable pulse. The idea that there could be two ways to die, either through cessation of circulation or through the establishment of a lack of brain function, has been an ongoing challenge to medical practitioners if only through the inability to

attain clarity in language. Not all practitioners accept the reliability of a neurologic declaration of death, with a few outliers arguing that a definitive state of brain death cannot be proven or adequately measured (Rady and Verheijde 2017; Shewmon 1987, 2012; Verheijde and Rady 2014). Recent work on “covert consciousness” in comatose patients (Edlow and Fins 2018) and the successful “restoration” of deceased pig brains (Vrselja et al. 2019), along with the persistent inability to harmonize the criteria and methods for brain death testing (Greer et al. 2016; Wijdicks 2002) maintain the precariousness of the validity of a neurologic definition of death.

The concept of neurologically determined death was promoted as a means of fostering the life-saving practice of deceased organ donation, and the two concepts are often perceived as being closely related (Lock 2002). Recent advances in organ donation now permit retrieval of organs following the cessation of circulation in patients who cannot be declared brain dead. That deceased organ donation is no longer restricted to brain dead individuals is a practical boon for transplant programs but an additional philosophical tripping hazard in the language of scientific death. How can hearts be donated after death has been declared because the heart stopped? Isn't the heart dead? Some supporters of heart donation following circulatory determined death have called for a reconciliation of the two types of death. They argue that all death is located in the brain and is caused when blood no longer circulates to the brain (Shemie and Gardiner 2018), a conception of life and death rooted in Western humanist traditions centering rationality and consciousness (Lock 2002). Protocols for heart donation after circulatory

determination of death raise further questions when they involve resuscitation of the heart inside the donor's body facilitated through surgical procedures that close off circulation to the brain (Dalle Ave, Shaw, and Bernat 2016; Page, Messer, and Large 2018). These advances in deceased organ donation technology further blur the scientific medical concept(s) of death and threaten the assumption that all organ donors are dead prior to organ retrieval (Joffe 2007; Nair-Collins and Miller 2016). Ongoing challenges about how and when to establish circulatory and neurologic death and how best to deal with the concern, "When is dead, really dead?" persist within the medical community.

The examples of challenges to the neurological declaration of death and the concept of heart donation after circulatory determined death make clear that the splitting of the scientific medical concept of death is multi-faceted. Spurred on multiple sides by family advocates, organ donation supporters, legal and ethical analysts, laboratory researchers, and concerned medical practitioners, contestations and cracks in the scientific concept of death are enabled by the liminal spaces between life and death made possible through advanced life-sustaining technologies. The in-depth examination of death made possible through the technologically sustained living/dying body highlights the cracks in "objective" scientific medical definitions concerning the reversibility and permanence of biological states. It also subtly draws attention to larger fissures in the practice of scientific medicine itself, with persistent tensions in its epistemological and ontological understandings of life, death, and the (universal) human body.

In some ways, death can be thought of as another “black boxed” technology of modern medicine, facilitating knowledge practices while itself remaining deeply ingrained and unquestioned (Latour 1999). Like other “black box” technologies and definitions, rational scientific death contains assumptions and expectations about the concept of death and about the concept of the human to which it is applied that have been stabilized into a form that can be used regularly (Benjamin 2019:34–36). Medical school curricula and clinical practice guidelines outline how death is a permanent and irreversible condition of the human body, one that can be established either through specific neurological testing or through more general examinations of the circulatory and respiratory status of the body. In what follows, I highlight a few of the many assumptions contained within this accepted definition.

A first assumption is that some normal, “natural,” human form exists as the basic template for the study of human medicine. This is the bodily form in which the “natural history” of diseases, and of death, can be inscribed. The “normal human” most commonly illustrated using Da Vinci’s Vitruvian man, itself contains culturally and historically contingent assumptions about what it means to be human, locating normalcy in a white, male, able-bodied form in which the circulation of blood and fluids are central to understandings of liveliness (Braidotti 2013; Kuriyama 1999). The practice of Western scientific medicine involves first characterizing disease as deviation from this norm and then establishing mechanisms for returning the body to a state of normalcy. However, as pointed out by extensive critical work in feminist science studies, de-colonial studies, and

critical disability studies, this “normal human” is not so representative after all. The stereotypical normal human fails to account for the many ways in which bodies can differ while still remaining alive, healthy, and functional in their own way (Clare 2017). Medical practice is benchmarked on standard normal laboratory values and physiologic measurements resulting from research on “healthy subjects,” a category which continues to either exclude or poorly represent women and racialized bodies (Epstein 2009; Liu and Dipietro Mager 2016; Tahhan et al. 2020). It is thus not surprising that recent contestations of the concept of scientific, rational death have been led by non-white “others,” those whose bodies have never quite fit into the “norm” of scientific medicine.

A second assumption contained within the scientific medical definition of death is the separation of the “nature” of the body from the culture of human society. This inference implies that “death is death” as applied universally to the material human body, while cultural practices such as rites of passage surrounding death are something entirely different, perhaps falling into the scientifically discredited realm of “beliefs” (Bernat 2013). The supposed separation of “culture” from scientific medical practice fails to account for the many ways in which culture is inscribed within medical knowledge practices. Objective investigations of diseases and their potential cures are always embedded within prevailing knowledge claims and available diagnostic technologies (Fleck 1981; Latour and Woolgar 1986). This is particularly evident when considering the scientific medical definition(s) of death, many of which would not be possible in the absence of advanced medical technologies and the capacity to interpret them (Lock

2002). The separation of “nature” and “culture” within scientific medical practice mainly serves to undermine the cultural knowledge practices of some populations while upholding the cultural knowledge practices of dominant (Western, Eurocentric) groups. Religious beliefs in an afterlife requiring the maintenance of the body until cardiac arrest or beyond are labelled “cultural” and thus non-rational and non-scientific, while medical support for organ donation requiring facilitation of life support until a suitable recipient can be found is considered rational, scientific, and thus unquestionable. The recent court case of the young woman described earlier has as a central concern whether “cultural and religious beliefs” should be permitted to factor into determinations of death, a verdict which could impinge on scientific medical power.

A final assumption contained in the “black box” of rational scientific death holds that the definition of death is an absolute state that can be objectively characterized, measured, and located inside of the human body. This assumption is directly related to the previous two premises, asserting that an objective viewpoint about human death can be maintained by referring to an abstract concept of the normal that is neatly severed from any “cultural” considerations. Thus, when critiques of the previous two assumptions are made, the concept of scientific objectivity becomes noticeably questionable. How can any observation be objective if it is always made through the framing of a stereotypical and perhaps non-existent “normal,” and without an understanding of its own grounding in scientific culture? Donna Haraway (1988) brought forward critiques of this particular formulation of scientific objectivity in her essay, *Situated Knowledges*, by pointing out

the inherent flaw in such a “view from nowhere.” Haraway critiques the form of objectivity of scientific medicine as, “the gaze that mythically inscribes all the marked bodies, that makes the unmarked category claim the power to see and not be seen, to represent while escaping representation” (1988:581). This viewpoint, represented well by Foucault’s concept of the “clinical gaze,” is the mechanism through which humanist scientific medicine makes claims about the “truth” of human death while escaping any acknowledgement of the historically, culturally, and materially contingent modes in which clinicians and medical scientist come to “see” in the first place.

Haraway (1988) argued that in place of an unexamined viewpoint, observers should acknowledge their specific cultural, historical, and material location in order to provide more contextually situated knowledge claims. The result is that each point of perspective yields a different picture of reality, a finding that has been demonstrated empirically in science and in medicine (Barad 2007; Mol 2003). For practitioners of a positivist formulation of scientific objectivity which bases observations on universal norms, this position appears to open the door to the relativist claim that all perspectives of reality are equally valid. However, feminist standpoint theory, into which the concept of situated knowledges has been adopted as a central tenant, avoids this shortcoming by asserting the strong objectivity made possible by a rigorous grounding of observations and truth claims in socially-situated knowledge (Harding 2004). Recent challenges to the rational scientific definition of death threaten the clinical gaze and the assumed concept of scientific objectivity by insisting on the possibility of alternate perspectives about what

it means to be alive and what it means to die in clinical spaces. Taking these historically marginalized viewpoints seriously threatens to disrupt the belief in a singular “objective” medical practice, and potentially a singular objective moment of human death.

Theorizing death amidst present-day complexity

The “black box” of the medical scientific definition of death is increasingly under pressure. It is showing cracks in the surface, in terms of when and how someone in a hospital bed can be determined dead, and whether neurological or circulatory definitions of death should prevail in specific circumstances. Persistent tensions in these surface cracks point to larger fissures within the underlying epistemological approach of scientific medicine in terms of its humanistic assumptions and exclusions, the separation of nature and culture, and the belief in objectivity achieved through the clinical gaze. Present-day contexts in which death is declared continue to become more complex as life-sustaining technologies get more advanced and new practices of deceased organ donation are piloted. At the same time, historically disadvantaged populations continue speaking out against exclusionary scientific knowledge practices of medicine. After decades of advocacy, patient’s rights groups now have more power than ever to determine the practice of medicine (if only through imposing the ominous fear of litigation).

How can we approach the question, “When is dead, really dead?” against the current backdrop of uncertainty and shifting power dynamics? What conceptual tools exist to think about this question in an ethical and socially just manner? The earlier analysis of

anthropological findings about rites of passage and social transitions has already demonstrated that an appeal solely to the “social” or “cultural” aspects of death and dying cannot escape flawed assumptions about the truth any more than “scientific” perspectives can. We need a new way of approaching death that takes into account but moves beyond the messy aspects of both “nature” and “culture,” one that does away with the impossibility of universal objectivity but is still ethically accountable. We need a mechanism for theorizing death that remains flexible and capable of embracing the inevitable future complexities encouraged by advanced medical technologies.

The theoretical approach of posthumanism offers a useful position thinking about technologically mediated death. Based on a feminist and post-colonial informed critique of objectivity and a moving-beyond of Eurocentric humanism, and combined with a commitment to decentering and dethroning the (ideal) human, posthumanism represents a transformative approach to critical theory (Braidotti 2013, 2018, 2019). A central component of posthuman theory is an emphasis on distributed and relational, rather than individual and rational subjectivities (Braidotti 2019). Thinking and knowing subjects are comprised of many extending and ongoing (“unfolding”) relational events between humans and non-humans, including technical apparatuses and geologic forms. Because of the post-humanist and post-anthropocentric commitments of posthumanism, humans are not viewed as holding sole epistemological authority. Instead, an insistence on egalitarianism and distributed subjectivities locates the capacity to know, and thus the capacity to affectively relate, to all matter (Braidotti 2013). In keeping with feminist

politics of location, the capacity to relate through knowing is also always grounded in a specific, multifaceted perspective. There is no “view from nowhere” to facilitate universal and unquestioned objective observations (Haraway 1988, 1997) in posthuman theory. Instead, all positions of knowing are acknowledged as partial and situated by the reality that the position of “human” is itself differentially constructed. As explained in a recent paper:

The posthuman is not so much an abolition of the human but an expansion of the terrain in which it is constituted, and an acknowledgement that the human is never neutral but rather structured by multiple grids, gradients, layers and locations. (Braidotti and Fuller 2019)

Taking this position seriously has implications for how we understand the limits of the human body and how we theorize the ethics of living and dying.

Before exploring posthuman theories further it is important to note the difference between *posthumanism* as a theoretical perspective seeking to move beyond or outside of an idealized human/Anthropos center, and *trans-humanism* as a quest for idealized human augmentation. These positions are often confused. Transhumanism, popularly championed by billionaires and eccentrics, is a movement seeking to channel money and material resources into the technical and scientific “advancement” of individual human bodies (Solomon and Bostrom 2005). Transhumanist projects seek to further solidify the tenants of the ideal human body and mind, promoting and investing in technologies to extend individual, rational life and enhance cognition and memory, for those who can afford it (Alcor 2020; Bostrom 1998). Unlike posthumanism, which seeks to continually challenge, critique, and dismantle the flawed and exclusive category of human,

transhumanist projects tend to promote an entrenched view of the position of Man as uniquely rational centre and unique leader of a technologically advancing world (Bostrom 2005). The two viewpoints do overlap in their acceptance of the subjective positions of cyborg or “more than human” bodies, but they differ substantially in their ethical and political positions on the nature of the category of human and the centering of rational scientific thinking (Braidotti 2019:59–60).

Feminist philosopher Rosi Braidotti has combined the tenets of posthuman theory with a version of Spinoza’s materialism to explore how all matter contains life (2006, 2013; Lloyd 1996). Where 17th century Dutch philosopher Spinoza controversially described this universal life force as the many attributes of God (Lloyd 1996; Surin 2010), Braidotti reimagines this pervasive life force from a secular position as *zoe*, that unnamed and untameable form of life that is within everything and that makes all things matter. In her work, Braidotti outlines how this form of *zoe* is a positive, celebrated element which fosters affective relations of knowing between distributed or nomadic subjects (i.e., subjects formed as a collective of relations, rather than imbued within any single physical body). This is a different *zoe* than Agamben’s “bare life,” which is considered worthless and expendable unless in the service of rational, political *bios* (Agamben 1998). Braidotti’s *zoe*, through its balance and flow in all things, is unending and continually unfolding in a promise of endless becomings in keeping with the transformative and relational subject espoused by Deleuze (2006, 2013; Deleuze and Guattari 1987).

Jane Bennett (2010), also working with the materialist philosophies of Spinoza (among others), provides a similar approach to thinking beyond the human with her concept of vibrant matter. Similar to the concept of *zoe*, vibrant matter emphasizes the liveliness of non-human things and is a way of describing how non-human matter, for example, life sustaining technologies such as breathing machines, come to have important roles in human agency (Bennett 2018:447). Bennett operationalizes vibrant matter as a tool for understanding how the ability to act (agency) is always an assemblage of human and non-human forms. Braidotti's concept of *zoe* in comparison, is used more in the services of describing how a post-human and post-anthropocentric shift also modifies the very capacities for subjectivity and thus for the production of knowledge (2019:50–51).

Ultimately both concepts of *zoe* as unnamed life force and vibrant matter are imagined as theoretical tools for moving past, “[t]he fetish of the exclusively human agent and the associated tendency to define social problems as moral failures – and the implicit assumption that it is we humans who are always in charge...” (Bennett 2018:447). Concepts from posthuman critical theory and feminist new materialism offer a novel mode for exploring and analyzing the affective relations involved in unfolding human and non-human distributed subjectivities. Their refusal to locate the human as the centre of all knowing and acting expands available analytic and ethical frames with renewed possibilities to conceive of a (better) world amidst technical complexities and shifting power dynamics.

The intervention of posthuman critical theory in thinking through technologically mediated death and the question, “when is dead, really dead” has a number of interesting implications. Posthuman theories get outside of limitations of the assumed divide between nature and culture and the Eurocentric, humanist ideal. Instead of imagining some biologic reality in the dying or dead body that is consistently interpreted (though perhaps differently by different cultures), a posthuman perspective is concerned with the specific materially embodied and affective relations that produce death in particular contexts. It becomes concerned with the question of which types of subjects die, and how. In addition, instead of understanding death as located in an individual body, a posthuman perspective would seek to understand how distributed networks of humans and non-humans interact through different relational connections to establish a materiality of death. The capacity to move beyond the focus on the individual, stereotypical affluent, White, male European human body and to instead include distributed assemblages of different human and non-human actors involved in producing material states of death is a significant strength of employing a posthuman theory.

The posthuman idea that life, as *zoe*, is unending and present in all things also turns historical understandings of death on their heads. Instead of locating death as the moment of the absence or end of power, as a loss, or as failure, the concept of *zoe* as a shared form of Life allows the death of one body or the destruction of one thing to be reconceived as a generative moment allowing for the continuation of Life and the ongoing formation of new affective relationships (Braidotti 2006). From a posthuman

perspective, while the demise of any subject is a social and relational loss depending on context, the death of the human holds no specific inherent loss. It is “merely a point... not the horizon,” against which the meaning of social and cultural life takes place (2006:247).

In her posthuman theory of death, Braidotti clarifies that this insistence on the power of *zoe* should not be misinterpreted as a religious call for belief in eternity but rather acknowledges our secular desire to be part of something larger along with the material reality that matter continues to be reconfigured and remodeled outwards in a continuous process of regeneration, cooperation, and multiplication of difference (2013). She also links this idea to a concept of ethics that is respectful of the differential power of individual subjects (keeping in mind that subjectivities are always components of larger relational networks) without invoking the social judgements often associated with concepts of morality (2006:247). Within this paradigm, death of the individual body is a locating of the specific ethical limits of that body, realized as a positive desire to enfold back into the endless becoming of *zoe*. In this way, death of the body and the dissolution of the subject can be approached as a positive, generative moment in which universal Life continues on. This death moves beyond the death drive of Freud and the being-towards-death of Heidegger, both of whom envisioned death as an act of destruction resulting in absolute loss of the human individual (and thus something to be actively repressed or avoided) (2006:240–47). Instead, the inevitable dissolution of the subject is configured as a positive becoming, another attribute along our collective trajectories

towards sustainable futures. Notably, this theorization of death does not demonize suicide as an immoral act but rather views the act of taking one's own life as an ethically viable conclusion for when a subject has reached their respective limits. Understanding death in this manner, as the moment of continuation of *zoe* rather than a devastating loss or absence of the human, has the potential to significantly shift the ways in which technologically mediated death may be perceived and analyzed.

A posthuman theorization of death offers new ways of thinking through this common but under-studied event. It gets beyond understandings of death as a culturally interpreted biological event and inspires a more dynamic look at the complexities involved in the technologically mediated death of the present and likely future. A posthuman approach also requires close attention to aspects of power (theorized as both the positive power to generate and the negative power to restrict possible futures), which, when using a posthuman theory of death does not simply avoid and end at death but in some cases seeks to establish death as an ethical and productive threshold. A posthuman approach to the question, "When is dead, really dead?" forces a re-thinking and revision of the question itself. We must be concerned with who is doing the asking, from which standpoint, and in what contexts. The material aspects of the question are also important, including which human and non-human relations are involved and ongoing, and which entities have the power (productive or restrictive) to modify how the future establishment of death is done. Finally, understanding the desired thresholds of the limits of the specific dead/dying body in question is required in order to understand the dynamics of each

particular establishment of death. A better question, from a posthuman, new materialist perspective, might be “*How is ‘dead’, really ‘dead’ in this specific context, and for this specific relational subject?*” The central role and commitment to ethics attended to by a posthuman perspective also entails the follow-up questions: what kind of future we are producing through a present that fosters certain mechanisms of death? Should or could we imagine a different future?

Notes on theoretical approach

In this project, I seek to take on these important questions to provide a cartography of the complexities, tensions, and contradictions of common forms of technologically mediated dying. I am interested in employing a posthuman perspective to rethink the materiality of technologically mediated death and to more accurately explore the complex dynamics of power involved in negotiating life and death in scientific techno-medical contexts. Drawing on the principles of posthumanism allows a focus on the material, relational processes through which states of dead and alive are produced and established, rather than relying on their historically assumed static nature (van der Tuin 2018). The reality of scientific techno-medicine is helpful in this task, as the many material and affective interrelations between human and machine bodies are constantly blurring conceptual boundaries. A core component of this project, supported by the ideas of posthumanism, is a persistent focus on ethics. Questioning and seeking to understand how to act amidst complexity and despite incontrovertible doubt allows this project to attempt to retain some element of the practical and relatable.

A necessary starting point for this theoretical approach requires acknowledging the particular cultural and historic location from which I am motivated to theorize about technologically mediated death. My exposure to and understandings of technologically mediated death (by which I mean death that is in some way established through the presence of life-support technologies) is based on several years of clinical research experience in adult intensive care units combined with several months of intensive fieldwork in the intensive care unit at a tertiary care hospital. I have worked on numerous qualitative and quantitative studies involving deceased organ donation, traumatic brain injuries, and care of critically ill patients, all of which have as a background the presence and sometimes inevitability of technologically mediated death. My interest in further studying this phenomenon grew from observations about the persistence of unanswerable but nagging questions about death in the clinical research communities I am immersed in.

I am not a trained medical professional, but I completed a graduate degree in science in a Faculty of Medicine and continue to be involved in clinical research projects with physician and nurse colleagues. My familiarity with some medical knowledge but no clinical techniques makes me an insider/outsider in clinical spaces, where I speak (some of) the language but cannot help with practical tasks like inserting intravenous lines. Research in the intensive care unit itself sits in a liminal position. The intensive care unit I visited has many ongoing studies and a reputation for high quality research, yet daily research tasks are not part of paid work for bedside staff. The result is that clinical research is often begrudgingly tolerated as, “part of what we do here,” but is not a

central concern for most healthcare professionals. I obtained a final disjointed articulation within this environment when I began studying critical social theory. My more recent training as a sociologist has again shifted my perspective about clinical experiences and has allowed me to question the assumed epistemologies and unequal power dynamics surrounding the processes of technologically mediated death.

My approach towards death in this project is specifically focused on technologically mediated death, death that occurs through the control and in the midst of scientific medical life-support therapies. This is not a death that happens only to an individual human body in isolation but a death that very clearly involves the coordination of non-human others such as life-support machines, drugs, monitors, and treatment protocols within larger social contexts positioning the value of certain lives. In the intensive care unit, these non-human others at the bedside can sometimes seem to be more animated than the human bodies beneath the bedsheets. Colorful lines dance on digital monitor displays, numbers flash, alarms beep in various tones and speeds. The technology at the bedside is both an active carer for the patient through automatic measurements and safety alarms, while at the same time requiring its own care as nurses set the alarms and tend to machine-body connections (Strauss et al. 1985). Meanwhile, the human body lies still save for the regular rise and fall of a chest or perhaps the occasional twitch of a foot. My perspectives and thoughts are informed by a posthuman theory that thinks beyond the centrality of the stereotypical human and seeks to understand the power and potential of *zoe* within all forms of distributed subjects in the

intensive care unit. A posthuman perspective further allows for the perception of this techno-medical care and the possible death that follows as products of an extensive assemblage of human and non-human relationships that run throughout the tertiary care hospital, from the patient's family and their bedside vigil to the lab technician processing blood samples in the middle of the night and the government funding that makes the hospital possible. From my perspective as an observer of technologically mediated death and the relational networks that contribute to its enactment I find rational scientific medicine and its associated positivism and clinical gaze objectivity inadequate as a descriptive and theoretical tool. Instead, the relational epistemology and material-affective ontology of posthumanism appears to do better justice to the task of understanding the realities of death in clinical contexts. By working with and building from the concepts and method of posthumanism, I seek through this project to provide an ethically grounded account not of, "When is dead, really dead?" but rather of, "*How is 'dead', really 'dead' in specific contexts and for specific relational subjects?*"

Conclusions

Over time, knowledge practices surrounding the material establishment of death have ranged from a focus on the "cultural," through studies about rites of passage and ritual, to a focus on the scientific and "biological," through a focus on the specific parts of the body that must die in order for death to be established. Both of these perspectives, while offering interesting tools for thinking through human practices and experiences of death and dying, fall short of providing a workable theory of death that is accountable to

our increasingly convoluted and technologically mediated future. The recent splitting and fracturing of dominant scientific medical definitions of death and the resulting anxieties produced in intensive care make clear that the underlying epistemological and ontological assumptions made when producing these ideas about death may not withstand present and future complexities. In this project, I attempt to approach current practices of technologically mediated death informed by my participation and integration in a single field site along with a theoretical understanding of posthuman critical theory. My aim with this project is to move beyond the current “pretzel twisting” of language accomplished by advocates of the scientific medical definitions of death towards a fluid and ethical accounting of death as a material-affective and relational process achieved through the many networked interconnections of scientific medical practice. Informed by a feminist, new materialist, and posthuman methodology, my aim is to think through new ways of becoming-through-death that are affirmative for the posthuman future and workable in present-day contexts of advanced life-support technologies. I am not seeking to deny practices of organ donation or assisted suicide but rather to address current tensions and conflicts and attempting to creatively imagine a future to which we can be accountable (Braidotti 2019).

Poised at the pinnacle of advances in life sustaining technologies, the intensive care unit offers an ideal location for exploring the material and subjective nature of death in present-day scientific medical practice. In the next chapter, I present a brief history of

this field site along with an introduction to this technically and medically intensive clinical space.

CHAPTER 3 | Introducing the Intensive Care Unit

The practice of intensive care medicine operates somewhere between, “*do everything medically possible*” and “*make sure she doesn’t suffer.*” If the emergency department is a location for the application of critical first aid and the ritual revival of bodies made possible through cardiopulmonary resuscitation (CPR) (Timmermans 1999), the intensive care unit is the hospital service set up to deal with the care and bodily maintenance that is required next. After restoring a pulse and installing a breathing tube in the emergency department, critically ill patients are rushed to intensive care where they are continuously monitored and treated by a team of nurses, physicians, ventilators, and cardiogenic drugs. This concentration of advanced medical technologies necessitates a continuous balancing act between maintaining tentative holds on life and facilitating peaceful death for the most severely ill and injured patients. From its inception, the intensive care unit has represented a convergence between the optimism of new technologies and advances in medical practice, the emergence of new professions to conduct this practice, the hopes and desires of a culture focused on life, and the changing nature of death and disease. Today, the modern intensive care unit presents innumerable opportunities for encountering the intersections between medical practice, death, and technology. As a result, the intensive care unit is an ideal location for the sociological study of present-day paradoxes of dying, and the tracing through of posthuman accounts of subjective endings.

Before I launch more fully into a detailed analysis of the application of sociological theory to this medical and technical space, it is worthwhile for readers to have an idea of the technical environment and the sociological significance of the modern intensive care unit. In this short chapter, I present first a brief history of intensive care units and intensive care medicine in North America. I follow this with a detailed description, informed by my ethnographic fieldwork, of the field site in which I collected data. I then review existing observational and qualitative work seeking to understand processes of death and dying in intensive care unit spaces and suggest ways in which my work offers new perspectives and new openings to thinking differently.

A brief history of medicine, hospitals, and intensive care in North America

From its inception, the social practice of medicine has involved assessing signs and symptoms from the body and assigning an appropriate treatment, be it social, dietary, religious, or otherwise (Kuriyama 1999). In Europe, specific, repeatedly observed patterns of visible signs and symptoms were eventually named and classified as diseases (Foucault 1973). In the early 18th century, Western medicine still implicated external forces (God and later, Nature), as the major cause of most diseases. The role of the medical doctor within this paradigm was to first correctly identify and classify the disease, and then to support the patient as best as possible through the natural course of the illness (Foucault 1973:9). Physicians were mainly tasked with alleviating pain and suffering and often used this knowledge to support patients as they died from their afflictions.

By the 19th century, changes in the socio-political structures of society and in medical practice had spurred a shift in understandings of disease. Instead of thinking about diseases as a naturally occurring, classifiable species the way botanists and zoologists had been describing the flora and fauna of the new world, disease gradually became understood as a specific and measurable abnormality of the organs and tissues of the body (1973:191). This epistemological shift in the understanding of how to know a disease (sometimes referred to as the “diagnostic revolution”) changed the role of the physician (Sandelowski 2000). Rather than supporting the patient through a commonly identifiable and inevitable disease process, the modern physician is tasked with an objective search through the patient’s body to identify the specific malfunctioning organs and tissues. Foucault described this scientific searching as the “clinical gaze,” an invasive form of looking and searching which can only be satisfied with a true diagnosis once the patient has died and an autopsy allows unimpeded access to the interior structures of the body (1973:143–46). In cases where offending organs and tissues are located prior to the patient’s death, medical practice is expected to restore normality through the administration of treatments in what critical disabilities scholar Eli Clare (2017) refers to as the “violence of cure.”

The shift from supporting patients through their convalescence or death to seeking out and labelling internal, often invisible and symptomless abnormalities had a significant impact on the practice of Western medicine and its broader role in society. Throughout the 19th century, physicians and engineers developed an array of technologies to assist

with the increasingly invasive task of diagnosis. The stethoscope, invented by French physician René Laennec in 1816 so that he could listen to the sounds of the body without having to touch his female patients, was an early example of a technical device used to extend the scope of observation beyond the skin of the body (Roguin 2006).

Thermometers and sphygmomanometers (also more commonly known as blood pressure monitors or gauges) soon followed as devices that could be used to look inside the living bodies of patients (Sandelowski 2000). More advanced technologies of life-saving, such as forced airway ventilation and cardiopulmonary resuscitation (CPR), were invented during the mid to late 19th century and used with some success (Timmermans 1999; Trubuhovich 2007). Subsequent developments in the field included a technique for successfully inserting a breathing tube into the trachea through the mouth (bypassing the need for a tracheotomy) (Trubuhovich 2008), and the infamous “iron lung” (Sherwood 1973). By 1913, the first patient-triggered, pressure-cycled ventilator had been invented and was used occasionally for specific respiratory indications (Hilberman 1975:160). Since physicians were soon consumed with the tasks of determining diagnoses, skilled nurses were required to perform the work of symptom control and patient support that physicians had once completed. Nurses were also helpful for conducting and recording frequent patient observations which helped physicians in their diagnostic tasks (Sandelowski 2000).

Prior to the 20th century, most medical care was performed by private physicians in the homes of affluent individuals. Those who could not afford private care were

relegated to hospitals, often run as charitable institutions by the wealthy (Gagan 1989), or maintained by religious orders. At this time, hospitals were more likely to be the locations of long-term care for the mentally unstable, destitute, and dying than centers of “state-of-the-art” medicine as they are often portrayed today. By the beginning of the 20th century, this had changed. As the new technologies of the diagnostic revolution became progressively more expensive for individual private physicians to maintain, high-society funders of hospitals began to see the opportunity of concentrating life-saving technology and expertise in one location (Gagan 1989). Locating the best technology in one location would attract the most skilled physicians, ensure that they received regular practice with using the technologies, and could help to make the cost of cutting-edge treatments more economical. In Canada, the passing of the Hospital Insurance and Diagnostic Services Act in 1957 also influenced funding models as the federal government began contributing increasing amounts to public healthcare services (Government of Canada 2019). Soon the nuns and recovered patients who had been providing regular care in Victorian-era hospitals were replaced by mostly female nursing students who provided several years of free labor in exchange for room, board and skills training (Gagan 1989). Many hospitals continued to provide free or reduced-cost care to poor clients, but began concentrating their efforts on attracting upper-class, paying patients with promises of technology and advanced care. Within a decade, the transformation from Victorian poor-house to pinnacle of modern medicine was complete across most of North American hospitals (Gagan 1989). Hospitals became the best location to go in order to be appropriately

assessed and diagnosed by qualified physicians using the latest technologies. Once a disease had been diagnosed, the hospital provided trained nursing care to ensure a speedy recovery. This model of the hospital and modern hospital medicine more or less continues today, with the slight modification that Canadian hospitals have been publicly funded since the mid 1960s.

In many ways, the intensive care unit represents the most advanced form of the concentration of medical technologies in hospitals that began at the turn of the 20th century (Gagan 1989). The name of this specialty unit provides a starting point for thinking about its history. The intensive *care* unit began as a location for the concentration of specialized nursing care in the early 1900s (Fairley 1961; Pearce 1961). As hospitals took on more, newer, advanced medical technologies, older technologies and procedures became commonplace. As a result, these older techniques were more likely to be delegated as nursing tasks, while physicians moved on to master the latest technical skills. Cynthia Toman (2012, 2016) documents how this process occurred with the practice of blood transfusions. Once considered a specialty skill that only physicians could do, the realities of emergency medicine and the regularity that blood transfusions were used in hospitals resulted in blood transfusions becoming a delegated act for specifically trained nurses. Once hospitals had taken the time to train nurses in specialty skills, they had an interest in retaining them as employees and in ensuring that they maintained a high level of competency (Toman 2012). Specialty trained nurses were also helpful in training other nurses as well as newer physicians, who less commonly learned

how to do the more mundane and routine, yet still complex tasks involved with managing very sick patients. Hospitals thus began to concentrate advanced technologies, sicker patients, and specialty trained nurses in special care units in order to optimize the use of both technology and knowledge, as well as to improve patient safety.

The administrative move to concentrate intensive caring with intensive technologies began in the 1950s during recurrent epidemics of polio throughout Europe and North America (Bion 1999; Kelly et al. 2014; Lassen 1953). Faced with a shortage of life-sustaining negative pressure ventilators (“iron lungs”), several hospitals moved severely ill patients into specific designated wards where positive pressure ventilation could be provided manually through around the clock nursing care (and in some cases, care from medical students) in order to keep patients alive (Berthelsen and Cronqvist 2003; Lassen 1953). Early reports of the success of these specialty units were sensationalized in the media, often presenting gripping stories of children afflicted with polio who were able to survive through the at once terrifying and miraculous use of the iron lung ventilator (Rutty 2016). However, even the founders of these first intensive care units noted the tension between increased costs and material investments which improved mortality while also prolonging inevitable death in those destined not to survive (Bion 1999; Lassen 1953).

The idea of a special hospital location for the provision of invasive artificial ventilation technologies and intensive medical care quickly spread across North American hospitals even after the decline of epidemic polio (Marik 2013). Medical

enthusiasm for the new technological caring units were bolstered by media stories of success (Dartmouth College 2004). Less attention was paid to the patients whose bodies failed to respond to extraordinary medical intervention. The intensive care unit became a place of miracles, where patients who might have otherwise died were given one final chance at life through heroic technological interventions. The new, technologically advanced intensive care unit fit well within the general optimism of the post-war 1950s, where it was lauded as “another step for progress” and a fitting treatment solution to a diagnosis of life-threatening illnesses (Fairman 1992:58).

The addition of advanced STAT laboratories⁷ to provide rapid turnaround times for blood test results for patients with severe infections and severe respiratory distress allowed intensive care unit physicians to closely monitor the body’s physiology and micro-manage patient care (Weil et al. 1981). Continuous electrocardiogram (ECG) monitoring was also added in the late 1960s (Luce and White 2009). Using electrodes placed on patients’ chests, staff working in the intensive care unit could identify and reverse common but treatable abnormal heart beat patterns (arrhythmias) using defibrillation and chest massage (Luce and White 2009). The advent of advanced physiologic monitoring technologies and artificial respirators led to perceived improvements in physicians’ abilities to sustain and save lives following critical illness and injury, though most treatment still followed haphazard and often experimental

⁷ A laboratory designed to rapidly complete testing required for immediate treatment decisions. STAT comes from the Latin word *statim*, meaning immediately, at once, or right away (Martin and McFerran 2017).

courses (Fairman 1992:58; Harvey 1996:84). The founding of the Society of Critical Care Medicine, development of specialized training programs, and the development of the academic journal *Critical Care Medicine* in the 1970s helped to consolidate this new medical subspecialty as its own distinct profession (Bion et al. 1998; Kelly et al. 2014). The integration of computer programming into life sustaining technologies such as ventilators commenced the “modern” era of intensive care (Marik 2013:176).

The history of intensive care medicine can be expressed as a timeline of innovation and discoveries of novel therapies that have pushed the limits of life and death and the limits of the human body, a scientific trend that has allowed many lives to be saved since it formally began in the 1950s (Bion 1999; Fairman 1992; Harvey 1996; Kelly et al. 2014). From this perspective, the intensive care unit is a secular location for the miracles produced through modern scientific medicine. However, this is not the only narrative made possible through the technical spaces of the intensive care unit. Evading or challenging the point of human death does not always or even often result in a return to life. The story of the intensive care unit is thus also one of the delicate and sometimes tense balance struck between a focus on restoring life (whose lives? What kinds of lives?) and facilitating an acceptable, ethical death. It is this second narrative that I seek to explore in more detail through this project.

Bringing the intensive care unit to life

I conducted my fieldwork in a university-affiliated teaching hospital in Ontario, Canada. Like many teaching hospitals in Canada, the clinical care wards of the hospital

are closely interconnected with clinical and public health research institutions, charitable foundations, and local businesses, with the resulting complex of buildings, expansions, and various “wings” feeling at first like an immense labyrinth. Walking entirely indoors, it takes about 10 minutes to get from one end to the other. Along this trajectory of hallways, escalators, stairwells, and unmarked doors is a vast interconnected system of clinical, research, retail, hospitality, and educational services.

The critical care wing is often one of the nicest areas of the hospital, a result of its ability to attract public and private investment for “cutting edge” medicine. At the same time, in most hospitals, access to the intensive care unit is highly restricted. In the location I observed, the double metal doors that lead to the unit itself are locked and are covered with stickers and signs on them ordering visitors to STOP and PLEASE CALL before entering. There is a black corded phone next to the door. Next to the phone, a printed document with instructions on how to call the clerk has been taped to the wall. This intensive care unit follows a “closed unit” model (Marik 2013), and the physicians and administrators who manage it keep a close watch over both the patients and the staff and visitors who come and go. To enter the unit, I am required to tap my hospital badge on a black magnetic card-reader and push the automatic door opener button. Both doors swing open with a characteristic mechanical drone and I walk into the main corridor.

The first things to notice when entering the unit are the sounds. The noise level in an average intensive care unit can range from that of a busy office to that of rush hour traffic or construction (Christensen 2007). In the unit where I conducted fieldwork there

are always many ongoing conversations, the sounds of flipping paper, ringing phones, and computer tones and alarms at various frequencies. In this soundscape of constant noise and alerts, medical crises are discernible by specific and sudden changes in tone and frequency. At first, each beep and blip made me jump, but over time I learned the different songs of the machines. There is the gentle hum and swish of the ventilators, the three-tone bird-like verse of the intravenous pump (*dee-dee beep-boop*), and the intermittent *ping* of the patient assist call or monitor alarm. Other regular noises are much less pleasant, like the gurgling and gagging that occurs when a respiratory therapist or nurse uses a long tube to suction phlegm from a patient's lungs. If I listen closely, I can hear the metal-on-plastic clatter of equipment shuffling in the nursing carts and the breakfast trays being loaded and unloaded from their carts by the orderlies. The intensive care unit has an overhead announcement system which can be accessed using any phone in the unit. Physicians, nurses, and clerks periodically use this system to make general announcements or to find each other without having to walk through all of the hallways. Occasionally there are also more immediately recognizable and at times gut-wrenching sounds: sobbing, yelling, laughter, and plaintive cries are layered into the otherwise mechanical and technical pulse.

Many large intensive care units, such as this one, are organized spatially through the designation of "wings" or "sides." Here, the main doors open into the main hallway, which first goes through side A of the unit and then continues through a small atrium into side B. Each side is arranged exactly the same: approximately 15 beds organized in a ring

surrounding a central organizational hub. This type of configuration maximizes observational capacity and is common in intensive care unit designs (Lusardi 2016). The organizational hub features the clerk's desk (behind which are printers, screens displaying the vital signs of all patients on this side of the unit, a staff bathroom, and a library of standardized forms, procedures, and order sheets), a small kitchenette with an ice machine, sink, and fridge, an office (on one side it is used as a room for viewing radiology scans and also the break room for the physicians while they are on rounds, on the other it is a shared office space), a medical waste disposal room, and a drug and equipment storage bay. The hub also features common desk space, chairs, and computers which can be used by anyone.

The patient rooms are arranged facing this central hub. Some rooms are shared (two beds in one large room that can be separated by a curtain), but most are separate rooms which can be sealed off by sliding glass doors. There are three rooms on each side that also have their own attached antechamber rooms, allowing for separate negative-pressure ventilation of the patient room and nursing observation room. This setup is in place to allow for the isolation and care of patients with highly contagious airborne diseases such as COVID-19, H1N1, tuberculosis, and SARS. In the intensive care unit, patient rooms are quite large in order to accommodate teams of equipment and people

when required. The centre of each room has two moveable “arms” reaching down from the ceiling (Figure 2).



Figure 2. An empty patient room in the intensive care unit (Fieldnotes, March 2019)

These arms have multiple electrical outlets, valve connectors to oxygen gas lines, and connections for different types of equipment to which various devices are clipped and plugged before being connected to the patient. At the back of each room is a toilet separated from the main room by a wall that reaches only $\frac{3}{4}$ of the way to the ceiling and has no door. The toilets are not very private at all, a sign of the fact that they are not commonly used by patients here. Most of the rooms in this intensive care unit have windows facing outside which allows natural light to filter in when desired. Each room also has windows facing the inside of the unit, which allows bedside nurses to sit outside

the patient's room and still be able to view the patient along with the information displayed on bedside equipment such as pumps and monitors. Each patient room has a dedicated desk, computer, and nursing cart outside the door. The carts are filled with equipment that nurses and other healthcare professionals might need such as gloves, blood tubes, syringes, medications, intravenous fluids, swabs, lines, gowns, etc. and are re-filled regularly in a central equipment bay.

Many different healthcare professionals and hospital staff perform roles in the intensive care unit. Each patient has a registered nurse (RN) assigned at their bedside. Sometimes there are other nurses or nurses in training who help out where needed. In addition to the bedside nurses there is a nurse manager, a clinical manager, and a team leader. The unit management team is responsible for organizing both staff and patients in addition to the logistics of new admissions, transfers, and any scheduling conflicts that occur during a shift. Many respiratory therapists (RTs) are also present in the unit. RTs are responsible for helping to shape and implement the care plans for ventilated patients as well as to care for and organize the ventilators. Patient care in the intensive care unit additionally engages the work of dedicated dietitians, a social worker, pharmacists, physiotherapists, and occupational therapists. Other allied healthcare professionals such as spiritual care workers and speech-language pathologists can often also be found attending to intensive care unit patients.

The usual structure for medical care is to have one attending physician, one fellow, and a group of between 3-6 residents on each side of the unit. Residents have

obtained a medical degree (MD) and are in the process of completing hands-on clinical training. Residents practice in the unit for a 6-week “rotation,” and may or may not wish to eventually practice critical care when they graduate. Fellows are physicians who have already completed their residency training and are now completing in-depth subspecialty training, usually with a specific interest in critical care. Attending or staff physicians are considered faculty at the hospital’s affiliated medical school and have permanent consulting positions within the intensive care unit. Many also have active research programs. Occasionally the team also includes medical students who have obtained permission to observe several days of clinical practice. There is an unspoken hierarchy of experience with attending physicians at the top and first-year residents at the bottom (and below them, medical students). Residents are required to do a considerable amount of the clinical work of the intensive care unit, under the supervision of the fellows. A team of residents is present in the unit at all times. The physicians divide up the patients so that they take turns covering overnight and on-call shifts. Attending physicians work in the unit for weeklong rotations and usually “hand off” to the next physician on different days so that there is always one senior physician who has at least a few days knowledge and experience with current patients.

In addition to the clinical staff, there are a number of hospital employees who work in the intensive care unit on a regular or occasional basis such as the unit clerks and administrative staff, people who clean the rooms and remove waste (housekeepers), people who stock the nursing carts, help turn patients, and help transport patients to and

from appointments elsewhere in the hospital (orderlies), research assistants collecting samples and data, bioengineers involved in setting up and fixing clinical equipment, software engineers responsible for setting up and managing computer systems, and infection control and audit staff who check in to make sure that hospital standard procedures are being followed. Specialist physicians from elsewhere in the hospital such as neurosurgeons, nephrologists, cardiologists, and palliative care consultants are also occasionally present to visit patients who have been transferred from other locations or to provide specialized opinions.

While the unique professional culture of each intensive care unit is apt to vary, the structural elements that give the space its particular character are more or less consistent. In many ways, the field site I observed represents a typical intensive care unit for a tertiary care hospital. Like the majority of intensive care units in North America, it operates under a “closed” model, meaning that care for patients is directed by physicians with special training in critical care medicine (Marik 2013). It is a geographically distinct hospital location and features full-time, specialist nurses, a concentration of life-sustaining technologies, and ongoing and iterative clinical monitoring and decision making for critically ill patients (Marik 2013). I also observed that despite its geographic separation from the rest of the hospital, the intensive care unit remains deeply intertwined and reliant on many connected hospital services such as laboratories, operating theatres, and clinical imaging services.

But it is more than the separate location and specially trained professionals that sets the intensive care unit apart as a unique configuration of medical care. Where the tertiary care hospital is a material repercussion of the diagnostic revolution, the organization of the intensive care unit can be read as the material consequence of the scientific clinical gaze. Michel Foucault (1973) outlined how medicine shifted from a hereditary classification of diseases based on observations of patients and their described symptoms, to a diagnostic classification based on direct bodily observations by the physician. This shift in understandings of disease from subjectively experienced illness and suffering to neutral and “objective” physical marker of abnormality resulted in a medical practice focused on developing a “clinical gaze,” one that could see beyond the voiced complaints of the patient and any changes at the surface of the body to the “true” impairments and organ irregularities hidden beneath the skin. As noted earlier, this type of objective gaze tends to employ a “view from nowhere” in which the historically contingent social and cultural position and authority of the viewing subject, in this case the physician as embodiment of scientific medical knowledge, remains unquestioned (Haraway 1988). In contrast, the object on which the gaze is cast, in this case, the patient and their disease, is rendered completely open and legible to interrogation. In living patients, the clinical gaze is facilitated through technological innovations such as stethoscopes, x-rays, blood tests, and surgeries that provide an approximation or temporary window into what is happening inside the body in ways that the patient themselves may not be feeling or experiencing. The ultimate clinical gaze, Foucault

described, is embodied through the post-mortem autopsy which allows physicians to directly apprehend diseased organs with their own eyes through the complete objectification of the patient into corpse (1973).

In the intensive care unit, physicians use the general tests of clinical diagnosis made possible through regular hospital services. However, the concentration of technologies available in this specialty care unit also afford access to an armory of additional devices for looking inside the body while it is still alive. In the intensive care unit, the “clinical gaze” used by the general practitioner is superseded by an “intensive gaze” that can be manipulated using a computer. Instead of a stethoscope and thermometer, patients in the intensive care unit are fitted with electrodes and body probes that feed digital results to be displayed on screens. Rather than periodic measurements, the unique organization of care and technology means that in the intensive care unit, patients are monitored continuously, their heart rate, breathing rate, blood pressure, body temperature, oxygenation level, and sometimes brain activity and brain temperature are displayed non-stop on bedside screens. Biologic samples from the inside of the patient’s body can be taken and analyzed at any time. Rather than needing to send a patient to a clinic for a sample collection or scheduling an appointment for a biopsy, physicians in the intensive care unit can request all manner of fluids and tissues from their patients whenever they determine these measurements relevant. Prompt collection and analysis of samples is made possible by the various access points available through existing tubes and lines in the body, the attentions of the dedicated bedside nurse, the administrative

work of the unit clerk, and proximity to the hospital stat laboratory. Additional assessments that cannot yet be performed by a computer, such as skin color, nerve reflexes, wound care, and degree of swelling are completed regularly and recorded in the medical chart by the patient's assigned nurse. On the hospital ward or in the general practitioner's office, nurses share multiple patients and as a result may only have time to complete a few nursing assessments on each patient. In the intensive care unit, the 1:1 patient to nurse ratio facilitates a much higher frequency of ongoing physiologic assessments and a much greater volume of data.

Rather than a qualitative shift in kind, the move from clinical to intensive gaze appears to represent a concentration of the type of disembodied objectivity employed in clinical care. The intensive character of this clinical viewing is also facilitated by the unconscious state of most patients – obtaining subjective expressions of symptom experience are often impossible even when desired. Still, clinical and intensive ways of looking are about more than the lack of patient input. Fundamentally they represent a mode of apprehending patients and diseases that is not always reflexive of how observing in medicine is both a specifically conditioned and learned skill and also contingent upon both the optimal functioning of technical material actors and the relative power and respect accorded to the position of the medical doctor.

Findings gleaned from the intensive gaze – assessments, measurements, and cultured laboratory samples – culminate in the patient's medical chart. Traditionally, the chart consists of a binder filled with various standardized forms with (sometimes barely

legible) handwritten notes. Over the past ten years, many healthcare institutions in Canada have begun to transition all hard copy patient charts into fully digital Electronic Health Record documents that can be rapidly searched, organized, and analyzed as care teams make day by day and sometimes hour by hour modifications and updates (Orion Health 2019). Through a combination of information from nursing assessments, direct invasive monitoring of the body, and the patient's medical chart with its summary of lab values, tissue culture testing, and diagnostic imaging, the medical team uses an "intensive gaze" to synthesize observational data, to see beyond the surface of the patient, and to attempt to locate the true nature of illness and disease.

The intensive care unit provides the technical environment for the implementation of an intense clinical gaze, an "intensive gaze," in which the surface of the patient's body is no longer a significant barrier to daily clinical management and diagnostic understanding. Where the stethoscope allowed the clinician to use a "clinical gaze" without directly touching the patient, the "intensive gaze" allows the clinical team to investigate a patient's condition without even having to be in the same room. The structural and material organization of the intensive care unit, beginning from its privileged, well-financed and exclusive location to its concentrated technology and specialized expertise represents the concentration of the "clinical gaze" and perhaps the cutting edge of diagnostic medicine. Technologically facilitated access into the body combines with the literal glass window of each patient's room and dedicated nurse to make possible the immediate deployment of the "intensive gaze" to locate and treat

disease. How does bodily death factor into such a space? What might a shift in ways of seeing, from intensive gaze to situated, rigorously reflexive positions of observation do to understandings of death as an objectively understood boundary of the human body?

Explorations of death and dying in the intensive care unit

In the presence of technologies designed to measure, track, and sustain bodily life, human death must often be intentionally permitted to occur. In the intensive care unit, up to 85% of all deaths occur following a clinical and family decision to remove life sustaining therapies (Faber-Langendoen 1996; Turgeon et al. 2011), though this proportion is highly variable (Quill et al. 2014). The practice of withdrawal of life sustaining therapies in the intensive care unit (which I refer to as the process of technologically mediated death) has several parts, and technology is implicated throughout the process. First, the treating care team or attending physician must come to a conclusion about the patient's possibility of survival and likely quality of life. Printouts from monitors and lab results, as well as reflection about the course of illness may influence the team's insights. During the process of prognostication and decision-making, conversations with the patient's family are held to present and frame technical and diagnostic information and to ascertain any preferences for end of life care the patient may have voiced prior to admission. At this time, the opportunity to donate organs may also be offered to families if the patient is medically eligible. Finally, the clinical team and the family make a decision to withdraw life-sustaining therapies and the practical processes of removing technologies such as ventilators and blood pressure drugs occurs,

resulting in the patient's death. The timeline in which end of life decisions occur is variable and may span hours or days of deliberation, depending on the context.

Sociological studies of these technological deaths have employed ethnographic methods to investigate in detail how technologies of the intensive care unit and the hospital system more broadly are implicated in organizing dying trajectories. One of the earlier studies on this topic includes the substantive works by Glaser and Strauss (1965, 1968), who demonstrated how the timing and character of hospital death was influenced by a number of social factors such as patient age and socioeconomic status, family and healthcare practitioner awareness and acceptance of death, and the training of medical personnel. The authors conducted some of their observations in the intensive care unit, but this site was not the focus of their study. Glaser and Strauss provided one of the first investigations into how the technology of the hospital influences processes of death and unveiled how seemingly "natural" aspects such as the timing of death are in fact largely contingent on social, technical, and material factors.

Subsequent work focused specifically on entanglements of technology and death in the intensive care unit include Cook et al.'s qualitative investigations of how life support is withdrawn (1999), Seymour's ethnographic study of social interactions during end of life decision making (2000), and Kaufman's detailed immersion in intensive care unit culture and exploration of how it shapes the character of dying trajectories (2005). All three ethnographic studies took Glaser and Strauss' observations further to demonstrate how specific intensive care unit technologies such as mechanical ventilators

and standard practice guidelines help to organize how and when patients die. Cook et al. and Seymour also described how technologies are imparted different meanings by healthcare providers and families, and how meaning making is strategically employed to orchestrate “natural” deaths. Kaufman took a broader view and considered the general practices of professional conduct and interaction that go into making this particular space a functioning bureaucratic apparatus in the ordering of death. All three investigations of the socio-technical construction of dying in the intensive care unit draw general attention to the tensions between life-sustaining technologies and the ordering of death. They demonstrate instances where health professionals and families must make deliberate distinctions between the technological saving of life and the technological supporting of death.

Anspach (1987) and Harvey (1996) took a more specific tack in their explorations of the implication of technology in end of life decision-making. Anspach’s work in a neonatal intensive care unit identified how “technological cues” (e.g. signs and signals from the body made clear through technological translations) were one of three core sources of information used in clinical decision making about the end of life (1987). They also observed that physicians were more likely to make decisions based on technological cues as compared to nurses, who preferred to interact directly with patients and their bodies. In contrast, Harvey (1996) sought to consider how “certainty” and “uncertainty” with regard to the possibility of patient survival are socially and technologically constructed concepts. They also looked at how these concepts are related to professional

power and elements of social control. Harvey concluded that medical professionals in the intensive care unit present technologies strategically when negotiating certainty and uncertainty as a method of gaining and maintaining social and professional control. Harvey and Anspach's work introduced the question of power into considerations of technology and death in the intensive care unit. Rather than treating life sustaining technologies as objects with various culturally attributed meanings, as Cook, Seymour, and Kaufman did, Harvey and Anspach considered how the technology of the intensive care unit is used as an active communication tool and is implicated in the power dynamics between various professionals and family members at the bedside. Notably, neither study used a symmetrical approach to analyzing technology and thus did not consider the ways in which the technologies (including standards and guidelines) of the intensive care unit also shape the possibilities for communication and can be active agents in determining the order of things and therefore in distributing power.

Empirical work employing this type of symmetrical science and technology studies approach includes Hadders' ethnographic work of how death is "enacted" in Norwegian intensive care units (2007, 2009) and Timmermans' ethnography of cardio-pulmonary resuscitation in American emergency departments (1998, 1999). Hadders used Mol's praxiography (2003) approach to consider how healthcare professionals (mainly nurses) enact multiple versions of death. Hadders observed that while death was sometimes the traditionally regarded "flat line" on the bedside monitor, there were also other understandings of what death looked like, such as observing when the ribcage stops

moving, or when the patients' skin color changed. Hadders emphasized that these differential understandings of death are at times based on the presence (or absence) of technology⁸ to translate signs from the body. However, similar to Mol, his analysis falls short of a critical interrogation of the power dynamics involved in determining which enactments of death prevail as "true" in particular contexts.

Timmermans used a "science and technology in practice" approach (2003) to studying the process of emergency cardio-pulmonary resuscitation at the end of life. Like Hadders, Timmermans also identified multiple enactments of death, including clinical, biological, social, and legal death. In his analysis he also hypothesized that the technology of cardio-pulmonary resuscitation in the modern emergency department may be used as a ritual to clearly demarcate death, even as it is at the same time an attempt to save life. Timmermans' methodology allowed him to reflect on how the standardized processes of emergency cardio-pulmonary resuscitation and its modification and adoption in practice by healthcare professionals have jointly changed the nature of sudden death. His study also introduces the anthropological concept of ritual into his science and technology studies-oriented findings as a novel way to consider the multiple roles of this specifically life-oriented technology in the organization of death. The work of both Hadders and Timmermans is methodologically and topically similar to my project in that it considers the relationships between advanced life-saving technologies and the

⁸ These findings add to a long history in Western scientific medicine in which signs of death are closely tied to the technologies – from flames to mirrors to "waiting mortuaries" – used to discern them (Green 2008:46–47; Lock 2002:66–71).

negotiations of life and death amidst the complex social networks of families and health professionals surrounding the dying patient. However, I strive in this work to insert a different critical and theoretical perspective and to provide comment on the epistemological, political and ethical elements of recognizing, orchestrating and determining death amidst the advanced medical technologies of the intensive care unit.

Conclusions

The intensive care unit functions as literal and figurative space for the operation of the honed clinical “intensive gaze” and for the technical and scientific production of life. Here, advanced life sustaining technologies and highly trained professionals work together in a complex web of socio-technical action that operates to sustain different forms of human life. How is it possible to die in contexts in which technical support of life is possible? How do we make sense of human death in situations in which it is both resisted and chosen, such as must take place for those who die following withdrawal of life sustaining therapies?

In the previous chapter, I briefly outlined some of the many ways in which human death has been theorized in Western medical discourse. I then suggested how applying a posthuman perspective to growing tensions in clinical definitions of death might permit us to think differently about the role of death in society and how this might subsequently shift broader understandings of power, and knowledge practices. In this chapter, I have presented the intensive care unit as an optimal site of study and surveyed existing work in this area to demonstrate how this project makes different contributions. In the next

chapter, I will outline in more detail the methodology and the specific practical methods applied in order to work towards a critical analysis of how life and death are configured in spaces of techno-scientific life-saving.

CHAPTER 4 | How to study death in the intensive care unit?

In the previous chapters, I presented an argument for why we might want to take a closer look into how it is possible for individual human lives to end in contexts in which death is under-theorized and scientific medical focus remains on the technological production and sustenance of life. A critical investigation of the conditions in which death occurs as part of an economic and social system promoting endless growth may offer new theoretical and practical insights about the limits of human life, and in particular, the shifting ethical boundaries that these limits entail. I also introduced the theoretical concept of posthumanism, which seeks to move past an anthropocentric perspective based on European Enlightenment-era humanism, as a novel theoretical approach to understanding the subjective and ethical limits posed by the end of life. Finally, I provided a brief historical background and ethnographically informed description of an intensive care unit and situated this work in relation to previous studies of life, death, and technology in intensive care spaces.

In this chapter, I describe how I set out to address my research question, namely, what are the conditions through which death becomes possible in the context of the lifesaving and life-sustaining technologies of the intensive care unit? I begin from the theoretical position of posthumanism and explore how this theoretical orientation towards knowledge production allows for a methodology that gets outside of traditionally grid-locked dichotomous categories (in particular, the age-old nature/culture divide) while attending to questions of ethics and power, and while also remaining objective. I draw on

concepts of agential realism (Barad 2007) and perspectivism (Viveiros de Castro 2015) to outline the methodological approach that I take in order to study the phenomenon of death and resulting ethical concerns. I then justify and describe in detail the specific ethnographic methods used, including participant observation and interviewing, and a pragmatic involvement with the subject matter which allowed me to draw from multiple existing sources. As part of my description, I engage with the idea that I personally form part of the apparatus used to generate my research findings, and for this reason I provide a background of my own position(s) within the field and some accounts of the diffractions I provoke through working with my research material. I provide a brief account of my time conducting fieldwork in the intensive care unit, including the preliminary relationship-building required to gain access, a general summary of the activities I engaged in, and a description of the research data gathered. I conclude with an overview of how the resulting data artifacts were compiled and reviewed as part of the qualitative analysis. Throughout this chapter I make a point of attending to the ethical consequences of each decision, including acknowledging and addressing the limitations of each choice that was made as part of the project design and execution, as well as providing an explanation of what could have been otherwise. My ultimate goal was not to unveil some kind of truth but rather to generate data useful for thinking critically about the paradoxes and ethical correlates of modern death and dying amidst the technology of the intensive care unit.

Posthuman methodologies, dying ontologies

In order to describe a methodological approach to studying death it is first imperative to settle on an understanding of what the event of death is taken to be in this context. What is this phenomenon we call “death”? Is it a natural, biological event with cultural interpretations and social consequences? Many cultural anthropologists have taken this position, focusing their work on rites of passage and cultural interpretations against a backdrop of assumed biological processes. For example, Kaufman (2005) explored relationships between cultural expectations of death with dignity and the social reality of hospital end of life care and found the desire to avoid hospital death encourages social and medical practices in which dying persons are kept alive at all costs or are shipped out of the hospital to die elsewhere. In Kaufman’s analysis, the bodily practice of death remains unexplored; critical analysis is focused entirely on the cultural and social understandings and responses to human death and dying.

Anthropologist Margaret Lock’s ground breaking work on organ donation and brain death (2002) takes a slightly more nuanced approach by demonstrating the ways that culture and biology co-determine one another. Through a comparison of social and cultural expectations surrounding practices of death and conceptions of the body in North America and Japan, Lock establishes how certain biological concepts become understood as inevitable in some places while remaining deeply controversial in others. Lock emphasizes that this difference is not due to a lack of scientific or medical expertise or reduced availability of technology but rather to contrasts in what is perceived as a rational and objective idea. Despite similar (or in some cases, better) access to technologically

advanced critical care and similar types of neurologic injuries, the idea that brains die before human bodies, and that deceased organ donation might occur as a result is simply not accepted as valid in Japan. Thus, the biologic profile of neurological death has a significant cultural component. Lock concludes that historically contingent processes of culture can factor larger than inherent biological structures of the human body in shaping the final character and trajectory of new forms of technological death.

Cultural foci on social processes of death provide a useful starting point for analyses such as Lock's, which aim to interrogate how natural and cultural understandings of death intersect. However, these types of approaches often take a broad perspective and do not center more "unthinkable" issues related to the subjectivity of the dying person and the agency to approach one's own death in technological and medical spaces. Comparative cultural analyses can demonstrate how biology is impacted by technology and culture, but may stop short of considering how this interpellation of effects evidences a shift beyond the idea of the human. Attempting to think outside of well-worn dichotomous categories such as nature and culture, we might attend to the possibilities that other-than-human beings may die, that not all deaths are moral boundaries of finitude, and most importantly that the process of approaching and crossing this boundary limit involves important differences for all beings/things that die in all contexts. A posthuman perspective insists on attention to these qualitative differences as a means of understanding ethical aspects and power dynamics inherent within the activity of dying.

So, how exactly might one go about thinking in this way? In her book, *Meeting the Universe Halfway*, Karen Barad (2007) argues that a posthuman approach, one that aims to get away from the limits of humanist and anthropocentric knowledge production, cannot involve simply choosing one end of the nature/culture divide (or choosing to be somewhere in the middle, for that matter). Neither, she insists, can it hinge on the simple invitation of non-humans into the realm of human analysis (2007:184). Both of these methodological options involve the perpetuation of the unquestioned categories of “nature,” “culture,” and “human,” and as a result run the risk of readmitting humanist knowledge production and human exceptionalism through a position of opposition. Instead, Barad insists that a posthuman approach to understanding should involve specific attention to what she calls the cuts and exclusions (which she refers to as “agential cuts”) that inevitably take place in order to form each perspective and account of the world. Each agential cut is a decision and a specific relationship or orientation in and to the world, a particular ongoing enactment that is involved in producing reality in a particular way, with the exclusion of other ways that it could have been produced (2007:178). Medical diagnoses, for example, are a type of agential cut made by the scientific medical system. This type of agential cut occurs based on a specific convergence of historical scientific medical knowledge, examination of a physical body and its parts, cooperation of an individual patient, and characteristics of one or many practitioners at a particular moment in time, and it results in an identification of a reality of disease or disability in a particular body. As anyone who has even been diagnosed with a condition knows,

agential cuts like diagnosis have affective and material implications and can fundamentally change the nature of reality for involved actors. They are also prone to instability and change over time, especially when cuts are based on wide networks of cascading decisions, as is the case with most diagnoses requiring input from laboratories, diagnostic manuals, symptom reports, and experimental trials, amongst other factors. The concept of ongoing agential cuts that produce specific, temporally stable configurations of the world is central to both Barad's ideas about objectivity and what she argues are the resulting possibilities for a dynamic ethical analysis.

First, I want to return to the issue of objectivity. How is it possible to maintain the presence of an objective reality that can be reliably studied scientifically if the world is being produced through an ongoing process of seemingly tiny but affectively and materially significant agential cuts? Barad claims that it is by specifically attending to the study of these agential cuts that we maintain a robust grasp on reality. She introduces the concept of the "apparatus" as that specific material configuration of agential cuts that allows a particular figuration of the world to come into being, in other words, it allows the active process of knowing to take place. For Barad, the apparatus is a tool for describing particular configurations of situated knowledge (Haraway 1988). Through interacting with an apparatus, part of the world, "mak[es] itself intelligible to another part" (Barad 2007:185). Drawing from her critical analysis of Niels Bohr and quantum mechanics, Barad describes six components of an apparatus, listed in Table 1.

Table 1. Components of an apparatus

<p>An apparatus is:</p> <ol style="list-style-type: none"> 1) A specific material-discursive practice 2) Involved in producing differences (boundaries) that form part of matter itself 3) A material configuration of the world 4) Itself a phenomenon 5) Without intrinsic boundaries (instead has open-ended practices) 6) Not <i>in</i> the world but rather <i>of</i> the world
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From page 146 of *Meeting the Universe Halfway* (Barad 2007).

Important to note, and as Barad herself insists, an apparatus is *not* a static assemblage that is constructed once and then endlessly reproduces the same perspective (Barad 2007:172). Instead, an apparatus is always in flux, always engaged in both the dynamic becoming of the world in addition to the dynamic material becoming of its own boundaries.

According to Barad, all contexts in which knowing takes place involve interactions with an apparatus, from the simplest apparatus of the eye to the complex apparatus of the scanning tunnelling microscope (Barad 2014). In the case of this project, we could imagine the intensive care unit and the contingent practices of scientific medicine and implementation of medical technologies as a complex apparatus through which specific configurations of knowing about life and death are possible. Learning to characterize the apparatus involved in each instance of knowledge production is what, Barad claims, allows the possibility for objectivity to occur. By describing and accounting for the specific apparatus that allowed the knowledge claim to come into being, we can trace the interactions through which knowledge claims are reproducible and thus derive a better understanding of how effects are produced in the material world.

The characteristics of an apparatus, as described in Table 1, introduce some ongoing tensions to this concept of objectivity. If each apparatus is an open-ended and unfinished practice/phenomenon itself, how can we ever ensure that knowledge claims are stable, reproducible or transferrable? This is where the critical possibility of ethics comes to the fore in Barad's work (Hollin et al. 2017). The reliance on and active engagement with an apparatus (again, ranging from an eye to the intensive care unit) in order to produce any knowledge about the world insists on the recognition that knowledge practices are not necessarily transferrable, reproducible, or relatable to all possible knowers. Rather than an overarching, disembodied, and transcendental truth about natural or cultural phenomena, as has been historically common through notions of Enlightenment humanist epistemologies, the agential realism proposed by Barad insists on rigorous attention to the specific material configurations of the apparatuses that make each knowledge claim possible and sustainable. Descriptions of these apparatuses involve accounting for the particular agential cuts made by various beings for different historically contingent reasons, and thus open up the possibility of knowledge production beyond the single narrative produced by the assumed "objective" and "impartial" scientific observer. Some might argue that this position strays dangerously close to relativism, since each variation of an apparatus could produce multiple perspectives of reality. However, Barad would insist that from an agential realist position, the same configuration of an apparatus always produces the same epistemic account of the world. The ethical component of this method entails responsibly accounting for the specific

configuration of the apparatus and then determining *which configuration* (i.e., which version of knowledge production, which version of knowing) to engage in particular contexts. It also involves attending to who or what is in a position of power to make decisions about what counts as real or truthful. Barad has thus termed her approach to knowledge production an “ethico-onto-epistemology” as it represents an entanglement of the responsibilities of ethics with the possibilities of knowing and being in the world (Barad 2007:185). This combination opens a point of entry for work which seeks to examine the ethics of knowledge production alongside an accounting of the material production of the world (Hollin et al. 2017).

A relevant example from the intensive care unit helps to clarify the ethical implications of particular knowledge practices. When a bedside nurse feels the absence of pulse in a patient, they may know (using the tactile apparatus of their hands, the structure of the patient’s blood vessels and skin, reference to a clock, and their prior culturally mediated knowledge of human physiology) that death has occurred. However, the particular configuration through which knowledge about death is produced through the apparatus of the intensive care unit discerns that preparation for the morgue and official administrative designation of death may not begin until a doctor arrives to perform and confirm the same assessment. There is a legal requirement in Canada for death to be declared by a physician; as a result, only physicians in the intensive care unit can officially declare death. A power imbalance, and therefore an ethical difference, exists between assessing and knowing death as a nurse and assessing and knowing death as a

doctor. For the doctor, this is the final assessment for the dying person in the role of patient. Depending on how and why the patient died, physicians may experience different emotional responses (Vanderspank-Wright et al. 2018; Whitehead 2014). Medical assessment of death also carries legal and administrative weight; the resulting course of action is to transfer the body to the morgue and issue a legal death certificate. For nurses, assessment of death may also produce affective responses and it has implications for family reactions. However, it may otherwise not change patient care until the physician confirms that death has occurred. In some cases, prolonged delay between the nurse's assessment of death and the physician's arrival for the official declaration of death can be disturbing to families (Weaver 2011). The distinct implications of each approach to knowing death invite the consideration of ethical choices. Should the nurse attempt to know death now, for this patient, or should he wait because he knows the physician on call is very busy at this time and will be delayed in confirming the diagnosis? The difference in ethical weight of knowing death is also inscribed in the clinical terminology used: nurses perform an "assessment of death" while physicians perform the more official "declaration of death" (Weaver 2011). The material practice of applying fingers to cold skin and watching a clock as well as the clinical biological death established is the same in each instance, but the ethical implications of knowing change depending on which healthcare professional is involved. The production of death via specific knowledge practices is particularly entangled in ethical questions. The concept of the apparatus and

the agential cuts that it produces to configure material realities offer useful conceptual tools for teasing out important sites for critical analysis.

Brazilian anthropologist Eduardo Viveiros de Castro (2015) has developed what I find to be a similar theory to that of Barad in his idea of perspectivism. Rather than thinking through the technologically mediated relationships involved in experimental physics, Viveiros de Castro draws from his extensive ethnographic fieldwork with Amerindian societies and from an in-depth knowledge of Amerindian cosmologies. He outlines his concept of perspectivism as a mechanism of producing a true account of the world depending on the perspective from which it is viewed. This initially seems to be a claim for relativism, but rather than relativism, Viveiros de Castro insists that the possibility for multiple perspectives is a function of *relationism*, of the many different (but specific) forms of relations that can occur between various entities in order to produce knowledge claims. He argues that through a particular configuration of subjects and objects, a point of view comes into possibility, which constitutes the possibility of the knowing subject as well as the possibilities for the production of knowledge about the world. These points of view can also be exchanged and transformed into alternative possibilities for knowing.

Building on the previous example comparing nurses and doctors' assessments of death, Viveiros de Castro might suggest that the patient could be at once both dead and alive. For the nurse, who has assessed the patient and come to know that death has occurred, the patient is dead. But for the physician, who is still seeing other patients, this

patient remains on their list of scheduled visits and is officially still alive. From a position of perspectivism, being both dead and alive at once is not impossible, even though both entail different roles within a relationship. The key point is that one cannot be both of these things to the same knowing subject, i.e. to the same point of view (Viveiros de Castro 2015:254). It is also important to note that these two different perspectives about the same person do not negate each other but rather are complementary in ways that produce specific patterns of difference in relations that come to matter in particular ways. For example, when the physician does show up at the bedside to make an official declaration of death, it is possible that the nurse will relay the time of death noted in their assessment of death, which in turn may influence the timing that the physician notes on the official death certificate. According to Viveiros de Castro, Amerindian societies function with the understanding that all beings have the potential to be knowing and relating subjects in specifically different ways, depending on the particular configuration of relations occurring in any particular context. Thus, animals can be human, and humans can be gods, depending on who is looking, and how. Perspectivism requires attention to the particular relations that make a point of view, a position of knowing, possible, as well as attending to relations between these views.

I find Viveiros de Castro's idea that knowledge claims are dependent on ways of relating and seeing from specific points of view very similar to Barad's idea of the apparatus as a particular configuration of material elements making the production of a knowledge claim possible. Both scholars insist on the need for a careful accounting of the

conditions of production of knowledge claims as a means of ensuring their ethical accountability. Viveiros de Castro's concept of perspectivism and Barad's concept of agential realism follow from a posthuman logic that does not restrict relationships of knowing to those espoused in humanist accounts of reality, does not necessarily foreground or centre the role of the human subject in knowing, and insists on the dynamic possibilities for knowledge as an ongoing, relational project of making the world rather than a static practice of bookkeeping.

Viveiros de Castro's concept of perspectivism, envisioned through interactions with human societies, is helpful for thinking about the role of bodies and relationships such as those produced through the phenomenon of death. Barad's complementary concepts of agential cuts and the knowledge production apparatus, drawn from interactions and close study with theoretical and experimental physics and its related technological artifacts, is especially helpful for analyzing technologies and related material practices of scientific knowledge production that take place surrounding death in the intensive care unit. Finally, it is the possibilities for an ethical accounting specifically permitted by the concepts of both scholars that are useful for considering associations of power that take place in all types of relationships surrounding death and dying.

The usefulness of this ethical perspective becomes more evident when considering its absence in alternative methodological approaches. Latour's (1993, 2005) Actor Network Theory (ANT), for example, with its attention to both human and non-human elements of scientific assemblages, arises at first as a seemingly obvious choice

for a project seeking to study how death occurs in technological spaces. As a methodology, ANT involves attending to the heterogeneous networked associations formed by human and non-human actors, paying attention to the ways in which particular configurations are maintained through material-semiotic processes of recruiting new actors to the network and translating meanings across network nodes (Callon 1989; Latour 1986, 2005).

This methodology of associations could be helpful for observing, analyzing, and conceptually organizing the various technological and social actors present in the intensive care unit and how they participate (or not) in various networks of practice and knowledge mobilization. However, I suggest that ANT falls short as a methodological choice in this project for two reasons. The first is that it does not provide a transparent mechanism for determining where and when networks end. This is particularly problematic in the intensive care unit, as Brown and Middleton (2005) discovered, due to the sheer volume of actors involved in patient care and the complex, dynamic environment presented by the tertiary care hospital. Even something as seemingly simple as ordering morning blood work to test hemoglobin levels involves: a legible written or electronic note and signature by a physician, the bedside nurse, a functioning arterial line, latex gloves (and possibly additional personal protective equipment such as gowns, masks, N95 respirators) three vacuum sealed, color coded glass tubes (already stocked in the bedside nursing cart, which has been arranged in a particular way and stocked earlier in the unit equipment bay by an orderly), the patient's blood vessels, a hospital-wide

network of pneumatic tubes, labels, plastic biohazard bags, paper requisitions (in triplicate), computer menus, electronic health records, laboratory staff, centrifuges, pipettes, telephones, standard physiology values, and appropriately prepared reagent solutions, to name but the most prominent elements of this task. This list does not even begin to consider the specific history of each element, the particular network of actors that sustains each practice within the hospital, or the different networks that may or may not be mobilized once the result of the blood test returns to the body of the patient. The intensive care unit is not neatly sealed off to the rest of the hospital or to other aspects of clinical medicine in ways that might make the boundaries of analysis easier to locate. As a result, it is necessary to establish arbitrary limits for analysis, and thus necessary to acknowledge how drawing these boundaries impacts conclusions. For this reason, I find Barad's methodological focus on material entanglements and resulting agential cuts to be more amendable to a study of the intensive care unit as it more readily permits the delineation of appropriate limits and insists on transparency about their construction.

A second argument against choosing a methodology of ANT for this project is its reluctance to engage with unequal power dynamics and politics, in other words, its reluctance to engage with ethics. As Braidotti (2019:55–61) has argued, a symmetrical approach such as that used by ANT takes all social actors, all humans and non-humans, as equal and thus erases positions of anti-racism, feminism, and anticolonialism that continue to oppose the unequal power available to those actors not traditionally included in the position of the subject. ANT, and its evolution into Object-Oriented Ontology

(Harman 1968) does not involve a critical analysis of the subject position of any actor, and thus does not permit an accounting of or any attempt to contend with the unequal power dynamics that make up the human and non-human world. Sayes (2014) puts this another way, arguing that although ANT can demonstrate the political and moral competencies of various actors, it does not provide an adequate mechanism for attributing responsibility, autonomy, or accountability to any specific actor. Instead, the focus remains on describing the stabilities and uncertainties of the interactions that make up a “flat” assemblage. This methodological shortcoming is particularly pronounced in analyses that take place in settings where power (both the power to take action as a subject and the power to prevent the actions of other subjects) can be glaringly unequal, such as occurs in a tertiary care hospital or a university (Corman and Barron 2017).

Annemarie Mol (2003), who employs an approach based on ANT in her study of atherosclerosis, comes up against the problem of a lack of attention to ethics after she concludes that multiple, though specific, configurations of the concept of atherosclerosis become possible in various locations throughout the hospital. Which configuration(s) of reality should prevail, and for whom? What to do? Mol struggles with these ethical questions towards the end of her analysis, having provided a detailed accounting of the material aspects (diagnostic tools, standards, knowledge practices) involved in enacting atherosclerosis in various settings, but without an adequate account of the subjectivities involved in making decisions (i.e., exercising power) about which realities to bring into practice. Mol concludes that the demonstrable existence of multiple possible and

networked realities should underscore the need for a central role of ethics in medical practice, and the need for a more detailed understanding of the decisions that bring certain realities into practice while others are left behind.

I take up Mol's suggestion and aim to begin from a methodology that incorporates a consideration of ethical choices right from its inception. Rather than employ a methodology such as ANT which would allow me to present a rich description of how various human and non-human actors relate in the complex environment of the intensive care unit, I chose to employ an agential realist or perspectivist approach that attends to the specific relational "agential cuts" involved in the making of reality, as well as the various and unequal subject positions necessarily created whenever and wherever a point of view is taken. The methodological position I take is therefore one of realism and of perspectivism. The intensive care unit, its employees, machines, and patients, and the event of bodily death exist as real material events, objects, and absences which can be studied objectively. This reality, however, looks different depending on which apparatus is used, how it is conceived, and depending on who (or what) is looking. As per Viveiros de Castro (2015), differences in perspective do not lead to relativism but rather to a relationism that attends to the particular relations between perspectives (or diffraction patterns, as Barad (2007) would call them). Important to my analysis is not only to describe various perspectives about the knowledge production involved in discerning and allowing death, the material apparatuses (in terms of Barad's definition as presented in Table 1), and the objects that make these concepts possible, but to consider the relations

of power between these perspectives in a way that informs ethical decision-making surrounding death and dying in the intensive care unit. Finally, my analysis is informed by an overarching posthuman position that remains aware of the exclusionary and contingent history of the category of the human and seeks to move beyond its mechanical re-inscription.

Posthuman ethnography

Approaching the production of knowledge from a posthuman stance that seeks to maintain an openness to multiple perspectives, multiple actors, and the potential for how things could be otherwise requires a flexible and iterative methodology. Ethnography, with its insistence on close observation, attention to detail, and investigation of local perspectives alongside an openness with regards to “what counts” as data, is well suited for this task. In its traditional form, ethnography involves long-term, sustained immersion in a field site in which the ethnographer does not seek to locate pre-defined concepts or characteristics but instead remains open to the possibility of encountering difference (Barad 2007). The production of knowledge claims using ethnographic data involves attempting to understand local concepts from the perspectives of the population studied and to build up resulting theories and narratives using a process of “thick description” (Geertz 1973).

Ethnographic methods have been useful for projects seeking to understand aspects of the dying process in the intensive care unit and in the hospital more broadly. One of the earlier studies on this topic includes the substantive works by Glaser and Strauss

(1965, 1968), whose ethnographic work demonstrated the ways in which the timing and character of hospital death was influenced by a number of social factors such as patient age and socioeconomic status, family and healthcare practitioner awareness and acceptance of death, and the training of medical personnel. Early ethnographies based exclusively in intensive care units focused on describing in detail how “technological cues” (e.g. signs and signals from the body made clear through technological translations) were used in clinical decisions at the end of life (Anspach 1987), how life sustaining therapies were withdrawn (Cook et al. 1999), the types of social interactions occurring during end of life decision making (Seymour 2000), and how the culture of these specialized hospital clinics shapes the character of dying trajectories (Kaufman 2005; McGibbon and Peter 2008). More recent ethnographies based in the intensive care unit have investigated ontological enactments of death (Hadders 2009; Hadders and Alnæs 2013), elements of technology and care in nursing work (Price 2013), interactions between culture and technology in shaping definitions of death (Lock 2002), the spatial arrangements of bodies and visibility made possible in the intensive care unit (Lusardi 2016), the production of “personhood” in intensive care unit patients (Koksvik 2016), the use of information technology in healthcare professional communication (Leslie et al. 2017), and the degree of involvement of patient’s families in clinical intensive care (Au et al. 2018). Though many topics have been investigated, the application of a posthuman perspective to material and relational aspects of technological dying has not been extensively explored.

Prior studies demonstrate how the use of ethnographic methods allows for consideration of the vast array of potential human and non-human informants and sources of information made possible in the complex environment of the intensive care unit. In addition, ethnographic methods that rely on observation and analysis of textual sources are valuable for use in the intensive care unit setting due to the relative inability to interview patients directly because of the severity of their injuries or illness. But despite its potential usefulness, it is important to note that ethnography is not innocent as a methodology. Much harm has been imparted by the application of a method that seeks to understand and speak for the voiceless other. In keeping with a transparent and ethical methodological approach, I find it necessary to first critically assess ethnography from a theoretical perspective before outlining the particular way that I have employed it in this project.

Ethnography was initially developed as a scientific method used by “modern” Europeans to study “premodern” societies, often for reasons of furthering colonial conquest (Rees 2018:9). Early ethnographic work, synonymous with anthropological study at the time, was deeply intertwined with racist, colonial perspectives of history that positioned Indigenous peoples as uncivilized and justified the theft and transnational sale of their belongings, bodes, and bones in the name of science (Bignall 2019; TallBear 2013; Willinsky 1998). As anthropology continues to reckon with its history, the methodology of ethnography remains rooted in a specific power imbalance between the ethnographer as researcher and local participant(s) as subject/object of research. The

distance (both physical separation and symbolic difference) from the subjects and objects of study allows the ethnographer to function as the privileged mechanism through which knowledge is produced.

Historically, this analytical distance was configured and reinforced through symbolic, humanist assumptions about the dichotomies between modern/pre-modern, civilized/uncivilized, culture/nature, subject/object, and ultimately, self/other. Distance was also facilitated through the financial and social capacity for ethnographers to physically leave the field of study to return to a world where their produced accounts of knowledge were consumed (Willinsky 1998). Within this particular epistemic dynamic, knowledge accounts of research participants (for example, worldviews, beliefs, knowledge practices) are not taken as valuable until they are processed through the interpretive framework of the ethnographer's lens (Viveiros de Castro 2015). The ultimate goal of this traditional style of ethnography is to make sense of a particular world through the categories of understanding used by the subjects who populate that world. In other words, to describe how people in the field come to know about their world using the words and analysis of the ethnographer.

I provide this simplistic account of ethnography in order to pick out two assumptions made by the use of the methodology that I aim to challenge from the perspective of a posthuman theoretical framework. First, I take issue with the concept that ethnographic work can in some way be produced at a distance (physical or metaphorical) from the world of the subjects and objects of study. As Barad (2014) points

out in her critical engagements with the brittlestar, seeing and being are synonymous, they are both forms of intra-action in the world. There is no vantage point from outside (the “view from nowhere”) from which ethnographers can quietly observe and formulate their accounts (Bright 2018; Haraway 1997; Smith 1999). Instead, ethnographic accounts are very much a production *of* particular worlds. In order to account for this inevitable intrusion on the data they produce, ethnographers often insist on practices of reflection and reflexivity, which presume to assist in helping the observer pick out, account for, or avoid the blemishes of their own assumptions (Schwartz-Shea and Yanow 2012). However, as Emerson et al. point out, reflexivity is all too often applied as a method when writing up final results, rather than an ongoing accounting of the decisions and assumptions made during fieldwork itself (2011:245–48). Further, as Barad (2007) explains, the metaphor of reflection implies that the researcher is only able to see a static image of themselves. This metaphor misses the ways in which researchers are inevitably changed in the field, and the ways in which they modify the environments and relationships they participate in (Fitzpatrick 2019). Barad suggests instead to use the concept of diffraction, of considering the blurred edges and the constructed realities of exteriority within as more useful metaphorical thinking tools for assisting with the ethical production of knowledge accounts (Barad 2007; Hollin et al. 2017). From this viewpoint, the ethnographer is never outside of the phenomena she aims to study, and any attempts to construct distance are inherently based in age-old assumptions about self/other, nature/culture, etc. As a result, the methods I have employed in this project involved

attempting to adequately trace the ongoing interactions, differences, and exclusions made between my field of study, my interlocutors, and my own assumptions, values, and ongoing philosophical and ethical engagements regarding the phenomena of intensely technological life and death. Rather than fret about the purity of my data, I have chosen a pragmatic approach towards data collection that aims to account for my inevitable involvement in my world of study, rather than pretend that I am somehow outside of it.

The second methodological assumption I seek to challenge is the idea that the goal of ethnography is to describe the ways in which participants in the field understand their world. Viveiros de Castro provides one critique⁹ of this conjecture, asserting that ethnography cannot be about “describing worldviews” because, in his opinion, “no world ready to be viewed exists [...] no world that would precede one’s view of it or precede distinction between what is “thinkable” and “unthinkable,”” (2015:17). Viveiros de Castro’s claim is related to the point made earlier about the inability to consistently separate subject and object. It also involves a challenge to the epistemic power of the ethnographer and the perceived separateness of the worlds that they study. Viveiros de Castro argues that subjects have always already formed a view of their world and likely a workable, philosophical account of how they make sense of it. The goal of ethnography, he insists, should be to “neither explain nor interpret,” but rather to “multiply and experiment,” including analyzing the consequences and effects of local perspectives on the ethnographer’s worldview and thinking (2015:19–24). This position involves taking

⁹ Though by no means the first or the only similar critique, e.g., see Smith (1999).

participants' accounts of their worlds seriously and making an attempt to understand these accounts in a way that permits a productive comparison (i.e., a diffractive resonance) with the ethnographer's understandings. This is critical approach to ethnographic work seeks to open up the possibility of knowledge production to all agents in multiple forms, rather than permitting only those who can speak the traditional humanist language of Enlightenment science to have a say. It is important to note that the insistence on inclusion, multiple comparisons, and focus on accounting for consequences does not permit the relativist conclusion that all knowledge claims are equally valid. Rather, a critical posthuman approach to ethnography employing concepts of perspectivism and situated knowledges requires a greater attentiveness to ethical accounting and accountability. Instead of assuming the privileged position of truth, we are challenged to critically account for our role and responsibilities in its ongoing production.

The posthuman ethnographic approach I employ in this project is one that makes use of the well-worn and successful elements of sustained observation and openness to multiple forms of data in a particular field. However, it aims to do so from a critical perspective. I position myself in the field as ethnographer-subject but also as an inherently messy and unfinished apparatus of data collection and knowledge production. As part of my fieldwork, I made a point to provide an account of the many relations and intra-actions that shaped my position as observer, and how it became possible for me to "see" various happenings in the field, in partial and unique ways. I also considered the

many ongoing ways in which I read local knowledge through my analyses and how my resulting conclusions form diffractive patterns within various theoretical contexts as well as with clinical and legal limit cases occurring at other intensive care units and reported in the media. The critical posthuman ethnographic approach that I employed was intended to remain open to the material unfolding of what life and death mean and how dying works in technical spaces, while also maintaining a critical eye towards the power imbalances and ethical choices inherent in the knowledge practices of the intensive care unit.

Methods of intra-action in the field

The ethnographic work that I undertook for this project involved a combination of observation in the field, interviews, participant observation, secondary data analysis, and diffractive reading through theory and limit cases as publicized in the media. Much of my work was facilitated through relationship-building activities with gatekeepers made possible through my existing network of contacts in intensive care and organ donation research. Each method of data collection was also mediated through my own position as the apparatus of data collection, which involved ongoing ethical decisions about what and who to attend to, and what and who to exclude. In this section I present a brief description of the methods used for intra-active data collection, including some characterization of self as apparatus of knowledge production.

Observations in the Field: Negotiated interactive observation

Classic ethnographic work is built on the method of participant observation, the ongoing partial integration of the researcher into the social world they are studying (Silverman 2013:447). In the traditional formulation, participant observation allows the ethnographer to get close enough to the phenomena under investigation to be able to formulate perspectives from the point of view of the locals. When and whether the ethnographer gets “close enough” remains up for debate and is a criteria on which validity is measured (Richardson 2000). However, due to issues noted previously, this type of classic ethnographic work becomes less possible after critical ethical reflection. Emerson et al. suggest that a more useful term to describe fieldwork is “participating in order to write,” where ethnographers begin their foray into the field with the clear target of observing enough to write about (2011:22–23). After extensive fieldwork in a rheumatology clinic, Wind (2008), a nurse-turned-ethnographer, argues that true participation in any form is not possible for ethnographers in healthcare contexts due to the nature of clinical work and the complex organization of the field. When ethnographers attempt to assume the participant role of patients, their observations may in most cases become quite limited. Much of the decision making and “nitty-gritty” work of the hospital, especially the work of producing knowledge about bodies, including knowledge of life and death, occurs outside of the individual experiences of patients. The participant role of a clinical staff member may be possible for those ethnographers with some previous clinical training. However, this position would imply clinical

responsibilities of patient care which can be quite demanding and thus preclude the ability to collect adequate fieldnotes. Instead, the role of researcher, which is not an unfamiliar role in hospital spaces, becomes the most likely and available position for most medical ethnographers to take up. Wind offers the concept of “negotiated interactive observation” to describe what she sees as the more fitting process of permanently partial, emotionally intensive, and always negotiated access of witnessing that for medical ethnographers can never truly be in any other role than that of the researcher. In what I see as an important link to Barad’s concept of the apparatus, Wind insists that negotiated interactive observation must involve paying attention to what the researcher is permitted to see (or not), and how access is gained (or denied) as important aspects of both the field site and the phenomena under study.

The negotiated interactive observation that I employed for this study took place at one field site, a general medical/surgical intensive care unit located in a teaching hospital in Ontario, Canada. Access to the site was obtained through a six-month process of relationship-building. First, I reconnected with a previous contact and commenced part-time employment with the research group. My work there involved physically going to the hospital intensive care unit once or twice a week to work in the research office reviewing patient charts and abstracting information for use in observational and clinical trials. Critical care physicians are notoriously busy, and my regular physical presence in the research office allowed me to have five-minute impromptu meetings to briefly discuss my work in between their meetings and clinical tasks. In this way I was able to slowly

begin building staff members' familiarity with me and my project, and to meet the team leaders and department heads whose approvals I needed for official administrative approval. My previous and ongoing professional relationships with a number of key staff members in the intensive care unit likely facilitated my ability to enter and network effectively in this space.

Prior knowledge of the research site provided me with initial ideas about how to approach the task of obtaining ethics approval. I began by creating a series of "one-pagers" about my project, which outlined the observational goals in terms of a focus on technology and its interactions with death and dying in the intensive care unit. The main goal of these documents was to have a brief, tangible outline of the project that helped to ensure gatekeepers that I was not planning to investigate or audit individuals but rather to consider the broader workings of the intensive care unit as a whole. I knew from previous experience that leaving gatekeepers with a material trace in the form of the one-pager helped to provide assurance that I was a legitimate researcher with a real plan. I briefly presented the project at the beginning of the critical care department meeting (to which all staff physicians working in the unit are invited) as well as the comprehensive care and interdisciplinary practice meeting (attended by team leads from nursing, physiotherapy, respiratory therapy, occupational therapy, and research). Gatekeeping processes at this intensive care unit follow a hierarchical pattern, so it was necessary for me to obtain unofficial approval in a stepwise manner from clinical research nurses, nursing practice, allied health professionals, unit managers (RNs), team leaders (MDs), department head

(MD), and finally from a clinical administrative director for the entire hospital before officially submitting the project for formal ethical review. As I moved up the chain of command, gatekeepers became increasingly busy, and organizing time and space to meet and explain the project became more difficult. During this time, I was also finalizing my research proposal for submission to the Sociology and Anthropology department at Carleton. The responses and conversations I had with hospital stakeholders helped me to formulate my planned investigation in a manner that was acceptable to them, but that at times caused conflict with my sociological research goals. Many physicians and nurses I spoke with expressed interest in a project that sought to investigate the tensions and paradoxes of critical care that they worked with every day. At the same time, I often came up against resistance and suspicion regarding my proposed qualitative observational methods. My uncertainty about specific aspects of the study such as what I was “hoping to find” and how my findings would “impact clinical care” caused some gatekeepers to request revisions of my proposal and resulted in tensions with the formation of the project in sociological language. In the end, I created two outlines of the project – one dissertation proposal written in theoretical and sociological language to be reviewed and approved by my committee, and one research protocol written in medical research terminology which was circulated and approved by clinical stakeholders and the hospital ethics board.

Once I obtained the required unofficial approval and recognition from key stakeholders that my project could go ahead, I began working on obtaining formal ethics

approval. For this project, I sought approval first from the hospital ethics board and then from the university ethics board (see Appendix for approval copies). Ethnographic studies are not common at the hospital where I completed my work, and the ethics board was initially apprehensive of my proposed methods. After some back and forth regarding the need for informed consent and assurances about privacy, the hospital ethics board granted approval for me to pursue the study. Once I had approval from the hospital, obtaining approval from the university was a relatively smooth procedure. Prior to showing up for my first day of data collection, I enlisted the assistance of the research manager to send an email to all nurses announcing my arrival and my intentions to broadly study death and technology in the intensive care unit. I also asked specific permission from the staff physician on duty to attend rounds, again reminding them of my intention to collect general observations about death and dying and assuring them that I would not be auditing their medical practice.

The negotiated interactive observations that I engaged in mainly involved the process of attending morning rounds with the physicians for three to four days a week over a 10-week time period from March to May of 2019. I would arrive in the intensive care unit on weekdays around 7:30am and I usually left after several hours. A typical day began by attending “handover” in the mornings, in which the team of residents who had worked overnight provided a morning report to the incoming residents and attending staff physicians. I would then travel with the group of physicians as they visited patients, discussing their management plans and making treatment decisions. As previously

described, the intensive care unit in which I conducted fieldwork had two wings. While I visited both sides on occasion, most of my observations were made in one wing in order to provide consistency and so that I could observe interactions surrounding certain patient cases for multiple days. On some days, I remained stationed near a bedside and observed nursing practices and the general work and occasional crises that occur over the course of a usual day. At times I followed physicians in their tasks of diagnosis and treatment, asking different members of the care team about their decisions and observing the many various actors involved on a daily basis in usual clinical care. In addition, I also attended 2-3 teaching sessions delivered to residents by more senior physicians and fellows, including one “Morbidity & Mortality” round and one “grand round” which was a larger public presentation facilitated by two staff physicians from intensive care.

I recorded field notes on paper and using electronic devices (phone and electronic tablet), and I spent time speaking informally to many healthcare and research professionals involved in various tasks in the intensive care unit. I also collected a series of documents related to the process of dying, including a “death package” and information relating to the practice of organ donation. At the end of each session of fieldwork I sat down in a quiet space outside of the intensive care unit and transformed my early “jottings” into more detailed vignettes (Emerson et al. 2011). In addition, I also periodically reflected on the processes of fieldwork and kept an ongoing account of interesting ideas in a written notebook. By the completion of my fieldwork in May, I had

compiled a total of 142 typed pages of written vignettes of fieldnotes, had written 30 entries in my reflection journal, and had collected 13 original documents for analysis.

Ethnography interviews

Another important element of ethnographic work involves formal interviews. As part of my study, I planned to interview at least one key informant from each aspect of patient care. I developed an initial interview guide that focused on how healthcare practitioners make categorizations about when and how they consider an intensive care unit patient to be dying. With these questions, I was interested in elucidating the nuances of ethical thresholds that I had been observing as part of my negotiated interactions. I completed two semi-structured interviews of about 40-60 minutes each with two health professionals whose work intersected with the intensive care unit. My preferred method of interviewing was to use a conversational approach that both challenged participants to reflect on their position and experiences and also followed the topics that they found most interesting and meaningful (Hermanowicz 2002). I found that healthcare practitioners were generally willing to talk to me and many wanted to engage in conversation and speculation about the ethical constraints they found themselves in daily. The choice to use this informal style of interviewing allowed me to obtain more candid opinions from my participants. However, it was also challenging to ensure that I stayed focused on discussion relevant to death and ethical choices and to ensure that I did not push participants into opinions they might not otherwise have voiced. My presentation of self

as a young, curious researcher with some background knowledge of the intensive care unit and hospital medicine but no clinical training certainly influenced what participants were willing to share with me. Both interviews were digitally recorded and transcribed verbatim. After completion of two interviews, I took a pause with data collection in order to review what I had gathered and reformulate new research questions.

Participant observation & ethnographer as apparatus

As ethnographer and apparatus of data production for this study I was also involved in a good deal of participant observation resulting from the many professional and informal relations that I maintain with the critical care research community. Throughout my fieldwork and over the course of this study I continued to be involved in a research project seeking to understand the physiology of death and dying following the removal of life sustaining therapies in the intensive care unit (Dhanani et al. 2021). As part of my involvement in this study, I took part in many research meetings as well as attended and presented at larger conferences on critical care medicine and organ donation. During these meetings I spoke with physicians, nurses, researchers, bioengineers, respiratory therapists, organ donation coordinators, surgeons, lawyers, laboratory technicians, donor families, and transplant recipients from across Canada and internationally about many different aspects of the process of death and dying in the intensive care unit, including its relationships to organ donation and transplantation, and the interesting ethical paradoxes that can imbue common clinical processes with

unsolvable tensions. My entanglement in this world of clinical research has resulted, over the course of my PhD work, in several publications (van Beinum et al. 2017, 2019, 2020) and involvement in a patent for an algorithm that predicts time from withdrawal of life sustaining therapies to death (Seely et al. 2019).

Some might see my ongoing involvement in the clinical research world of organ donation and intensive care as a potential conflict or as detracting from the validity my work. The traditionally imagined threat is that too close of an association between the ethnographer and the participants and settings under study impairs objective observation. However, ethnographic knowledge production from an agential realist, posthuman perspective refuses the construction of some arbitrary distance of objectivity and instead encourages an ethical accounting of the particular inclusions and exclusions made when constructing any research data. Like many ethnographers, I embody the “awkward union” of participant and observer (Seim 2021), having already been deeply immersed in the clinical research world for years prior to commencing this study. My capacity for objectivity in these settings is related to the characteristics of knowledge production obtained by engaging with sociological, anthropological, and philosophical theory, rather than any relative positioning. My relationships within intensive care research communities permit access to certain conversations and moments of knowledge production, but it is my reading of sociological and posthuman theory that prompts reflection and diffraction of observed moments into insights relevant for thinking about theoretical and ethical implications (Clifford and Marcus 1986). In addition, I believe it is

my continued integration within these communities of existing practice and knowledge production that has the potential to positively expand the relevance and usefulness of my conclusions.

Secondary data analysis, media cases & diffractive insights

From a more practical standpoint, my ongoing involvement in clinical research worlds of death, dying, and organ donation in intensive care has facilitated access to relevant research data. In 2018 I was approached by the Chief Medical Officer of the Trillium Gift of Life Network (Dr. Andrew Healey) to help lead a survey exploring Canadian physicians' experiences with families that request continued organ support for patients who have been declared dead using neurological criteria. I agreed to help lead this study and was open with Dr. Healey that I saw this as opportunity to speak with Canadian physicians about the production of death in the intensive care unit, a topic with direct relevance to this dissertation. As a co-leader of the survey project, I suggested that we also conduct qualitative interviews with physicians to supplement the quantitative data. We recruited 12 Canadian physicians from across the country who participated in semi-structured interviews ranging from 30-60 minutes in length which I conducted by phone (with one completed in person). A copy of the interview questions is attached in Appendix C. All interviews were transcribed verbatim and analyzed as part of a mixed-methods study published in the Canadian Journal of Anesthesia (van Beinum et al. 2020).

Ethics approval for the mixed-methods study was granted by the William Osler Health System, the research ethics board associated with Dr. Healey's place of work. In January of 2019 I requested permission from Dr. Healey and from the William Osler Health System Ethics Board to conduct a secondary analysis of the interview transcripts (see Appendix D for a copy of the approval). I also submitted an amendment to the Carleton University ethics board (see Appendix E).

In addition to this interview data, which I used in part of my analysis, my participation in clinical research spaces facilitated several opportunities in which I encountered perspectives and positions informing my analysis about the production of death amidst lifesaving technology. Specifically, these side projects involved qualitative interviews with families who had to make decisions about withdrawal of life sustaining therapies and about organ donation for a loved one dying in the intensive care unit, and interviews with healthcare practitioners who felt they had witnessed autoresuscitation (spontaneous resumption of circulation after a declaration of death). I have been personally involved in conducting interviews and in the process of transcript coding and analysis for the first project and I conducted, transcribed, and analyzed all interviews for the second. Space and time do not permit integration of all of this data in the present analysis, but my ongoing and in-depth involvement and the novel perspectives encountered have invariably shaped how I understand the dynamics of how death occurs in the intensive care unit.

While working on this project I also became interested in several “limit” cases which have occurred in intensive care units and which had relevance to my theoretical analysis of death in technological spaces. Though I did not observe these cases in person, the wealth of newspaper and legal publications related to these high visibility cases makes many aspects of these stories available for analysis. Following a method of diffractive analysis, I at times employ details of unusual cases such as that of posthumous pregnancy to explore new figurations of cross-cutting themes encountered in my analysis.

The final combination of negotiated interactive observation, interviews, participant observation, secondary data analysis, and integration of high visibility media cases come together to provide a wealth of data from multiple sources from which I draw on to formulate my thoughts about how death occurs in the intensive care unit. My unique configuration as ethnographer/clinical researcher/employee/graduate student has shaped my role as the particular apparatus of data production in this project. In keeping with principles of situated knowledge, such as those described by Barad (2007), Haraway (1988), and others (Harding 2004), this configuration allowed for one objective, albeit particular, accounting of how death occurs in the intensive care unit. However, taking Viveiros de Castro’s points about perspectivism seriously, the unique specificity of any perspective is not what matters, rather, it is the relations between perspectives that we should be concerned with. It was not my goal to provide a definitive answer about the conditions of possibility for death to occur amidst lifesaving technology. In fact, it is my opinion that no single definitive “answer” to this question exists. Instead, my aim was to

use a valid but specific rendering of some ways in which death occurs in the intensive care unit to think critically about the nature of modern technological death and its role in society, to relate my observations with existing theories about ethical thresholds and accountable deaths, and to imagine possibilities for how things could be otherwise.

Analytic approach

For this project, the goal of analysis was to be able to draw substantive critical theoretical insights about how death and dying come to be possibilities in spaces where the use of technologies of lifesaving and life-sustaining is pervasive. As mentioned, I generated a wealth of data from a number of different sources. While I produced and collected data, I was also reading social theory and philosophy, exploring relevant clinical cases in the media, as well as maintaining various paid and unpaid clinical research engagements. In order to capture and attend to the many diffractive insights I came across while existing in this space between sociology and medicine I maintained a daily journal of my experiences through fieldwork, participant observations, and later analysis and writing. Written notes allowed me to recognize the transitions in my thinking between the physical and metaphorical spaces of the clinic and the classroom, as well as the commonalities and missing links between them. These seemingly innocuous jotted thoughts also helped to guide me in the eventual theoretical direction of my analysis.

The first step for the formal analysis of data was to transform all relevant written notes, including all written fieldnotes, into digital documents to be uploaded into

qualitative analysis software. This step included listening to and transcribing digitally recorded interviews, as well as transcribing written journal entries and notes in the margins of my research journals into typed documents. As I produced electronic documents, I uploaded them into Atlas.ti (Scientific Software Development 2016), a qualitative analysis software with which I had previous experience. Once in digital project form, I employed the process of applied thematic analysis (Guest, MacQueen, and Namey 2014) to construct coded themes and narratives for inclusion in the final analysis as presented here.

The process of deciding which narrative cases to include for analysis was guided by my research goal of aiming to describe the usual conditions under which death becomes possible in the intensive care unit in order to conduct a critical theoretical analysis. For this reason, I focused on locating moments “at the threshold” of knowing, where actors could be observed to struggle with decisions or time points surrounding death. In my analysis, I looked for discussions about decision making, observations of changes in number or degree of technology present, and overt conversations about ethics and thresholds that occurred in any research data. Through a process of constant comparative coding and much revisiting of my notes I was able to bring forward three core thematic analyses which form the basis for the constructed narratives guiding the following chapters.

My analytical choices were also shaped by a number of ethical limitations. As part of my ethical commitment to my participants, I chose not to expose moments of

perceived clinical negligence (nor did I attempt to observe any such moments). The goal of this project was to be able to describe the intensive care unit as a phenomenon in itself, a conglomerate network of possibilities, flows, and intra-actions. My goal was not to pinpoint specific individuals and audit their practice, nor to identify unusual events, as I reassured my participants and gatekeepers time and again. I later decided to include an analysis of several unusual clinical cases as described in the media as examples of “limit cases” of technologically mediated death. Since my project focus was on describing elements of the intensive care unit as a phenomenon and not focused investigating unusual aspects of care, I do not feel as though the choice to exclude unusual elements of clinical care from fieldwork strongly influenced my results. In addition, the inclusion of unusual cases as presented through highly publicized media accounts allowed me to draw diffractive insights in relation to my “usual practice” findings.

Another ethical choice that I adhered to during analysis was to exclude any detailed observations of family members. Though the interactions of patients’ family members certainly shape the production of ethical thresholds in the intensive care unit, I did not have clearance from the site research ethics board to include any detailed observations in my analysis. I was not permitted to speak with family members nor to enter patients’ rooms; thus, my observations of patients and families are mainly general descriptors or narratives filtered through healthcare worker accounts. On a number of occasions, I was invited by healthcare practitioners in the intensive care unit to attend them on their visits and discussions with patients and families. I always respectfully

declined these invitations and explained the limitations of my ethics approval. As part of my analysis, I chose to maintain indirect and general descriptions of family dynamics that were voiced by healthcare practitioners and only when needed for understanding contexts. These indirect and general inclusions allowed me to retain some of the ways in which families figure in trajectories of dying in the intensive care unit but necessarily pose a limitation in that they do not follow these important actors in detail.

The analysis for this project was conducted in an ongoing, iterative manner that subsequently informed the need for and direction of future data collection. The topic of how death becomes possible in the intensive care unit is immense, and it seems possible to continue to pursue it from many angles for a sustained period of time. Ultimately the decision to end the collection of data and to draw this analysis to a close was driven more by time and funding constraints than anything, a position not unusual for the ending of ethnographic work (Fitzpatrick 2019). Nonetheless the data collected to date has allowed for a number of detailed descriptions which have facilitated the construction of narratives for use in critical theoretical analysis.

Conclusions

In the intensive care unit, death involves a nuanced moment between almost-dead and almost-alive, one fraught with possible ethical questions and entangled with the involvements and knowledge practices of many actors. For this project, I have chosen not to foreclose the many configurations that death may become. Instead of taking sides with biological or cultural determinism, I have proposed an alternative, posthuman stance that

focuses on the particular mechanisms through which perspectives (and thus, research data) are produced and sustained. This approach is in some ways similar to ANT but moves beyond it to ensure active and accountable consideration of the power dynamics (and therefore ethics) at play in any configuration of relations. I have insisted on a methodological approach that encompasses an active accounting of ethics as ethical thresholds comprise one of the main phenomena I wish to know more about.

I have chosen to pair this theoretical and methodological orientation with a pragmatic version of ethnography that encompasses many messy forms of data collection and has not shied away from being close to, and indeed integrated within, some aspects of the world of study. Through a process of negotiated interactive observation, interviews, participant observation, and secondary data analysis I compiled a variety of textual data that I then analyzed using a qualitative method of iterative, constant comparative thematic coding. The resulting analysis is comprised of a series of narrative thematic accounts that illustrate various elements of the networks that make death possible in the contexts of the intensive care unit. Drawing from these narrative accounts has permitted an interesting and productive engagement with the theoretical and practical elements of my research questions. In the following analysis chapters I present the bulk of my encounters with the core research question motivating this work, how is death made in contexts of intensive lifesaving?

CHAPTER 5 | Logics of lifesaving and the denial of death in the intensive care unit

The patient lying in bed is a petite elderly woman, whom the nurse informs us is over 90 years old. She was admitted from a nursing home and is at high risk of bedsores due to her thin skin and bruising from the insertion of intravenous access lines. This patient came to the hospital for an assessment of possible pneumonia but then went into respiratory and cardiac distress in the emergency department. Despite a documented DNR¹⁰ at the nursing home and a signed form indicating she did not want to receive invasive therapies, she was intubated and brought to intensive care.

Outside the patient's room, the healthcare team discusses the case and what can be done about a possible seizure that the patient appeared to have had this morning. While the doctors converse, I notice the patient slowly bringing her thin arms up towards the tube in her mouth, as if to grab it. The nurse also notices and runs into the room to gently push the woman's hands back down to her sides. She speaks kindly to the patient, instructing her not to touch the tube, and then returns to the discussion. As soon as she is out of the room, the patient again begins to reach her arms up. The nurse notices the movement and walks quickly back into the room. The physicians have also noticed the patient's movement. The attending, standing beside me, says softly, "do it," as if he were encouraging her to pull the tube out. In the room, the nurse readjusts the patient's arms, and this time pulls the blankets over them. She then goes behind the bed and makes some adjustments to the drug pumps. When she returns to the discussion she says, "Sorry, just not wanting to try a self-extubation right now. At least not on a Cat 1." The patient remains still.

Five minutes later, at the conclusion of the discussion about the case, the attending leaves orders for the bedside nurse to, "Extubate when awake." Removing the breathing tube is delayed, however, because the patient fails to wake up enough for the nurse and the respiratory therapist to feel comfortable with this procedure. They feel that the patient will die when the tube is removed, and they are anxious about a lack of communication from the patient's family and lawyer. The bedside nurse feels that ethically there is no concern with continuing care and prefers to do this until a "clear plan" is in place. At the end of the day, the patient remains lying in bed with her eyes closed, her white hair illuminated by the artificial hospital lights, the hum of the ventilator and the tube down her throat her only constant companions.

(Fieldnotes, Apr. 25, 2019)

¹⁰ DNR = Do Not Resuscitate order. The hospital also uses a "Category Status" system to designate desired levels of care, with "Category 1" ("Cat 1") signifying full treatment ("do everything"), "Category 3" signifying "comfort care" (no escalation of care, treatment only to increase patient comfort), and "Category 2" somewhere in between, usually signifying a desire for no intubation.

Long after I concluded my fieldwork, I continued to feel an uneasiness about cases like the one presented above where patients with a clear intention or at least apparent comfort with reaching the end their lives were admitted to intensive care and were administered life-sustaining interventions seemingly against their wishes. These cases ranged from elderly and terminally ill people with previously documented DNRs to those who were admitted and resuscitated after attempted suicide. There were also cases in which very sick but still conscious people requested assistance in dying or no further invasive interventions, even after the medical team had saved their life and continued to offer treatments. To me, these cases did not seem to be a product of particular practitioners or types of patients, but rather appeared to occur as a result of the underlying organization and structure of care in the intensive care unit. Cases like these highlight how categories such living and dying are constantly challenged and manipulated by the technologies and practices of intensive care.

These types of cases in which clearly documented or stated desires for death are overwritten by healthcare practitioners and institutional policy are not the majority in the intensive care unit. Indeed, most of the time, patients and their families desire intensive life-saving interventions and the chance to continue living. However, the observable and regular occurrence of cases in which patients and families in the intensive care unit desired the contrary points to an underlying tension between the saving of life and the allowing of death. When is it acceptable to make the transition from one objective to the other? Where, when, and who is permitted to “draw the line” between the activities of

lifesaving and death facilitating? Could permitting and facilitating a patient's death, instead of saving their life, ever be an ethically justifiable decision in the lifesaving environment of the intensive care unit?

The question of a desirable death and whether and when it could be ethical to allow a death to occur amidst life-saving technologies is challenging to frame. Medical practice has a long and troubled history of eugenic practices and social injustices. From death camp experiments to forced sterilization, medicine has been synonymous with untimely death for large populations of people. How to consider that human death could ever be ethical or desirable in the contexts of ableism, ageism, sexism, racism, and all of the other many unjust structural inequalities that continue to insist on the unworthiness of certain lives? How to think about ethical bodily endings and decisions not to save and sustain life in the contexts of a medical practice that at times effects murder?¹¹ And finally, how to consider these questions against the reality, made clear through ongoing patterns of climate change and socio-political crisis, that endless growth and consumption are not possible, and that all human bodies must eventually die? Understanding how and when the denial of subjectively desired death occurs amidst technological capacity to save and sustain life offers one location for thinking through some of the complex elements of important, ongoing ethical tensions and difficult questions surrounding human death.

¹¹ The case of Joyce Echaquan, a 37-year old Atikamekw woman who was ignored and mocked while she died in distress at a Quebec hospital, provides a recent, tragic example (Lowrie and Geraldine Malone 2020).

On the surface, there are many bureaucratic and communication complexities that seem to perpetuate scenarios in which patients are prevented from dying on their terms. Research in hospital settings has demonstrated that patients with clearly documented DNR orders can nevertheless go on to receive cardio-pulmonary resuscitation (CPR) for various reasons including a lack of communication or inability to locate forms indicating end of life wishes (Baxter et al. 2018; Wong, Duane, and Ingraham 2020). Similarly, while documented advance directives and care planning have been celebrated as tools to inform medical teams about patient desires for lifesaving interventions, they can be difficult to practically interpret in critical care and emergency settings (Hartog et al. 2014). Educating healthcare professionals about the need to consult the medical chart prior to commencing life-saving interventions is an ongoing effort, and perhaps in the case of the elderly patient described, may have prevented her from ending up in intensive care. But in addition to the challenges with establishing and managing end of life documentation in the hospital, one must take into account the underlying motivations triggering the patient's transport from the nursing home to the hospital in the first place. All of the healthcare professionals involved in this case seemed to demonstrate compassion and concern for this patient's immediate wellbeing, which I evidenced through their ongoing attempts to mitigate her pain and to handle her gently. Likewise, they did not seem opposed to or ignorant of her desires for limiting life-sustaining interventions. Instead, they were simply unable to carry them out. To me this points to something more at play in these types of cases than a lack of training or a misreading of

documents, something that goes beyond the individuals involved at the bedside and the bureaucratic practices of hospital administration.

In this chapter, I investigate these tensions and conflicting narratives of life and death by exploring in detail cases of denied bodily endings. First, I consider how the practice of intensive care is oriented towards a particular mode of lifesaving. Primarily, this is the saving of individual and autonomous human lives which I call the “logic of lifesaving.” I trace how this logic is enacted through material practices of intensive care and consider how the denial of death is consequently facilitated. I conclude by considering the implications of honoring desired death, including a response to those who would see this as a eugenic practice. The purpose of this chapter is to investigate one smaller aspect of my broader research question – how is death decided in spaces of ongoing lifesaving and sustaining? Here I explore the question by taking up the phenomenon of desired deaths that are denied as a means of illustrating some factors contributing to the deciding of death in technologically intensive spaces. As the opening vignette of the elderly patient demonstrates, in spaces of lifesaving and life-sustaining, pre-stated desires for individual death are not always sufficient to permit its occurrence.

My methodological approach in this chapter involves analyzing vignettes and cases from ethnographic fieldwork data and diffracting it through the various embedded and embodied histories and realities of the intensive care unit. Rather than interrogate the idiosyncrasies of individual action, I aim with this chapter to piece together possible perspectives from which to consider the broader ethical implications of the intensive care

unit as a relational whole. The goal of this form of new materialist analysis is not to “individualize responsibilities and put the blame on other agents,” such as specific doctors, nurses, or patients, but rather to “give attention to the affective and relational dimensions” of the intensive care unit (Van de Putte et al. 2020). In this chapter I am not aiming to provide a comprehensive description or explanation of all relationships which occur in the intensive care unit, nor am I proposing an overarching theory about the social structural positions of life and death in technological spaces. Instead, I aim in what follows to propose one possible way of (re)thinking the role of intensive, technical forms of medicine and how these processes of clinical care and intervention produce and deny certain possibilities for living and dying.

The logic of lifesaving

“They’re coming? They’re coming. Alright. We’re ready.” With an ominous click the charge nurse hangs up the phone and announces this same sentiment to the nurses, orderlies, physiotherapists, and respiratory therapists currently completing their morning tasks, “They’re coming.” Immediately nurses and support staff begin moving into action, readying equipment carts, obtaining forms, preparing IV lines. The bright fluorescent lights in an empty room are switched on, ventilators and defibrillators are wheeled around. The team is getting ready for a new admission, a “Code Blue” from the Cardiac Care Unit that was announced on the hospital overhead just minutes ago. A feeling of excitement and anticipation seems to now animate what was just moments before the regular morning routine: conducting patient assessments, recording vital signs on nursing flowsheets, reviewing scheduled appointments and procedures for the day. As she rushes past me to the administrator’s desk around the corner, the charge nurse says aloud, “We save lives.”

(Fieldnotes, Apr. 11, 2019)

A resident approaches the bedside of a patient to review the chart before rounds. He begins chatting with a fellow from another service who is also reviewing the chart. Soon after the fellow gets up to leave from the bedside and says to the resident, “I’m sure I’ll see

you around.” The resident smiles and replies, “Keep saving lives!” The fellow laughs as he walks away, “Yeah, one prescription at a time.”

(Fieldnotes, May 9, 2019)

“Saving lives,” as stated by the actors in these vignettes, is the collectively understood underlying goal which drives much of the work of the intensive care unit. The first scene, the frantic preparation and buzzing anticipation that precedes all new emergency admissions, plays out daily in intensive care units across the world. Those who have never had to enter this part of the hospital may nevertheless be familiar with this exciting drama as it occurs often on television screens and in movies. The intensive care unit is always there to bring the protagonist back from the brink of certain death after the gunshot wound, bout with cancer, overdose, car crash, or other accident. We accept and appreciate the fact that hospital services such as the emergency department and the intensive care unit are relatively available to save lives, should they be required. But what exactly does it mean to “save lives”? What types of lives, or what types of “life” are being saved in these highly technical spaces? And importantly, when life cannot be saved, what types of death are being facilitated?

The concept of “saving life” appears at first to be obvious: saving involves honoring and perpetuating the unique and irreplaceable abilities and capacities of a human. However, a closer look at the concepts of “saving life” and “human life” draw attention to the ways in which this seemingly simple and taken for granted imperative is host to a plethora of underlying assumptions and social processes. In this section I trace a brief history of thought about the concept of “saving life,” from religious roots to

population control. Next, I consider how despite its grammatical presentation, “saving life” has never been generally applied but rather is always focused on the perpetuation of individual, independent, human life – the ideal human life as imaged during the European Enlightenment period. Returning to the practice of intensive care, I argue that an individualistic and anthropocentric focus on lifesaving obscures the possibility of affirming the unfolding potentials of a more broadly conceived Life as ongoing and intersubjective relation.

Saving life is honoring precious gifts from God

Lifesaving is an idea with strong roots in many religious traditions in which mortal life is a gift granted from God that human subjects are responsible for preserving and honoring (Parsons, Fox, and Lidz 1978). The highest form of honoring this gift is by productively and devotedly adhering to the religion. Religions such as Catholicism promise a high moral reward for devotees who spend their lives ensuring that vulnerable or ignorant individuals don’t waste God’s gift, in other words, ensuring that non-believers convert and thus “save their lives” (Green 2008:25–30; Parsons et al. 1978) It is not surprising that many early formal institutions responsible for “saving lives” in a corporeal sense were also closely connected to and often run directly by religious groups that simultaneously aimed to “save lives” spiritually. Many large Canadian hospitals can trace their histories back to simple institutions funded and maintained by religious orders (Humbert 2004; Hurrell 2017). While lifesaving was initially achieved primarily through

baptisms and deathbed conversions, it later became more closely aligned with resuscitation technologies and practices such as CPR (Timmermans 1999:31–33). Though most hospitals in Canada have now formally split from the church and scientific medicine claims to be entirely secular, religious influences on the practice of lifesaving in medicine remain present and relevant. Moreover, these influences appear to be most common and discernible where the concept of lifesaving is in question. For example, practitioners with strong religious beliefs are more likely to refuse to participate in the decidedly life-ending but, in Canada, legal practices of abortion (Abdel-Aziz, Arch, and Al-Taher 2004) and medical aid in dying (Bator, Philpott, and Costa 2017). Quantitative investigations have identified religious affiliation as a contributing factor in which types of ventilation are employed as life-sustaining intervention (Garrouste-Orgeas et al. 2014). Vestiges of a focus on preserving the physical and spiritual lives of both saver and saved leads to such ethical inconsistencies as dying patients requiring medical transport in order to receive assisted dying services (Dying With Dignity Canada 2019; Fraser 2017), and the deaths of pregnant women as a result of denied abortions (Berer 2013). The practice of lifesaving remains historically tied to religious beginnings in which the absolute greatest moral good lies in saving souls, today more commonly encountered as a secular push for saving bodies (Green 2008:22–25). However, while religious beliefs continue to have some degree of influence on intensive care practice, we must also account for the ways in which the meaning of life has continued to change in a largely secular world (Green 2008). To move further into a critical analysis of what it could mean to “save

lives” in today’s intensive care unit spaces, we need a better exploration of some ways in which “life” has been thought in postmodern, advanced and secular capitalist society.

Saving life is a form of maintaining power

In a postmodern society, ideas about life as a gift from God have been generally replaced by the idea of life as a powerful and productive force to be harnessed and controlled. From controlling the lives of laborers to eliminating the livelihood of dissidents, the structures of neoliberal capitalism cultivate productive forms of life as power. Foucault’s concepts of biopower and biopolitics (1978, 1992) helped to make these links, with biopower pertaining to the power and responsibilities of individual lives and skin-bound human bodies, and biopolitics governing the ways in which life as population is controlled. Foucault’s post-structuralist analysis focuses on the interconnections of power that allowed certain types of individual subjectivities to become possible, while other forms of life and power become devalued (1978, 1992). Within this paradigm, life becomes not a biological given that resides in a body, nor a precious gift from God, but a responsibility of the individual, something owned or granted to the self that must be nurtured and maintained and which can be taken away. Similarly, living populations are perceived to hold an amorphous but real power which can be attended to and enhanced (e.g., through public health campaigns) and/or actively corroded (e.g., through genocidal or eugenic practices) through disciplinary powers wielded by larger institutions and systemic discourse. This is the classic “make live” or

“let die” of population management policies, and the concept of biopolitics provides a useful tool for exploring how various relationships of power have a direct influence on demographic trends (Li 2012). While the classic biopolitical lens is focused on life as a productive power of populations, this same concept can be re-thought as death-facing through the mirrored term of necropolitics, the cultivation or predisposition of certain populations for death (Mbembe 2003).

The concepts of biopolitics, biopower, and necropolitics have been re-worked in the 21st century to account for new and widespread forms of life and its management, including in the forms of genes, viruses, and artificial intelligence (Haraway 1997). An analysis of the present-day “regime of biopower” (Rabinow and Rose 2006) demonstrates how saving and sustaining life in a biopolitical sense has expanded beyond the control of human bodies to include such complex non-human assemblages as reproductive rights, genetic modifications, and structural racism. Rose (2009) suggests that contemporary forms of biopolitics no longer consider populations in terms of controlling bodies through birth and death rates but are instead focused intently on cultivating vitality. In this new paradigm it is no longer sufficient for disciplinary power to ensure the promotion of human life. Instead, it must attend to the quality of lives lived and the inherent vitality and liveliness of human life (Chen 2012). Framing the power of life as vitality permits analyses to consider how non-human objects and even material elements such as lead can appear at times as more alive and with more agential power than certain human bodies (Bennett 2010; Chen 2012).

In the intensive care unit, a present-day biopolitical framing might consider the actions and meaning of lifesaving as producing and sustaining the vitality of human life. In addition, this framing would consider how the actions of lifesaving are always part of larger structures of power. Where religious influences were primarily focused on the saving of individual human lives, a biopolitical analysis permits consideration of both the individual and the collective population. At the individual level, saving life in intensive care is a means of sustaining and enhancing the powerful vitality of human bodies. Lifesaving connections permit the recognition of animacy and vibrancy in bodies that would otherwise be still and cold. The maintenance of vitality also permits important practices such as deceased organ donation, in which the liveliness of organs can be transplanted into other bodies in need. At a broader, population level, the work of lifesaving in the intensive care unit can be seen to operate in simultaneously life-affirming and death-facilitating modes. On one hand, the intensive care unit appears to operate as a small part of a larger social strategy of public health and medicine. The processes and practices of intensive care are responsible in part for maintaining population health and large-scale vitality through saving the lives of those on the brink of expiry. Narratives of the “cutting edge” and “heroic” lifesaving medicine practiced in intensive care affirm a political economy of hope in which, “hope for the innovation that will treat or cure stimulates the circuits of investment and the creation of biovalue” (Rose and Novas 2005:6). On the other hand, the intensive care unit can be seen to operate within the paradigm of necropolitics as a location in which discursive ideas about which

lives are worth living and which lives are worth letting go are put into operation through the orchestration of provision of lifesaving interventions to some and withdrawal of life sustaining therapies for others. In places where healthcare is privately funded, the high costs of intensive care ensure that lifesaving is a luxury of the rich and well-insured, with poor and chronically ill lives less likely to be saved.

Despite their broad influence, both religious and biopolitical analyses of the concept of lifesaving tend to center the production of meaning on *human* life. As I explored earlier in Chapter 2, a focus on the human includes a focus on those traditionally assumed to fit within humanist definitions of Man, that is, White, male, independent, objective and rational subjects. This exclusive and anthropocentric position focuses on the salvation of Man's soul, the power of the working Man's body, and/or the inherent vitality of Man's mind. But there is an additional perspective on saving life which does not center this exclusive and elusive human, and which provides instead new ways for thinking about narratives of lifesaving and the denial of desired death in the intensive care unit.

Saving life is a means of maintaining ongoing and unfolding relations

Recent scholarly work has pursued the potentials for thinking about vital life as a relationship, rather than a biological repository of power. In an attempt to move beyond the concept of biopower, Braidotti (2006, 2010) draws on Deleuze's (1977, 1987) concepts of power as multifaceted and relational, granting all subjects (including non-

human subjects) the power to affect and to be affected. Instead of critiquing the colossal crush of centralized or dominant power and finding ways to endure its oppressive control over all aspects of our lives, Deleuze's philosophy of complexity brings forward the concepts of molar (large, slow-moving, oppressive) and molecular (small, fast-moving, creative) potentials for power, and thus seeks to create space for movement and change through particular diffusions and relationships (Deleuze and Guattari 1987). Braidotti picks up these concepts and works with them to consider the many possibilities for change that exist in a world with endless opportunities for molecular variation, along with our collective ethical responsibilities for sustaining viable options for an "otherwise" (2006, 2010). For Deleuze and Braidotti, as for poststructuralists, the subject position is not an inherent given reserved only for human bodies. Instead, subject positions are created through unique configurations of power to affect and to be affected. Certain bodies, real or imagined, have been historically produced and upheld as subjects worthy of interaction and knowledge while others are ignored, marginalized, and forgotten. This is a product of molar power relations such as historical processes (e.g., the historical processes of racism and colonialism which converge to produce racialized bodies as not-quite-human and less than desirable subjects), alongside more molecular movements that have the potential to change the story, but always also the potential to be reabsorbed into molar narratives (e.g., the celebration and subsequent fetishization of the racialized body). Where Foucault's analysis of life as productive force posits a diffuse dominant power to "make life" on one hand and the individual oppression of being wholly

controlled on the other, a posthuman position in which life is an ongoing relation keeps in mind a “both and” strategy of complex composition, rather than oppositional organization, and considers how everyday material and relational practices affect and are affected by the many human and nonhuman subjects they sustain.

Life, from a posthuman perspective, is therefore not even necessarily associated with a subject at all. Indeed, Braidotti (2006) puts forward a convincing argument for re-founding the concept of *zoe* not as the silent unwanted sister to Agamben’s (1998) rational, political, powerful, and qualified life, *bios*, but as the underlying, pervasive material and secular-spiritual Life that runs through everything. Where Agamben marks life as *zoe* as non-human animal and therefore worth less, Braidotti’s posthuman politics take the animal as worthy subject and *zoe* as all-powerful in its unbound flows. For Braidotti, *zoe* is the essence of what springs up to persist even after conditions seem impossible or contradictory. Its character is in the hair and nails that grow on after death, the pattern of cell division that occurs in both cancer and pregnancy, and the giant isopods and other “tentacular kin” (Donna J. Haraway 2016) that emerge to devour dead crocodiles lowered to the bottom of the Gulf of Mexico (Louisiana Universities Marine Consortium 2019). The life force that is *zoe* is present in all beings, but it does not belong to any one of us and cannot be owned or controlled in the way that a human body or soul might be. It is a powerfully connecting and generative force, but also one that can be cruelly destructive. *Zoe* is the classic life cycle of everything pushed down the wild hill of the universe – the cycle of death and rebirth is endlessly repeating, but there are always

bumps in the road causing detours and irregularities. The trick is to keep the wheel moving. Thinking with Braidotti, life as *zoe* is not an individual right, but instead a collective, mutual responsibility that we sustain through affirming our ongoing and unfolding connections with others (2006).

How might such a posthuman perspective consider the concept of saving life? Certainly, the follow-up question of what exactly we are “saving” life *from* seems more relevant. With *zoe* in mind as powerful, persistent, and infinitely ongoing in its flows of connection and destruction even after and sometimes only as a result of bodily endings, saving life (not *a* life), would mean all attempts to “keep the wheel moving,” so to speak, our collective endeavours to sustain conditions in which life in all its many forms can continue to cycle along. This would seemingly include all forms of climate awareness, activism, redistributive justice, and all their complex inter-dependent components that aim to build allegiances and sustainable cooperatives. “Saving life,” from a posthuman perspective, does not immediately call to mind the saving of one or even many individual lives, since life itself is not perceived as a specific thing to be owned and presided over by any particular individual (Bennett 2010). Threats to this life are not the immediate injuries or illnesses experienced by human bodies, or even to “humanity,” since the persistence and power of *zoe* reminds us that life in some form will carry on, indeed is already carrying on in populations of people never deemed to fit the definition of “human” in the first place. Threats to posthuman life are threats to the narrative possibility of continuity and relation, they are threats to the greater universe of

possibilities for this life-force to continue in its unfolding (Braidotti 2006:247). They are assumptions of finitude and absolutism and their accompanying fears. Thus, saving life, from this perspective, requires maintaining respect, relation to, and responsibility for the Life that will always carry on in some form.

Is it possible that this conception of life could be applied to the statements made by healthcare workers in the vignettes presented earlier? The intensive care unit does save lives, and as a result it could be argued that it contributes to facilitating the ongoing unfolding of this nameless life force of *zoe*. In fact, the capacity of the intensive care unit to detect and sustain decidedly nonhuman life forces, such as the unsettling heartbeat and spinal reflexes that continue even after the declaration of death using neurological criteria, the persistent electrical activity of the heart following cardiocirculatory death, or the unconscious bodies sustained through life-support machines, make the intensive care unit an ideal space to encounter the emergence and unfolding of new forms of life not traditionally included in the category of human. But the perpetuation of *zoe* in new forms is not the focus of most practice in the intensive care unit, as I explore in greater detail in Chapter 6. Instead, the practice of intensive care medicine is primarily focused on the saving and sustaining of individual human lives with the intent to return patients to some desirable and imagined state of “normal.”

The focus on producing independent, “normal” lives ties in with what Clare (2017) has called the “violence of cure.” Clare draws from his experiences living with cerebral palsy to describe how the medical impetus to “cure” becomes enacted as a

forceful and dangerous emphasis on producing a pre-determined idea of “normal” and “natural” human bodies and minds. He demonstrates how this insistence for “normal” has been used as rationale for medical elimination of the “trouble” of disability through selective abortions, corrective surgeries, and specialized psychiatric reform treatments. But instead of becoming the “normal” ideal independent, rational, White, male, human, these invasive treatments serve to both devalue the unique differences and capabilities of disabled people as well as to mask the role of broader social relations in organizing the boundaries of abled/disabled.

I argue that in the intensive care unit, it is death, instead of disability, that is configured as the primary undesirable “trouble” that is to be avoided. The treatment provided by the intensive care unit rarely aims to provide “cure” to patients – instead it is focused on sustaining and maintaining bodies. As one attending physician stated, in the intensive care unit, “we can probably get your heart started again but we [can’t] fix the reason you died” (Fieldnotes, Apr 23, 2019). The “violence of cure,” in this case, involves invasive intervention on the body in the name of preventing bodily endings. But the result of this invasiveness, in some cases, is a devaluing of the responsibility entailed in the subjective recognition of one’s relationship with death. In addition, lifesaving intervention can prevent the establishment of potential connections with *zoe* as the life force that continues unfolding after bodily endings.¹² By insisting on the normativity of individual and independent human life, the denial of desired bodily endings may be

¹² The process of deceased organ donation, which facilitates perpetuation of a body’s life force through the transplant of solid organs, offers one such possibility.

overshadowing important and necessary distinctions that not all subjects desire to live or to be saved.

The medicalized enforcement of “normal” bodies and the denial of death through invasive lifesaving efforts are nonetheless deeply valued by some people, as Clare also recognizes, even those who are consequently violated and subjugated as part of the process (2017). There is an unresolvable tension between the desire for “normalcy” and for life, the ethical thresholds of violence on the body, and patterns of social exclusion which mark certain bodies and subject positions as more or less desirable. The ways in which these tensions play out surrounding lifesaving/death facilitating call for renewed ethical attention. A posthuman perspective in which human death is not a trouble to be avoided but rather part of a larger relation to be maintained helps to consider new analyses of desired and denied death amidst life sustaining technologies, even as it cannot resolve all relevant arguments.

Multiple meanings are imbued within the concept of “saving life” as it pertains to the underlying processes of the intensive care unit. Religious roots may cause some to understand lifesaving as a means of spiritual redemption for both savior and saved. From a poststructuralist position, “saving life” can be read as an attempt to discipline human life into a productive force to increase economic and social value – dead bodies cannot work, thus saving lives is profitable and increases power. In a more nuanced analysis, we could consider how “saving life” infuses bodies with a valuable and powerful vitality, perhaps opening the possibility for deceased organ donation, and creating unequal

markets for the consumption of material goods like IV lines, ventilators, and even human organs (Scheper-Hughes 2008). “Saving life” in the intensive care unit from a biopolitical framing may be less about preventing death than it is about maintaining vitality and therefore maintaining some degree of power and productivity from human bodies. Finally, a posthuman position of life as cyclical relation focuses on how the intensive care unit provides a unique space for the myriad unfoldings and possibilities of life as *zoe*, and for individuals to come to terms with their own relationships to death.

Encountering the idea of “saving life” through fieldwork vignettes creates diffractive patterns (Barad 2007) that make visible the interactions and multiple interpretations possible when looking at what life saving could mean in the context of invasive life support capacities. The patterns of difference between approaches make clear that “life” in general can be interpreted and valued in many different ways and as a result, actions of saving life and denying death hold multiple meanings. The many possibilities for understanding the value of life open up space against which to explore specific patient trajectories and the material and social relations that contribute to perpetuating specific types of subjectivities. In the next section, I explore in more detail cases of desired bodily endings and draw attention to the mechanisms of lifesaving power through which these are facilitated, delayed, and denied.

Denial of dying in the intensive care unit

“I think we feel a bit like we’ve lost, when someone dies. We really do our best and we really do want to save everyone...but, some people can’t be saved. And some people don’t want to be saved.” - Healthcare worker in the intensive care unit

(Fieldnotes, May 9, 2019)

Death in the intensive care unit is more than the loss of life for an individual. It is a loss for families, and a loss for healthcare workers, who must also contend with grief. As this informant notes, patient death can also be experienced as a “feeling like we’ve lost” for healthcare workers whose mandate is to save and sustain the vital forces inherent in human bodies and consequently to deny the ever present and irritating “trouble” of human death. In a space set up for the saving and maintaining of individual human life, how is it possible to apprehend and contend with those who don’t want to be saved?

In what follows I provide a more in-depth analysis of cases of denied bodily endings in the intensive care unit. I consider cases of denied bodily endings to be those in which an acceptance of or desire for death was made available through documentation (DNR, Category status forms), the advocacy of family caregivers, or at times from patients themselves. Specifically, I consider how cases such as the elderly woman presented at the opening of this chapter are facilitated through underlying narratives of lifesaving and technological intervention, a perception of the desire for death as deviant, and a strategic devaluing of the autonomy and desires of dying patients when compared to those who opt for life. Throughout this section I present fieldwork observations to

demonstrate how availability of technologies and narratives of lifesaving can overshadow and repudiate the inherent value of the dying person and the possibility of a meaningful relationship with death. I draw from observations throughout the intensive care unit to describe broader trends and to locate commonalities observed between different cases of denied bodily endings. Again, it is not my intention with this work to point out shortcomings of care, nor to place blame on any particular healthcare workers, patients, or families. In addition, I acknowledge that cases of desired death, though they do occur regularly, are not the most commonly encountered situations of the intensive care unit – most patients and families enter desiring that life is saved and that physicians “do everything.” As a result, the cases presented here may not be representative of all intensive care unit practice, and the patterns theorized here may not be generalizable. However, in keeping with the overall aim of this project, I find these cases intriguing and interesting starting points with which to challenge the reader to consider how new perspectives and ways of thinking might open up space for reimagining narratives of lifesaving and death facilitating in technologically intensive spaces.

Material consequences of lifesaving narratives

In terms of deciding whether or not to admit a patient to the intensive care unit, “there may not be a right thing to do, but there will be a pragmatic thing.” – Fellow, in-service training

(Fieldnotes, May 9, 2019)

In the hospital, where the underlying objective is to save and sustain individual life, the “pragmatic thing” that can be done in any clinical situation is often to implement life-saving interventions. There are a plethora of lifesaving technologies available in modern teaching hospitals, and their administration, as has been demonstrated by Timmermans’ work on CPR, is more or less automatic (1999). Once patients enter the hospital, lifesaving interventions become the norm, even in the presence of documented wishes for the contrary, as the opening vignette of the elderly woman demonstrates. I explored earlier how this push for lifesaving can be thought of as grounded in a particular history of understanding life as individual human life, and death, as bodily ending, as always inherently troublesome and necessary to prevent. While a desire for resuscitation may be present in a majority of patients who enter the hospital, it is not true for all, and this discrepancy has repercussions.

Here, I want to explore how universal application of lifesaving actions has material consequences for patients and for the healthcare practitioners who treat them. In addition to forging new physical connections of dependence between patient bodies and machines, the normalcy of lifesaving also situates resuscitation and organ support as the “pragmatic thing to do,” possibly precluding a more nuanced consideration of patient cases. In the presence of advanced organ support therapies, for example, I observed that the administration of life-sustaining interventions can be perceived as an “easy” decision that can be made in absence of more information about prognosis or the patient’s wishes.

The team is discussing whether to give a patient vitamin D. The resident assigned to the patient is mulling it over, presenting both pros and cons of adding another intervention,

considering when vitamin D is contraindicated and whether it might have side effects in combination with other medications. The attending cuts in, irritated, “You’re giving vitamin D, you’re not doing a frontal lobotomy.” He goes on to explain how when faced with “easy” decisions like this, where there is low risk of harm and the potential that the intervention could help, they should just move ahead with treatment. “Then we can see tomorrow whether it worked or not.”

(Fieldnotes, May 7, 2019)

Resident: I’m hesitant to start feeds given [this patient’s] poor prognosis. It’s just another therapy that we’ll have to withdraw later.

Attending: Well if we’re treating her, we’re treating her, right, and when we’re in this grey zone of not knowing where things are going, and you have an intervention like starting trickle feeds that is low risk and potential benefit, it’s better to just do it.

(Fieldnotes, May 30, 2019)

Both of these scenarios involve the administration of minimal risk life-sustaining interventions – vitamin D and “trickle feeds,” or tube feeding. In both cases, less experienced physicians (residents) raise concerns about whether interventions should be initiated given the complexities of the patients’ cases, but these are dismissed by more senior physicians who insist that they move ahead with administration. For attending physicians with a longer period of training and experience in critical care medicine, these decisions are comparatively “easy” – they fit within the overarching paradigm of lifesaving that underlies all actions of the intensive care unit. Further, since they are minimal risk, they are not perceived as having the ability to significantly impact patients or cause substantial side effects in the way that ablative brain surgery might.

However, though low-risk interventions like food and vitamins may not cause physical harm for patients, their symbolic value and the material consequences of additional life-saving connections to the patient are not without significance. As the

resident from May 30th intuitions, initiating tube feeding in a patient in whom prognosis is unclear could be, “just another therapy that we’ll have to withdraw later.” Nutritional interventions, in particular, have been demonstrated to cause considerable grief for families when they feel as though the decision to remove life support necessitates a decision to “starve” a loved one (Miller 2017; Pool 2004). Families may perceive decisions to continue organ support, even using low-risk interventions, as indication that the patient has a chance of recovery. Liao and Ito (2010) describe a case in which a one-day delay in declaring death using neurological criteria caused a patient’s daughter to move from full acceptance of the end of her father’s life to complete denial that the end had been reached. After all, if doctors can choose to delay what appears inevitable for one day, why can’t they delay for weeks or months? If the medical system can produce a sustainable disabled life, how come this life can’t be maintained? The “right thing” to do is often incredibly difficult for physicians to discern, especially in emergency situations in which it is impossible to know in advance whether patients will be able to recover and to what degree. It is therefore arguable that the universal application of lifesaving interventions in all cases is beneficial, since it will inevitably lead to the recovery of some patients who may have otherwise died. However, as the creators of the first intensive care units demonstrated, this can also result in “delayed deaths amongst patients destined not to survive,” (Bion and Bennett 1999:3; Lassen 1953) and the additional burden that this may cause to families.

Decisions to initiate low-risk treatments in the name of saving and sustaining life are made in harmony with an underlying narrative that is focused on the same. In the presence of the many available therapies in the intensive care unit, these decisions often result in new physical connections to patients. And as demonstrated in the case of the elderly woman presented earlier, material connections of lifesaving and life sustaining can and do directly impact patients' ability and desires to die.

One case that I observed involved a patient who was transferred to the intensive care unit where the decision was made to start hemodialysis. "Dialysis" as it is often called, is a treatment consisting of a machine used to filter the blood when the kidneys are injured, diseased, or otherwise compromised due to temporary swelling, hormone imbalances, blood loss, etc. Like many life-sustaining interventions in the intensive care unit, dialysis has the potential to save lives, but also the potential to become a life-long connection, requiring permanent catheters and regular twice-weekly visits to dialysis clinics. As a result, implementation of this life-saving intervention includes the possibility of incurring significant, long-term impacts on patients' livelihoods, identities, and social interactions (Kazemi et al. 2011).

As we walk to the next patient's bedside, I ask the attending, Do physicians have to get consent before starting hemodialysis? He says, probably someone was asked about it [referring to the decision to start dialysis in the patient we just rounded on], but it's random which intensive care treatments require consent and which they can just do. He continues, It doesn't make any sense – I don't need consent to do a bronc [bronchoscopy], but I need consent to give blood or to put in a PICC [peripherally inserted central catheter]. Usually in ICU the decision to start dialysis is a life-or-death situation – if you don't get it, you die. The pharmacist, who has been walking along beside us, also chimes in, Once you're admitted to ICU that's basically consent for a lot of things, for full treatment. Dialysis is part of that.

(Fieldnotes, Apr. 25, 2019)

While certainly more deliberation goes into decisions to start dialysis than decisions to administer vitamin D, the underlying assumption guiding the material connections involved in both treatment choices is that patients are admitted to the intensive care unit because they want to be “saved,” and because they want “full treatment.” As I argued earlier, the entire apparatus of the intensive care unit is oriented towards this goal of saving life, and the result is that most patients who pass the threshold of the intensive care unit are treated with all available therapies.

Breathing machines, dialysis, surgeries, and experimental drugs are the first line of approach once admission is granted, which is great news for many patients who want their bodies to be saved and maintained. But what about those who desire different endings, who never wanted invasive therapies or who subsequently reach their limits with intensive care? Patients with expressed wishes for no further invasive therapies, no dialysis, no intubation, even specifically no admission to intensive care nevertheless end up, as the elderly woman at the beginning of this chapter, intubated and sedated in an intensive care bed.

We walk to bed 15, another new admission. The resident who assisted with admission is describing the medical issues, explaining why certain decisions were made. At the end of the report he says, “One last, other issue. So his [Category Status Form] says he’s a Cat 1 [full treatment], but apparently there’s some documentation [...] that he didn’t want intubation.” The team collectively sighs - the patient is currently lying in bed, intubated.

(Fieldnotes, May 16, 2019)

The immediate material availability of life-sustaining therapies and the underlying imperative to provide this type of lifesaving care operate as one mechanism through

which those who desire different bodily endings are prevented from expressing, exploring, or carrying out their subjective wishes. Though some of the confusion over category status and DNR forms is certainly due to administrative issues with documentation, it is also important to consider how the underlying narrative of lifesaving articulates with the material availability of life-sustaining technologies and results in situations of denied death.

Contravening the lifesaving narrative is perceived as “difficult”

Morning handover is again interrupted when the attending assigned to intensive care follow-ups (for patients who have recently been discharged to the floor) comes into the conference room in search of a pager. The resident and fellow who were on call last night take the chance to inform him of a patient on the floor that he will likely be seeing today. The patient in question has a dissociative psychiatric condition with two personalities. According to the fellow, one personality is “lovely and wants to treat their condition,” while the other is “difficult” and does not want any further treatment. The fellow explains the challenge encountered last night when one personality decided they were a category 1 (full treatment) while the other personality wanted category 3 (no further interventions). The fellow explains that he made a decision to listen to the category 1 personality, “I’d rather be sued for inappropriately saving someone’s life than ignoring them.”

(Fieldnotes, Apr. 23, 2019)

Though no longer in intensive care, the patient in this story beautifully illustrates another mechanism that converges to prohibit desired bodily endings amidst life-sustaining technologies: the desire for death, and by proxy, the desire for limited treatment, can result in perceptions of patients as “difficult.” In this vignette I note that this patient’s mental illness does not result in a reconsideration of their capacity to consent or to make treatment decisions, nor is it the mental illness itself that results in the trouble. Instead, it is the expression of desires to limit lifesaving treatment that acquires

the judgement of “difficult” while other expressions of personality intent on pursuing lifesaving are considered “lovely” and worth listening to. Desires for death go against the current of lifesaving that imbues the very nature of the intensive care unit, resulting in cases where personal thresholds of meaningful bodily ending are denied.

Being labelled as difficult, deviant, or non-compliant with the underlying momentum of lifesaving in the intensive care unit results in further denials of the capacity to direct end of life care for patients who desire to die. For many patients, this materializes through enforced periods of waiting between when their desires for death are expressed or located and when they are facilitated by the healthcare team. Since the expressed desire for death causes patients to be interpreted as irrational and deviant, additional work must be done to validate these wishes with friends, family members, and lawyers (as in the opening case of the elderly woman) to vouch for wishes that have already been laid out by patients themselves.¹³

At bed 10, we begin rounds on an older woman who was admitted from the floor by the Rapid Assessment team due to respiratory distress while on dialysis. The nurse begins her report by relaying a message from the patient: “She’s indicated that she’s had enough.” The nurse reads out the assessment notes left from the night shift, “Patient states: I’m done, I want to end my life.” She explains that the patient is requesting MAID [medical assistance in dying] in order to facilitate her end of life wishes. The fellow nods and describes how she had encountered this patient’s requests overnight but had told the patient that her respiratory system was improving and that she should “just sleep on it.” The nurse replies, “Well, she’s really regretting that right now.”

(Fieldnotes, Apr. 15, 2019)

¹³ Again, this is not always the case, and there are certainly instances where patients’ wishes are unknown or have been unclearly stated. In these ambiguous cases, checking in with family would seem to make logical, legal, and emotional sense. However, I am focused here on cases where a pre-stated desire for death or for no further treatment has been clearly articulated either verbally by the patient themselves or through recently written and witnessed documentation.

In the example above, another older woman is met with bureaucratic requirements and push-back when she asks for assistance with ending her life. Instead of respecting her wishes, the fellow insists that she “sleep on it” since the life-threatening condition of respiratory distress for which she was admitted seems to be getting better. As mentioned by the nurse, the patient appears to regret this decision, and indeed continued to push for MAID over the course of her first full day in intensive care. Ultimately, by the end of the day, the bedside team had made arrangements for this patient attempting to make treatment decisions against the grain of lifesaving to be transferred back to the ward she had initially come from. Responsibility for the difficult task of helping to negotiate the end of life is shunted elsewhere, despite intensive care being an ideal location for dying, and indeed, the location of many deaths facilitated through controlled withdrawal of life sustaining therapies. The large, private rooms, available nurses with extensive experience administering analgesics and sedatives and facilitating end of life care, and relative availability of patient support such as social workers and spiritual care would seem to make the intensive care unit an optimal location for managing MAID. However, procedural and administrative requirements for MAID requests to come from patients who are “conscious and competent” – presumably excluding intensive care patients who request their own deaths after being “saved” – result in this practice rarely, if ever, occurring in the intensive care unit (Curtis and Tonelli 2017; Goligher et al. 2017; Lazaridis 2017).

In addition to labelling patients who desire their own deaths as difficult, the work of helping to negotiate the uncertain boundary between life and death is perceived by healthcare workers to be challenging. The nurse in the above vignette provides some evidence – in advocating for her patient’s decision to die she must argue with the physician team and speak up against their opinions. For nurses, speaking up about the end-of-life desires of patients can constitute “overstepping their bounds,” though I learned that many nurses cultivated a sense of “which docs they can overstep” (informal conversation with an intensive care nurse, April 15, 2019). Despite having the most intimate contact with patients, some younger nurses were hesitant to get involved in conversations around the end of life.

“The docs have a better ability to make decisions, they have more statistics about that. They’re usually right. It’s really not our place to say anything. I’ve had patients where I thought, she’s gonna die for sure, and then the patient gets discharged. And patients where I thought, he’s gonna live, and then he’ll literally die the next day.” – Intensive care nurse

(Fieldnotes, Mar. 21, 2019)

Physicians similarly perceived end of life conversations and decision making as difficult, advocating instead for taking the “path of least resistance” – implementing lifesaving technologies first and then “dealing with it in the morning” (Attending physician, teaching rounds, May 9, 2019). Going along with the expected underlying push for saving and sustaining human life is framed as the easiest and most “pragmatic” available option, and it is the option that is assumed to be most desired by all other participants in the apparatus of the intensive care unit. As another attending physician

commented, “Patients don’t want end of life discussions, they want treatment”

(fieldnotes, Mar. 26, 2019).

The legal repercussions of misinterpreting a patient’s wishes also impact physician actions, as the fellow contending with the patient with multiple personalities notes. Clinical decisions can land physicians in court, either on charges of assault and battery, for the provision of unwanted treatment, or for murder when treatment is unduly withheld. In the absence of clear wishes from the patient, many physicians unsurprisingly opt for the former. Though this makes sense in emergency situations, hesitation and opting for the legally and apparently ethically “safe” option of continued treatment even in cases of clear patient desires for the contrary indicate a deeper underlying challenge with identifying and acknowledging desires for death. Note that I am not implying that physicians are somehow unethical in their practice of maintaining life, nor that they are lazy or uncaring in their decisions. Instead, I argue that the logic of lifesaving extends from medical into legal spaces to configure saving and sustaining life as the most ethical, thoughtful, and caring choices that can be made in complex situations, masking the nuance possible when we acknowledge that individuals might in some cases desire their own bodily endings.

In the intensive care unit, this desire for bodily ending is perceived as deviant and difficult, both in terms of the patients who dare to enter this advanced and technologically intensive space only to demand death, and in terms of the actions and professional risks that healthcare workers must take on in order to help them. While some might assess this

pattern as evidence of a system which upholds the value of all lives, I think there is a need to consider how mechanisms that deny desired death also diminish the potential for meaning that is inherent in the relational process of dying.

“Let the patient decide” –strategic calls to patient autonomy

The clinical team discusses the plan for weaning the patient in bed 9 from the ventilator. The attending explains why it is best in these cases to “let the patient decide” how long these trials should be for, since physicians often underestimate patients’ capacities. The patient stares out at us blankly while we discuss his case. The nurse reports that the patient may have signs of delirium and that his neurological status still remains in question, “I’m not sure how much is there.”

(Fieldnotes, Apr. 17, 2019)

Patients who opt to contravene the narrative of lifesaving are labelled as “difficult” or as inappropriate cases for the intensive care unit. These patients have their subjective capacities for decision making overruled by the pervasive logic of lifesaving. In contrast, the bodies of patients who are cooperating with life sustaining initiatives are granted agency to “decide” aspects of their care. In the observation recorded above, a patient, earlier described by his nurse as “progressing well,” is challenged with “deciding” the length of time he should be permitted to be disconnected from the breathing machine as part of a strategy for re-building lung capacity. With this statement, the physicians are not suggesting that the patient be verbally asked his preferences for how and when he should be disconnected from mechanical ventilation. Instead, the act of “letting the patient decide” involves moving ahead with the clinical action or decision

(i.e., disconnecting the ventilator) and seeing how long the patient can comfortably sustain the act of breathing until he begins to show signs of distress.

This case is notably different from one in which a patient is requesting to disconnect life-sustaining therapies in order to end her life. Deciding to die and helping with treatment adjustments are decisions with markedly different outcomes. However, the juxtaposition of the denial of clearly stated prior requests for limiting or stopping life support with advocacy of the ability for semi-conscious, delirious patients to help “decide” aspects of their treatment brings into focus the preference for lifesaving over preferences for honoring patients’ wishes. I argue that calls to patient autonomy are strategically employed in decisions that resonate with the dominant direction of lifesaving and life-sustaining. In contrast, as described earlier, patient autonomy is more likely to be devalued and overruled in those cases in which patients have made choices to limit therapies or to end life.

Another example I observed of the apparent devaluing of patient autonomy in situations of treatment denial was with a patient who was refusing blood transfusions for religious reasons. As noted by a statement from an attending physician that I presented earlier, blood transfusions are one of the life-sustaining and life-saving interventions in the intensive care unit which require explicit prior consent, usually granted by substitute decision makers. In this patient’s case, consent for transfusions was denied since the patient’s family knew based on prior stated wishes that this would not be an intervention with which the patient would agree. Despite this clearly stated and documented objection

to blood transfusions, the treating care team, spurred by multiple emergencies and serious bleeding events, approached the family more than once to ask about the possibility of transfusing blood. The family was also asked to reaffirm this position by each new external specialist called in to consult about the patient's complex conditions. Eventually the family explicitly asked not to be questioned any further about blood transfusions, and the patient ultimately recovered sufficiently to be discharged from the intensive care unit without receiving any blood. In this case, the patient's decision to refuse blood even in situations in which it could have been immediately lifesaving challenged the narrative of saving life. As a result, the ability of this patient to "decide," even though it was symbolically granted through a consent form, was repeatedly overlooked by the logic of lifesaving in the intensive care unit. While physicians never actually initiated treatment that was contrary to the patient's wishes – they never transfused blood – their actions of continually questioning the legitimacy and stability of this decision could be read as strategically undermining patient autonomy in a pattern that does not appear to take place when patients have "decided" in the dominant direction of lifesaving.

Strategic devaluing or overlooking of patient autonomy in cases in which life-sustaining therapies are declined or where death is desired become more evident, as I have shown, in comparison to cases in which patient autonomy is called upon in order to justify lifesaving intervention. When patients request death, they are cautioned and told to "sleep on it," like the woman who requested medical assistance in dying. In comparison, patients who are evidently dying but express the wish to live are not asked to consider

palliative care nor challenged to contend with their imminent bodily ending. Instead, they are granted their request and their bodies are “tested with life.”

The team is rounding at bed 10, a post-operative patient who has been here for two weeks. He is not doing well. The fellow and the attending discuss their frustration with general surgery, who can't seem to provide a clear answer about whether or not the patient can receive more surgery. Presently the surgery team has written in the chart that they want to wait a few more days before they are ready to operate again. The fellow says she's concerned they will keep waiting and waiting and then it will be too late, the patient will no longer be able to receive surgery. She says she would rather know that truth now. So, he's not a surgical candidate? The attending asks. They won't give a clear answer, replies the fellow. Because [the patient's condition]'s not surgically fixable, the attending concludes. The worst part about this, notes the attending, is that when you look at the list of issues this guy has, he is going to die. But when you talk to the patient, he wants to live. The fellow agrees. The nurse explains how the patient is very cooperative, always talking about going home, helps out as best he can with his care because he wants to get better and get out of here. The discussion returns again to this patient's very poor prognosis. The fellow says, Dr-- (who was on last week) said he'd never seen a patient come in looking like this and make it out of the hospital. The attending says, Let's do a try everything strategy and see what happens. Let's test him with life. We might be surprised, right. Before you write him off. But if something bad happens, he's toast.¹⁴ Heads nod, the clinical team agrees. He concludes his recommendation; Let's take away all the question marks... but I think we know where this is going.

(Fieldnotes, May 21, 2019)

In comparison to cases of denied death, this scenario of a patient being “tested with life” demonstrates how the intensive care unit is materially structured to accommodate requests for life-sustaining interventions. Treatments are available; the “do everything” strategy is the lifeblood of intensive care, it is part of its origin story and the

¹⁴ This analogy of “burnt toast” had been used earlier that morning at a hospital-wide “grand rounds” presentation about unmet palliative care needs. “*Nobody needs someone to go around telling you, you burnt the toast. People know when they have burnt the toast. And there's no way to un-burn toast. What we need is help, we need a reminder to pop the toast up before it's burned.*” This is the presenter's analogy for palliative care, that people usually know when they haven't provided ideal palliative care but need more help identifying when to provide better care. Most physicians, the presenter says, rely on certain “triggers” to remind them to provide palliative care consultations such as critical events, poor prognosis, or a terminal diagnosis. (Notes from grand rounds, May 21, 2019)

reason for its existence (Ibsen 1952; Reisner-Sénélar 2011; Trubuhovich 2004). In contrast to this narrative, the choice for bodily death or limitation of therapy is encountered as challenging, difficult, and questionable. In some cases, patients, families, and healthcare providers who opt for this decision face additional barriers and time delays that are not present for those who choose the path of intervention and life at all costs. The mechanisms of material connections, perceiving requests for death as troublesome, and the strategic denial of patient autonomy convene within the apparatus of the intensive care unit to produce situations such as that of the elderly woman presented at the beginning of this chapter. This patient's autonomous, pre-stated, written decision for no life-saving interventions was overlooked, resulting in physical connections to life support therapies that further increased the complexity of permitting her death to occur. Her own attempts at resistance by attempting to pull at the breathing tube were treated as deviant and potentially dangerous actions and were suppressed by the clinical team. In the end, at least for the time in which I observed, this patient was denied the ability to approach death on her terms in a clinical space and cultural context in which lifesaving and life sustaining operate as the most pervasive and valiant goals.

After reading this far one might draw the conclusion that I am against the preservation of human life or opposed to the clinical mechanics of lifesaving. Rest assured that is not the case. I do seek, however, to introduce the reader to the possibility that the narrative of saving life in the sense of preserving vitality of individual human bodies might be narrow in its conception. Further, it may be preventing a more nuanced

and inclusive, even democratic understanding of bodily death. An approach to understanding death that contends from the beginning with its relational inevitability alongside its transformative power to perpetuate Life in its many forms, as encompassed in the posthuman perspective I have outlined, might allow for such a rethinking. In what follows, I think through some of the implications and challenges were such an approach to understanding thresholds of individual life endorsed.

From heroic lifesaving to complex responsibility

The case of the elderly woman presented at the opening of this chapter is a situation in which a patient appears to have indicated some desire to allow bodily life to end. This desire appears materially through the signed DNR order and the hospital category status form indicating a choice for no further administration of invasive treatments. It also appears to be expressed through the physical movements of the patient's body attempting to pull out the breathing tube and disconnect from life-sustaining therapies. In the vignette as presented, the patient is denied the possibility of reaching this threshold, first through a series of emergency decisions which overlook the wishes expressed in written documents, then through the administration of sedatives which calm and control the body, and finally through a procedural delay which requires that the patient first "wake up" before the breathing tube can be removed. The logic of lifesaving, which I have argued is a pervasive component of the apparatus of the intensive care unit, denied this patient the ability to die.

The material relations of care imposed on this patient's body in the name of intensive lifesaving are not negligible. The "violence of cure," in this instance directed at a denial of bodily death, has physical and affective consequences. Lifesaving, as described previously, involves a process of installing new material relations with and on the body, relations that change the subject irrevocably in ways that can be unpredictable at the time that life-saving decisions are made. Though these interventions install the possibility for life for many patients, my argument here is that they inevitably also restructure the possibilities for death. In the case of CPR, for example, attempts at lifesaving resuscitation may preclude the ability of family members to be present at the deathbed, and/or for death to occur in a location of the patient's choice. Physical tethers to life-sustaining interventions such as ventilators and dialysis machines may prevent seriously ill and unconscious patients from leaving the intensive care unit, requiring their deaths to occur as a result of removal of these therapies, rather than by autonomous choice as they may have preferred through accessing MAID. In the opening case of the elderly woman, the initial lifesaving intervention of the breathing tube extended the timeline of dying, while subsequent denials of extubation ensure that the patient dies in a controlled manner experienced by bystanders as a peaceful and dignified death.

This case sticks with me because it appears to negate the work that must go into the difficult choice of a subject's decision for when they want to die, their personal ethical threshold with their relationship to life. Given the changes that new relations of lifesaving can impart, refusal of these interventions, especially in "life or death"

scenarios, may express not only a desire for bodily death but perhaps also the desire to remain the subject that one already is. We are already collectively aware of this sentiment; it exists in the phrase, “I’m so happy right now I could die.” Death is the only way that specific iterations of our subjective selves can be stabilized. Otherwise, we are carried along by the endless new relations we form with others, connections through which we affect and are in turn affected, thus perpetually becoming other than ourselves. Braidotti (2006) is quick to point out the potentially exhausting and intense nature of this form of endlessly changing subjective life, and as a result does not frame the active choosing of the limits of life, alternatively known as suicide, as a morally negative action. Some subjects feel the weight and emotional effects of the relations of life continuously, while others can tolerate higher thresholds of intensity. It seems reasonable to acknowledge that at some point all subjects have had enough, have reached their limits of relational connections, and desire an end to bodily existence. The vestiges of Freud’s death drive become evident in an argument that at a certain point, all subjects become aware of and seek to facilitate their own creative dissolution (Braidotti 2006:247). Why, then, should we be denied control and responsibility for this final transition that we know will eventually occur?

One could argue that failing to insist on an imperative of saving and sustaining lives and opening up the possibility for subjectively determined endings opens the door for eugenic practices of selective killing. Respecting subjective responsibility to negotiate thresholds of bodily endings might result in widespread acceptance of untimely deaths

due to unjust social, economic, and political pressures. As disability rights group Not Dead Yet argues, when “psycho-social disability-related factors [become] widely accepted as sufficient justification for assisted suicide,” the act of assisted death itself becomes discriminatory (2020). In other words, if being faced with having to receive dialysis or take medications for the rest of life is widely accepted as a viable ethical threshold for bodily ending, it sends a broader ableist message that needing dialysis or regular medications is a condition worse than death (Reed 2020). Proponents of this argument claim that the individual choice to end life is never made in isolation; processes of discrimination, political and economic exclusion, colonization, and inter-generational trauma directly influence individual desires to die (Persad 2017). Disability activists would point out that the social and material challenges of existing as a person with a disability or chronic illness should not be shouldered as an individual burden because they are inherently connected to broader patterns of social interaction and organization (e.g., healthcare funding). As a result of socially entrenched ableist policies and attitudes, many disabled people are denied the freedom to live fulfilling lives. In this context, granting disabled people the power to end their lives becomes a death-facilitating and a eugenic move, rather than one of personal ethical relation.

This position is valid and raises points for consideration, namely that responsibility to determine subjective thresholds of existence requires a recognition that limits to existence are always negotiated within a larger social milieu in which certain lives are held to be more valuable, acceptable, and “normal” than others. However, the

argument that honoring subjective thresholds of bodily ending is a eugenicist practice relies on the understanding of human death as an absolute evil to be avoided rather than an inevitable reality and a threshold that all living things eventually pass through. It is an argument against the ableist position in which death is offered as preferable to life with a disability, as articulated by Singer (1994). However, this is not the same position that I take. My understanding of “life” in this instance is not fixed to the idea of individual human life, but rather encompasses life in its many forms, including the many types of people who have been historically excluded from the category of human such as people with disabilities, racialized people, queer people, etc. In my argument, I want to acknowledge the marginalized position of these historically and continuously excluded subject positions, while also acknowledging that these subject positions must still ultimately at some point contend with their own thresholds of bodily endings. Rethinking dying in this manner as necessity and ethical responsibility does not take away from the need to collectively improve our conditions of living and of freedom. On the contrary, I wonder whether the responsibility to determine one’s own threshold of existence might inspire renewed focus and energy to improving the conditions needed for flourishing in what I argued earlier might be a more posthuman approach to “saving life.”

Not Dead Yet notes that a moment of inspiration for the disability rights movement sprung from outrage following court rulings in which disabled people’s ultimatum, “give me liberty or give me death,” was met with unambiguous permission for the latter (2020). The medical and judicial system, in granting assisted suicide solely

to “terminally ill” and thus disabled people, identified disabled lives as not worth living (Herr, Bostrom, and Barton 1992). I agree that this is an ableist and unjust approach. However, rather than circumscribe the responsibility for any subject to negotiate their personal threshold of death, I argue for an opening-up of the responsibility to determine thresholds of existence to all people, not just to those self-identified or socially labelled as experiencing disabilities. Assisted suicide and the ability to refuse life-sustaining treatments should be available to all people, no matter their mental or physical state. I also argue that the delineation of limits on one’s life be considered a *responsibility*, rather than a right. Death is an inherently social event and always impacts and is impacted by others; thus, the decision to determine its character is a responsibility which must take others into account.

My argument here also rests on the idea that *actively denying death*, when and where it is desired by an individual, *does not equate to securing liberty*. Instead, I have argued that the denial of death achieves the opposite – a denial of autonomy and authenticity to the subject’s capacity and responsibility to know their own ethical limits. Securing liberty might be more appropriately achieved through a recognition of the responsibility and ethical consideration that must go into deciding one’s own ethical threshold with life alongside renewed and concerted attention to understanding the social processes and conditions of exclusion, marginalization, or conversely, hope, satisfaction, and connection which influence different subjects to approach the inevitable ending of bodily existence in different ways.

The idea of extending the subjective responsibility to approach the end of life to all persons might seem impossible and the implications unresolvable. However, when listed, the changes that would be required to operationalize such a shift turn out to be undertakings that are already imperative. I present some changes at both the level of the intensive care unit and society more broadly here.

First, work would be needed to improve systems of communication in the intensive care unit to enhance the capacity of unconscious patients to participate in their decision making. Rather than strategically “letting the patient decide” in ways that further the logic of lifesaving, technologies such as functional magnetic resonance imaging for unconscious persons might allow a greater ability for subjects to communicate their own ethical limits and participate in negotiating thresholds of life and death. Tools and protocols used to detect “covert consciousness” in otherwise unresponsive patients have demonstrated that such technologically-mediated approaches to communication are possible (Claassen et al. 2019; Giacino and Edlow 2019; Owen et al. 2006). In addition, the urgent requirement for ongoing clear and informed consent about the often disruptive and traumatic realities of the consequences of intensive care has already been proposed by some clinicians (Herridge 2017).

Second, in addition to advancing capacity-enhancing technologies, campaigns would be required to encourage all people, not only those in situations of presumed terminal illness or proximity to dying, to normalize and discuss their inherent relationships with death. Though these conversations might be difficult (as acknowledged

by one physician who suggested that asking a 20-year-old person in the emergency room for an ankle fracture about their CPR preferences might actually cause harm and loss of trust) it is increasingly necessary for all posthuman subjects to come to terms with the necessity of our inevitable bodily finitude and to take responsibility for how this threshold should be crossed.¹⁵

Third, renewed inquiries into trends of untimely deaths would be necessary, not to imagine modes of control for preserving and sustaining life, but to seek to expand livable conditions for flourishing. This would involve a greater focus on work already being done which finds strong links between the presence of intangible social factors such as a sense of community, purpose, connectedness, and sovereignty and the physical health and mental well-being of populations (Auger 2016; Czyzewski 2011; Persad 2017). In so many cases, lifesaving intervention need not involve a ventilator or a dialysis machine but would be better encompassed through adequate social funding for caregivers and opportunities for social inclusion. In my opinion, the enhancement of these factors and the subsequent production of real freedom deserves more resources and attention than a routine and expensive logic of lifesaving which works to “heroically” deny death to some already at their subjective ethical limits of existence. Extending more broadly - not just to those with disabilities or terminal illness but to everyone - the responsibility for approaching the threshold of death forces a social reckoning with deeply difficult

¹⁵ The past two decades have seen an emergence of initiatives to help facilitate pre-emptive discussions about death, from community initiatives such as death cafés (Fong 2017) to legal and policy activities surrounding advanced care directives such as “Speak Up Canada,” an organization promoting the need for advanced care planning (2021).

questions. If we cannot create and sustain conditions in which people desire to live well and cultivate a commitment to living, is it ethical to force them to remain alive? Ongoing attention and activist work would be needed to ensure that the responsibility to enhance conditions for freedom and flourishing is neither evaded in a eugenic move nor overpowered through the dramatic but routine logics of lifesaving.

Finally, if we were to extend responsibility for establishing endings to individuals, the ongoing production of technical and medical solutions for those who are determined to have *no* end to their bodily existence require further inquiry. Endless technologically sustained life is the material repercussion of a celebrated and enforced logic of lifesaving. In this transhumanist dream, the logic of lifesaving as applied to all sick and dying bodies becomes mutated into a technological immortality (Bostrom 2005; Solomon and Bostrom 2005). Though currently imagined as fiction,¹⁶ the capacity for human life to continue forever in some form may not be that far off. Silicon valley start-ups with the goal of making life endless, for those who can pay, have been well funded by those with the resources to live forever (Alcor 2020; Warner 2018). Most criticism of this position homes in on the certainty that such life-extension technology will be affordable only to the very rich and thus will exacerbate existing inequalities (Fukuyama 2004). But in addition to this obvious point, technological immortality, even if it were feasible and affordable for all humans, would still be unethical, irresponsible, and unsustainable. This type of future is not life sustaining, in a posthuman sense, as it allows no space for the

¹⁶ Examples include recent TV series “Upload” (Amazon, 2020) and “Altered Carbon” (Netflix, 2018) which imagine futures in which human consciousness can be maintained indefinitely.

continuation of life in its many unfolding forms. Instead, life becomes fixed into an individualistic trajectory of endless resource consumption in order to perpetuate and maintain the eternal functioning of human bodies and minds. In this type of world, available material and affective resources are not used to reimagine or affirm what is possible, but rather to maintain what already exists for prolonged periods of time. While democratic extension of the ability to decide the end of one's life will not negate the logic of lifesaving, it may permit an opening to advocate for greater consideration of our ethical responsibilities surrounding death, including the need to make space for the other and to embody practices of long-term sustainability.

Conclusions

This chapter has interrogated the concept of “saving life” in the intensive care unit and has outlined a historical and political basis for what I have named the logic of lifesaving. The work of saving and sustaining life, understood as individual, rational human life, is deeply engrained in the practice of medicine. Lifesaving has roots in a religious ideology that connects salvation of body and soul and confers validation on both the social role of the heroic healer and the sick body that fights (Green 2008:22–30). Secular iterations of this ideology focus on the salvage and sustenance of vitality as a means of controlling life itself, a critical driver of economic productivity and political power (Scheper-Hughes 2008). The material space of the intensive care unit functions as one particular embodiment of the logic of lifesaving, but, as I argued, does not necessarily promote the saving of life in a more broadly conceived, posthuman sense.

Encounters with fieldwork data helped to identify mechanisms through which the logic of lifesaving is enacted in the intensive care unit. By analyzing the exceptional cases of patients who clearly advocate for death or for the limitation of lifesaving attempts, I have illustrated how material practices, discursive labelling, and strategic deployment of the concept of patient autonomy converge to deny, delay, and devalue subjective desires for death. Throughout, I have argued for the potential significance of permitting subjects to decide the moment of their death, providing responses to those who would object to this argument as perpetuating a eugenic logic. My main point in this chapter has been to describe the phenomenon of denied death and to demonstrate how it is a product of the apparatus of the intensive care unit and the logic of lifesaving. Finally, I have suggested that broad extension of the responsibility for posthuman subjects to determine their own ethical thresholds of ending could be a means of enhancing, rather than circumscribing, conditions for collective freedom.

This chapter has focused on cases of patients who appear to desire death and have their wishes delayed or denied by logics of lifesaving. In the next chapter, I take up an opposite case – situations in which patients are determined to be dead through medical practice but whose families and pre-stated desires suggest they remain invested in life. Exploration of these cases and the medical responses to them identify additional trends and logics at play surrounding thresholds of bodily endings, while also allowing for a different perspective of the larger social and political aspects that contribute to seemingly personal and private moments of death.

CHAPTER 6 | Must we believe in death in order to die?

The patient lies on her back in the hospital bed, her eyes closed, and the white sheets pulled up to her chin. The rigid plastic tube in her mouth is connected at the bedside to a metal and plastic box on wheels that forces air into her lungs, causing her chest to rise and fall with each artificial inspiration. The breathing machine traces the dips and falls of air pressure on its digital screen. Clear fluids flow through intravenous lines directly into the blood still pulsing beneath the patient's warm, brown skin. A monitor next to the bed displays the electrical signals collected through a network of thin wires and small band-aid-like pads stuck to the patient's chest, displaying the regular sinus rhythm of her beating heart. Occasionally the patient's toes and feet twitch, disturbing the otherwise crisp bedsheets. The nurses assigned to care for the patient diligently rearrange them when they come in to turn her, as they do for all patients in the intensive care unit, to ensure that skin does not slowly decay during periods of prolonged physical immobility.

According to the hospital, the treating physicians, and the Supreme Court of Ontario, this patient is dead and has been dead for more than 6 months, since two physicians first followed nationally accepted clinical guidelines to determine a complete lack of neurological function. According to the patient's family, she is still very much alive and is deserving of ongoing ventilator support until such time as her heart stops beating. The family asserts that the patient's beliefs are at odds with the definition of death that has been applied, one that centres all meaningful life in the brain.

The scenario described was that of Taquisha McKitty, a young Black woman who suffered an anoxic brain injury¹⁷ secondary to a drug overdose in September of 2017. After physicians at her Ontario hospital issued a death certificate pursuant to their finding of death determined through neurological criteria, McKitty's family mounted a formal legal challenge. Taquisha McKitty's heart finally stopped beating at 3am on December 31st, 2018, one year, three months, and ten days after her death certificate was signed. Both the initial court ruling and the decision by the appeals court reaffirmed the medico-legal authority of the determination of death using neurological criteria, but neither decision completely ruled out the possibility that definitions of the threshold of a human life could be based on personal beliefs.

The "McKitty Case" as this widely publicized legal challenge is known, made clear a number of tensions that continue to exist between biology, philosophy, law, and medicine. Must one believe in death in order to die? And if so, what do we do in the contexts of conflicting beliefs? These are important and relevant questions in a time where the technical possibilities for sustaining human bodies are reaching new heights, and a fascination with defining and harnessing the power of "life itself" remains a central concern in social and clinical scientific fields. Against a continually shifting landscape of medico-technical capacity, attending to who, or what, is permitted to die is part and parcel to understanding which emergent forms of life are endorsed as legitimate and worthy of affective and material support.

¹⁷ Injury caused by a lack of oxygen to the brain.

In this chapter, I take up the seemingly impossible question of whether one must believe in death in order to die. Rather than approach this as a philosophical conundrum, I expand the inquiry to include a materialist analysis of the contexts in which contestations about the limits of life occur. Instead of arguing about whether or not the neurological definition of death is a scientifically valid threshold of human life (a different question entirely), I aim to consider through a critical lens both the contexts in which the concept of brain death arose, along with present-day situations in which it is challenged. For this analysis, I first briefly situate the concept of brain death within its historical contexts. This genealogical grounding allows for a greater depth of analysis as I next look to transcripts of interviews conducted with Canadian physicians about their experiences with conflicts surrounding the neurological determination of death. Using vignettes and examples from my conversations with physicians, I explore how different agential cuts (Barad 2007) of the moment of death allow for an examination of power differentials and the role of individual beliefs in delineating bodily endings. Exploring physician responses to challenges to the concept of brain death against the genealogical contexts in which this construct came to exist demonstrates how “belief” in the possibility and incontestability of death becomes an influential factor in determining whether and how one dies. Tied in with this critical analysis is a consideration of how social characteristics such as race, gender, ability, and class affect perceptions of beliefs, and therefore possible enactments of death. This chapter concludes with an analysis of the ways in which human death is fundamentally political and returns to the McKitty case

to consider whether and how space could be made to integrate individual thresholds of the end of human life.

Who believes in brain death? A concept with a purpose

The idea that the cessation of neurological function should be equated with human death is relatively recent. Prior to the 20th century, Western medicine largely determined human death through the absence of heartbeat and circulation, and before establishment of knowledge about the circulatory system, upon visible signs of bodily decay. Even the understanding that cessation of circulation is equivalent to human death has been a relatively recent accomplishment since it first required more technical and scientific knowledge about the physiology of the body (Ribatti 2009). As interest in opening up the body grew, Western medical and scientific practitioners made arguments in favor of separating social (i.e., spiritual) death from bodily death in order to permit the practice of autopsies (Green 2008:39–45). A brief review of the history of human death reveals that modifications to the boundaries between life and death are not new. Rather than a given biologic or “natural” ending to an individual body, human death is a threshold determined in no small part by the social and technical contexts in which it occurs (Bayatrizi 2010; Green 2008; Lock 2002). Neurologic criteria for the determination of death provide a contemporary example of the tinkering activities which scientific medicine has been performing on the boundary of death for centuries. A closer look at the contexts in which this new criterion emerged reveals the presence of social and technical motivations beyond the limits of individual biology which both assisted this new definition in

emerging as well as permitted it to become established in North America. Historical analysis of the conditions in which the concept of brain death emerged are not new, and many have pointed to the intersecting interests of the transplant industry (e.g. see Giacomini 1997; Lock 2002). I present here a brief summary of this work, which takes into account some additional overlooked social critiques. A concise critical genealogy helps to situate questions about who serves to benefit from locating human death in the brain and thus generates lines of inquiry for further critical analysis.

The definition of brain death as a new form of human death was first formally proposed in 1968 by a committee of faculty members at Harvard University (Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death 1968). The Committee defined “irreversible coma” as the presence of a “permanently non-functioning brain,” determined through a series of clinical reflex and technological monitoring tests (1968). Prior to their publication, scientific experiments in animal models and with severely injured patients had already established understandings of the connections between circulation to the brain and the maintenance of consciousness (Machado et al. 2007; Settergren 2003). It was well understood in clinical circles that a sustained lack of blood flow to the brain inevitably resulted in death. However, most reports recounting an absence of brain activity and function (including loss of respiratory drive) described a novel mechanism of injury which led *to* human death rather than a new form *of* death itself. Thus, the incurably unconscious patient was in a condition likely leading to death, rather than already dead. The groundbreaking publication of a report on

coma dépassé, the brain-death-like condition described by French clinicians Mollaret and Goulon (1959) as coma with irreversible loss of respiratory drive stopped short of equating this novel state of profound unresponsiveness with human death.

Deceased organ donations and transplants of kidneys commenced prior to the Harvard Committee publication, and also operated under the premise that transplant surgeons had to first wait for circulation to cease prior to commencing organ retrieval surgery, even if doctors had established a diagnosis of *coma dépassé* (Machado 2007:28). Normal practice for deceased donations was to transport the donor into the operating room alongside the recipient, prepare each patient for surgery, and then to remove ventilator support from the donor and wait for the heart to stop beating. Following cessation of circulation, organ procurement surgery would begin (Machado 2007:28). As a result, early attempts at organ donation using “brain dead” donors involved first facilitating establishment of traditional, circulatory determined death before proceeding with organ procurement and transplantation (Machado 2005). Prior to the Harvard Committee publication, “hopeless coma” was a state leading to inevitable circulatory determined death, even in instances of organ donation.

Several scholars have argued that the timing of the assembly and publication of the Harvard committee report was strongly influenced by concurrent advancements in human organ transplantation, including the world’s first heart transplant which had been conducted only one month prior (Giacomini 1997; Lock 2002). The chair of the committee, physician and ethicist Henry Beecher, requested permission to convene a

working group on “the Problems of the Hopelessly Unconscious Patient” (Giacomini 1997), ostensibly to produce ethical commentary on how to proceed clinically in such contexts. However, convened members of the Harvard Committee included “the father of nephrology,” John P. Merrill, who had led the world’s first successful kidney transplant, and transplant surgeon Joseph Murray (Merrill et al. 1963). Inclusion of these two well-known surgeons ensured that transplant outcomes were taken into account in discussions. In the Harvard committee’s final publication, two justifications for the need for a new criterion for death are stated:

(1) Improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only partial success so that the result is an individual whose heart continues to beat but whose brain is irreversibly damaged. The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients. (2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation. (Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death 1968:677)

In her detailed critical analysis of early drafts of the report and the correspondence between committee members, Mia Giacomini (1997) demonstrates how the desire to increase availability of organ donors was a central concern throughout. She argues that “resuscitative and supportive measures” such as heart-lung machines and ventilators had been available in North America since the early 1950s, and that the state of “hopeless unconsciousness” had hardly provoked public angst (1997). The first intensive care units had already been established as of the early 1950s, and life-sustaining technologies had been maintaining patients in comatose states for years prior to the Harvard committee’s

deliberations. The 1950s were a time of optimism and scientific advancement in North America; comatose patients in some ways represented the pinnacle of scientific medicine's expanding lifesaving capacities. Newspapers reported regular updates of specific and personally identified coma patients, often including explanations of the novel medical and technical therapies they were receiving (Haseltine 1950; The New York Times 1951; The Washington Post 1950). The release of the Disney classic, *Sleeping Beauty* in 1959 provided the state of prolonged coma with mysterious, fantastical, and romantic possibilities and was met with widespread public acceptance.¹⁸ While it is possible that by 1968 the public had begun to question the need for maintaining comatose bodies on life-sustaining therapies, it seems implausible that this urgent need, previously absent, arose at exactly the same time at which organ transplantation was taking the public imagination by storm.

The first human to human heart transplant was performed in December of 1967 by South African surgeon Christiaan Barnard (Barnard 1967). Alongside ventilators, intensive care units, and electric defibrillators, the successful implantation of a healthy human heart into a dying recipient appeared as a high point in the "golden age" of lifesaving medical advances (Burnham 1982; Stevens 1996). The first transplant surgery was reported internationally and touted as a success, even though the recipient died

¹⁸ The idea of prolonged, hopeless coma and the concept of brain death continue to be confused and romanticized in current day media portrayals. See Colbeck (2016) for a discussion of how fiction surrounding the portrayal of coma can be read as part of a postmodern existential crisis with medicine and technology, and Lewis et al. (A. Lewis, Weaver, and Caplan 2017) for an analysis of how brain death assessments represented in popular media perpetuate false ideals about the process.

within 18 days (Lock 2002:80–82). Barnard performed a second operation shortly afterwards, again to much media fanfare (Nathoo 2009). This time, both donor and recipient became international celebrities, with American news media reportedly shelling out \$25,000 (almost \$200,000 in today's dollar value) for exclusive rights to interviews with the White South African dentist, 58-year old Philip Blaiberg (Koretzky 2017:416). The funeral for 24-year old Black donor, Clive Haupt, drew massive crowds and was reported worldwide (Koretzky 2017:413). The globally celebrated experiment came as a shock to American surgeons who had announced their intent to perform a heart transplant just weeks prior (Hoffenberg 2001; Richmond 2006). In 1968, the year of the Harvard committee's deliberations, over 100 heart transplants were performed around the world, many unsuccessful (Hoffenberg 2001; Stolf 2017). As Hoffenberg, a colleague of Barnard's, wrote years later, "What inhibited US surgeons were ethical and legal considerations rather than technical skill" (2001:1479). Ethical and legal requirements for the declaration of death were unclear in the USA during this period of transplant experimentation, while in apartheid South Africa, the law required only that a physician perform the declaration of death (Cooper 2018). The ongoing performance of transplant surgeries in absence of a clear statement on death caused the spectre of legal challenge and the possibility of a subsequent moratorium on transplantation to loom large in the minds of the Harvard Committee participants (Giacomini 1997).

Media frenzy surrounding heart transplantation overshadowed ongoing work in kidney transplantation, which was also ramping up during this period. Development of

the capacity for long-term dialysis and advancement of immunosuppressant drugs led to a USA government report in 1967 which established these new, expensive, life-prolonging therapies as medically necessary and effective treatments for people with end-stage kidney disease (Rettig 1991). However, despite the relative successes of human kidney transplantation, surgeons were having a difficult time convincing living family members to donate their organs (Giacomini 1997). In addition, transplant success was compromised by the use of kidneys that had suffered damage during the process of dying (Giacomini 1997). In a medical conference on the topic of kidney transplantation held in 1966, some surgeons advocated for commencing organ procurement surgery prior to removal of the ventilator in patients who met the clinical conditions for *coma dépassé* (Machado 2007). This suggestion was met with hesitation by many at the conference who inferred that to do so would be to remove organs prematurely from still living patients (Giacomini 1997; Machado 2007). The need for a clear statement on the characteristics of human death was acutely felt by the kidney transplant, as well as the heart transplant community.

Despite justification about the need for a criterion of death that would assuage the grief and guilt of family members, the focus of the Harvard committee appears more concentrated on their second stated reason, the need for a formal statement on death in the midst of a global frenzy for human organ transplants (Giacomini 1997; Lock 2002). A lack of clear consensus on when death had occurred limited the availability and quality of transplants, and also increased the legal risk of these exciting new surgeries. The Harvard

Committee reached consensus and published their statement within several months of their first meeting, notably without public consultation, without acknowledging the presence of glaring conflicts of interest, such as the transplant surgeons sitting on the committee, and without referencing any of the many previously published clinical accounts of brain-death-like conditions (Giacomini 1997). The proposal of a new way to understand the physiology of human death established blanket criteria for the management of ethical human organ transplants and the flow of human bodies through life-sustaining therapies. Some have argued that the Harvard committee did not have an overt interest in transplantation (Machado et al. 2007), or that if they did, it was as an afterthought (Wijdicks 2018). However, it is clear from the report and from its timing that the social contexts of North America in the late 1960s (in which the success of human organ transplantation played a significant role) actively fostered the ability of clinicians to equate irreversible neurological damage as a form of human death (Lock 2002).

Many transplant surgeons and neurologists seemed keen on adopting this new criterion for death. After all, it would help to establish a moral and professional backing for the types of decisions about end of life and organ transplantation that were already being made. Medical practice fixated on the production of “normal” human bodies, consigning those that did not fit to institutions or subjecting them to experimental and violent cures (Clare 2017). The sanctioned ability to assign as dead bodies that still breathed (with assistance) but were never anticipated to regain normal human functioning

aligned with existing principles of a profession mainly focused on saving individual, independent human lives.

The concept of brain death seemed to make sense within existing paradigms operating in much of clinical medicine, but what of the rest of the population? While physicians sought the use of a new criterion for death in order to facilitate the legality of cutting-edge transplant surgeries, what were the perspectives of those who were most likely to be on the other end of the knife? In her well-known study on brain death and organ transplantation, anthropologist Margaret Lock suggests that cultural factors such as religion, technology, and politics play an important role in delineating the acceptability of “tinkering” with the end of life (2002:11). The Judeo-Christian background of most North Americans (especially in the 1960s) helped to usher in the success of deceased organ donation by deftly matching shared underlying narratives of charity and rebirth (Parsons et al. 1978). Similarly, widespread cultural acceptance of scientific arguments reaching back to Enlightenment humanist values that the essence of rational human life is located in structures of the brain made acceptance of the equivalence of brain death with human death more cognitively plausible. By comparing the uptake of the concept of brain death in North American and Japan, Lock demonstrates how reluctance to embrace brain death and subsequent deceased organ donation and transplantation is not strongly correlated with scientific or technological progress. Instead, subtle differences in where each society draws the lines between “nature” and “culture” cause diffractive repercussions for how physicians and families come to view dead bodies (Lock 2002). In

other words, it is a belief about what constitutes human life and what facilitates its end that most strongly influences perceptions around brain death. In addition, the concepts of brain death and of organ transplantation, interlinked at the moment of their conception, are not easily separated in public perception (Long, Sque, and Addington-Hall 2008).

While a majority of the North American population may have accepted or been largely unaware of the new proposed criterion for death, subsets of the population raised concerns. It was notable that in apartheid South Africa, one of the first heart transplants occurred from a Black donor to a White recipient. Koretzky's (2017) reading of the Black American media demonstrates how writers and journalists interpreted this transplant experiment as a reason for hope that racial divides might diminish after biological evidence had so clearly demonstrated that skin color made no difference - a Black heart could save a White man. However, not long afterward in the United States, a Black man's heart was removed for a transplant into a White recipient without consent from the donor's family (Jones 2020). 54-year-old Bruce Tucker lost consciousness after a falling off a ledge during a work accident at a packing plant. His heart was transplanted into Joseph Klett, a White man from Orange, Virginia. Following the publicity of this case, Black activists and journalists became critical of brain death and organ transplantation and began to directly question the ethics and power dynamics involved in the neurological determination of death (Koretzky 2017). Opinion pieces in the Black news media criticized organ transplantation as yet another opportunity for those with power to take what they wanted in the service of the privileged few.

Organ transplantation, and the requisite determination of brain death, did not emerge as a symbol of technological hope and progress for everyone. For people whose lives were already publicly undervalued by pervasive overt and systemic racism, the proposed universal application of the concept of neurological death appeared to indicate that certain bodies were more valuable dead than alive (Koretzky 2017). As the scientific and medical world celebrated the social and technical progress represented by human heart transplantation, activists and social justice organizers were reeling from Martin Luther King Jr.'s assassination and ongoing violent race riots across the United States. In these historical contexts, it is not difficult to imagine how surging enthusiasm for transplantation and modification in acceptable limits to human life could be perceived as simply reinforcing the privileged White classes. Black journalists and activists lamented society's ability to solve seemingly insurmountable scientific challenges like human heart transplantation while remaining unable and unwilling to assure basic needs such as education and housing for large proportions of the population (Koretzky 2017).

The family of the Virginia man whose heart was removed without consent in 1968 lost their wrongful death lawsuit, as it was deemed by an all-White jury in court that physicians had correctly followed procedures to ensure the declaration of death using neurological criteria prior to organ donation (Anon 1972). Although this case is markedly different from the present-day McKitty case, in which organ donation was never a concern and in which physicians never conducted medical acts like removing the ventilator while the family contested the presence of life, the similarities are also striking.

In both cases the life in question is racialized and has ended up in intensive care as a result of processes of social inequality (unsafe and menial work, for Tucker; drug addiction for McKitty). In both cases, the balance of power hangs in favor of legal and medical authority, rather than with alternative ideas and understandings held by minority families about consent, death, and what it means to be alive.

At the time of the publication of the Harvard Ad Hoc Committee report in 1968, those who believed in the acceptability and the promise of brain death were many of the same people invested in the emerging industry of human organ transplantation. Physicians, surgeons, and patients who had exhausted all available forms of treatment for their chronic diseases saw promise in a new medical practice that could legally establish a supply of high-quality organs. The people most likely to be organ donors (accident victims, suicides, overdose cases), a more amorphous and disadvantaged group, were perhaps too busy advocating for basic needs of life to be publicly concerned with new criteria for establishing death. When they did mount formal challenges, such as in the Tucker case in Virginia, the prevailing authority of scientific medicine and its close relationship with the law assured that outcomes landed on the side of the surgeons. The conditions under which criteria for the declaration of death using neurological criteria were first proposed were times of technical and social possibility for many people in North America, but these conditions were not experienced equally. The privileged few could afford to see transplantation as technical prowess and medical opportunity, while

disadvantaged populations viewed it as evidence of scientific excess in the face of ongoing social injustice.

Over time, the concept of the neurological determination of death has been integrated into medical practice and into law. In the United States, the 1981 Uniform Declaration of Death Act established the general acceptability and permissibility of using neurological criteria for the declaration of death across the country. In Canada, only two provinces (Manitoba and Nova Scotia) have formally adopted a definition of brain death. In the rest of the country, legislation permits death to be declared using “medically acceptable standards,” and recent cases have demonstrated the courts’ willingness to accept national medical guidelines on the declaration of death using neurological criteria (Ontario Superior Court of Justice 2018a; Shemie et al. 2006b). The concept of brain death remains broadly uncontested despite concerns voiced in published medical and bioethics literature.¹⁹ The idea that brain death is equivalent with the death of a human being continues to be questioned from philosophical, biological, and medical perspectives (Bernat 2019; Halpern and Truog 2010; Matheny A.H. 2010; Shewmon 2018; Veatch 2018). Persistent challenges include whether the possibility for consciousness remains in brain dead individuals (Robbins 2019), whether dissolution of the brain constitutes the end of meaningful life (Bernat 2019), and whether the condition of brain death can be proven to be irreversible (Shewmon 1987). Although recent guidelines for the neurological determination of death advocate for the maintenance of “public trust” in

¹⁹ Though some have interpreted the growing number of legal challenges in brain death cases as evidence that the concept is now “under attack,” (Lewis and Pope 2017; Pope 2018, 2019)

this medical process (Russell et al. 2019), large-scale public discussion or consultation about the concept of brain death has yet to occur outside of academia.

This short history of the conditions in which the concept of brain death was proposed in North America demonstrates how social and technical conditions contribute to the manipulation of “natural” thresholds such as death. The Harvard Committee’s suggestions for new criteria for death were allegedly due to the increased grief caused by excessive use of life-sustaining technologies. However, a closer examination appears to indicate an additional narrative: that the human organ transplantation industry had much to gain from the invention of the brain-dead body, much to lose with a potential wrongful death lawsuit, and a convenient lack of sustained public dissent from populations most likely to be exploited. Instead of consulting with populations likely to meet criteria for brain death, the people most apt to benefit (e.g., those with connections to the transplant industry) simply proposed the change and later filled in an outline of its inescapable logic.

Today, reference to the contexts in which the concept of brain death originated commonly omit consideration of the role of transplantation, instead emphasizing connections between the use of ventilators and the proliferation of bodies in irreversible comatose states (Machado et al. 2007). Neurological criteria for determining death are publicly framed as inevitable and natural medical states which just so happen to also be useful for solid organ transplantation (Ariane Lewis, Cahn-Fuller, and Caplan 2017). The ongoing tendency to modify the boundaries of death in order to satisfy the needs of the

transplantation enterprise has been likened by some to a “gerrymandering” of the definition of death (Truog and Miller 2008). The Harvard Committee report and subsequent official publications illustrate this on a broader policy and epistemological level, though tinkering also occurs on a micro-social level when death is negotiated in clinical settings. Considering some of the details of these instances of tinkering illustrate just what is at stake for individuals, families, physicians, and the broader practice of scientific medicine.

Tinkering with death: agential cuts and acceptable exceptions

In this analysis, I take up Karen Barad’s concept of the agential cut, an ethical decision of drawing boundaries which has material consequences. Examining the power differentials through which these cuts are made permits a critical understanding of social contexts in which some actors are permitted to enforce definitions and beliefs about the world while others are only allowed to experience them. The decision to view death in a particular way effects an agential cut with significant power – it literally determines the end of a life. Death is a particularly interesting moment to study using this concept, since it entails many material possibilities. An agential cut of death can be social, cardiac, neurological, emotional, philosophical, and most often, a combination of several. Practitioners of scientific medicine (i.e. medicine based in a bio-medical epistemological framework) argue that an “objective” account of death, such as death determined through cardiac or neurological measurements with special tests or technical devices, is necessary in order to ascertain the end of a human life (and especially when practices of organ

donation are involved) (Dhanani 2018; Shemie et al. 2014). This empirical idea of objectivity is based on the premise that reproducible physical observations can guarantee the truth about the world, including human death.

Barad (2007, 2014) proposes a modification to this empiricist assumption by insisting on the requirements for an acknowledgement of the ethical and epistemological underpinnings that make up material ontological formulations of the world. As explored earlier, Barad calls these ethico-onto-epistemological considerations, agential cuts, and she embraces the possibility of material objectivity by advocating for transparency in everyday decisions of perception (i.e., the agential cuts) that inevitably make up our “objective” observations. Exploring and analyzing agential cuts is a means of identifying the specific choices and material and social contexts that contribute to perpetuating or challenging certain conclusions about the world. As noted, Viveiros de Castro (2015) takes a similar position in arguing for transparent renderings of the perspectives from which statements about the material world are made. As Viveiros de Castro states, with any knowledge claim, “it is necessary to take sides. We always already have” (2015). Accounting for agential cuts and the relative positions of knowledge making allows us to better understand the complex epistemological positions and power relations from which claims are made. It also permits a better vantage point from which to suggest potential creative openings for change.

I am interested in investigating the power dynamics involved in making specific claims about the threshold of human death, and I do so from the position of having found

death to be a decision most likely to be in the hands of persons and systems of power. In the Canadian context, this includes medical professionals operating within an accepted framework of scientific medical practice. Troubling the category of brain death, in particular, leaves much at stake: the lives of individuals, the authority of scientific medicine, and more broadly, an understanding of who and what counts as human. The McKitty case and other similar legal conflicts highlight how the concept of brain death, begun as a practical construct to permit organ donation, has grown into an epistemological claim about the fundamental nature of the limits of human life. It is my goal in this chapter to interrogate the material elements of this construct in order to better understand present epistemological assertions. Exploring these elements against the history of brain death helps to provide a location in which I position my findings. In the following vignettes, I introduce different contexts in which an agential cut of death is materially enacted, attending to both the physical and social effects and the relative positions of power involved in processes of materialization. Examples are drawn from interview transcripts with Canadian physicians, part of a project I conducted on physician experiences with conflicts surrounding the concept of brain death (van Beinum et al. 2020).

Agential cuts: clinical

The clinical agential cut of death is made through a formal “declaration,” “determination,” or “pronouncement” of death as enacted by a licensed and qualified medical physician. Unlike a diagnosis or prognosis, a declaration or determination of

death is understood as a singular, precise moment that is universal and objective

(President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1981; Russell et al. 2019). Two interview participants explained this difference to me:

Interviewer [AvB]: *Do you feel that [death is], in those conversations that it's, similar or different to any other diagnosis? [...] to me it seems as though it's got to be on a different level than giving a diagnosis of some other condition.*

Participant [MD]: Right. It's not a diagnosis. You're dead. You're telling, this is [...] this is exactly the point. You're not telling them that they've had a heart attack or that they've had a stroke [...]. You're telling them they're dead. And if you don't say that, clearly, if you don't use that word, then, then what you're signaling to the patient, or to the family, is that it's unclear. Or that you're not certain. Or that there's a question. Or that there's a possibility that something's going to happen. (Interview #2)

Participant [MD]: [Brain death cases], in a way, are more simple because it's not about prognosis, it's about, are they dead or alive. And that is much more objective to me than um, you know if we all know that this person is alive, but their, their prognosis is absolutely grim and they won't make it, those are hard because families have hope [...] in my view, these ones around brain death are more straightforward and easier to manage.

Interviewer [AvB]: *Because there's a, sort of definitive end point.*

Participant [MD]: Yeah. (Interview #5)

As explained by these participants, certainty in conveying that neurological death is a discrete and irreversible physical state is imperative. While medical diagnoses and prognoses such as “heart attack” or “liver disease” may be open to multiple interpretations, the state of human death is viewed as an undeniable fact that can be clinically declared or determined with the requisite skill and technology (Wijdicks 2015). Part of the strategy for successfully establishing a clinical agential cut of death at the bedside involves insisting that the moment of death is enacted as a point after which no

further medical changes or treatments can be made on a logical or rational basis, and a point after which the physician has no further obligations to the patient (Pope 2017). As another participant remarked, “The patient is dead, we have declared them dead. They are dead. Why, why are we keeping a dead body, if they are not consenting to organ donation, why are we keeping that dead person on a ventilator?” (Interview #12). Here, the logic of asserting the moment of brain death also includes the practice of deceased organ donation in what is now a relatively uncontroversial connection. Contravening this logic is perceived by this physician as irrational and wasteful, a view also shared by others in the field (Paris et al. 2014).

The ability to make a clinical agential cut of death using neurological criteria depends on the presence of several material contingencies. It is also tied to the relative position of power held by the bedside physician in comparison to the comatose patient and the grieving family. Clinical guidelines for the determination of death using neurological criteria outline the usual process that physicians take when enacting the clinical agential cut of death (Russell et al. 2019; Shemie et al. 2006a). A determination of death using neurological criteria requires: a waiting period to establish specific clinical signs, the technology of scans, spinal and brainstem reflex tests, blood gas analysis, and the presence of two fully trained and qualified physicians to confirm the declaration. Each of these requirements presents logistical and administrative constraints that shape the material realities of the precise moment of when and how brain death is declared. One

interview participant specifically mentioned the difficulties of ensuring the presence of two physicians:

Yeah, so, well the brain death declaration is not, it's planned but it's not, you must recognize you need two physicians. [...] So, it can be difficult sometimes to schedule, if you're in a smaller community hospital... (Interview #11)

Finding time in which two staff physicians confident in the criteria for the determination of brain death are available to perform testing can be challenging in less well-resourced centres, as this physician mentions. As a result, establishing a clinical agential cut of death using neurological criteria can be difficult depending on the day and time, sometimes leading to delays in asserting death, which can be confusing to families (Liao and Ito 2010).

In most cases, the relative power of physicians and of clinical scientific medicine fixes brain death as the moment of human death, even despite material contingencies. Physicians alone are empowered with the capacity to make a determination of brain death. Nurses, respiratory therapists, families, spiritual care workers, and others who may be present at the bedside of the dying patient, though able to make suggestions and contributions, are denied the formal power to officially “declare” the moment of death (Weaver 2011). The bedside physician performs the final assessment and signs the legal death certificate, establishing with authority the universal and irrevocable nature of this state. Death is “not a diagnosis,” and no room for reassessment, other than that formally required through standardized clinical guidelines, is generally permitted. The authority of the application of a scientific medical fact is made to stand on its own. Thus, in clinical

contexts in which a ventilator, testing tools, adequate training, and a second trained physician are present, brain death is declared as death by a physician once physical evidence for the state of death using neurological criteria has been discerned. Religious or moral input or objections from the family and/or the presence of bodily movements do not have the power to impact the timing or enactment of this cut. Instead, changes in physician scheduling or availability of scans and blood gas laboratories may impact whether the test is delayed. The clinical agential cut of death demonstrates the authority of scientific medical knowledge in establishing what is acceptable as the end of human life. Nevertheless, some exceptions do occur.

Agential cuts: legal

The legal cut of death is enacted through legislation, and it discerns whether and when life insurance can be released, if certain actions can be prosecuted as murder, and who or what counts as a living human for the purposes of rights-based legislation, among other things. In Canada, the legal agential cut is intertwined with the medical clinical cut, since most provinces consider death to be legally established by licensed physicians using “accepted medical criteria” (Canadian Council for Donation and Transplantation 2003). In Ontario, the McKitty case has established that nationally accepted medical guidelines for the determination of brain death are considered legally acceptable for declaring death (Court of Appeal for Ontario 2019; Ontario Superior Court of Justice 2018a). However, it became clear through my interviews that the relationship between medicine and the legal system is not without inconsistencies. Indeed, as Pope (2017:294–308) has argued in the

American context, legal requirements outlined by the Uniform Declaration of Death Act do not always align with the medical tests used to determine brain death. Legal requirements also introduce additional material aspects, such as forensics investigations and the involvement of coroners, which must be negotiated in order to permit the establishment of death using neurological criteria.

One interview participant provided a salient example: the tension between establishment of death using neurological criteria and the requirement for examination by a coroner in cases of suspicious or accidental death:

I think that the lack of clarity around brain death declaration is, is a big problem. And, I'll give you a very specific example of that [...] it appears that coroners don't certify brain death. And so, in the case of a suspicious or accidental death, the coroner has to be involved [...] Well, the coroner is usually just a family physician who has training in forensic [medicine] or, [is trained] under the coroner's act. And so, they don't have the ability to independently certify patients as brain dead. And they don't want to, to just go by hearsay, effectively, which is another physician's determination. And so, it's usually not a problem because the removal of life support equipment typically is on the same day as the declaration of brain death, at least in our institution. But it seems that if it is not on the same day, and the coroner is the individual that has to fill the death certificate, they will date it for the date that they attended. Rather than, and when life support was removed and cardiac death was achieved, rather than for, for the brain death date. And so, to me that's a huge problem, because it essentially says that this confusion around is brain death even death, structurally, extends beyond the family. We, our legal system says that once the coroner is involved, there is no such thing as brain death anymore, because they will certify the date of death as the date of cardiac death. (Interview #3)

Published literature, medical guidelines, and the recent McKitty case court ruling insist that the declaration of death using neurologic criteria is irrefutably the moment of human death. Once two qualified physicians have made a comprehensive physical assessment of the patient and ruled out any potential confounding factors, a time of death is declared,

and a death certificate is written. From this moment on, the patient is no longer a living person but a corpse.

The observation that coroners, physicians who are specifically tasked with investigating the mechanisms of death, do not perform their assessments on brain dead bodies, indicates that contexts of accidental and suspicious deaths modify the agential cut of the end of life. Timmermans also notes this discrepancy in his study of American medical examiners, describing in detail the mutually exclusive goals of forensic death investigators and transplant surgeons (Timmermans 2006:226–29). As noted by the participant quoted above, this modification is not usually perceived as “an issue” since the date of declaration of death using neurological criteria, the removal of life sustaining therapies, and the date of coroner examination almost always coincide. But in instances when these timelines are disjointed, for example due to time provided for family to gather prior to removing the ventilator, patients could end up with two distinct moments in which they are declared as dead. In those cases, deciding between the neurological determination or the circulatory (coroner) determination of death as the legitimate agential cut of death becomes a question of legal and administrative demands, such as pathology reports for court cases or the death certificates needed for release of life insurance, rather than any inherent clinical or physiologic state.

This interview participant also astutely points out how “confusion” around brain death extends structurally, beyond the family, an observation which aligns well with a new materialist interpretation. Brain death, as a condition, requires many interacting

structures to be in place, from access to the emergency resuscitation which prevents sudden death and precipitates admission to the intensive care unit (Timmermans 1999), to the availability and maintenance of ventilator support which makes identification of devastating neurological injury possible. The technology for performing a neurological determination of death (flashlight, ice-cold water, syringe, arterial blood gas point of care testing machine, the presence of two trained and qualified staff physicians) must also be present and available (Russell et al. 2019). Finally, establishing the legitimacy of the diagnosis of brain death requires the maintenance of administrative systems and legal processes such as the issuing of death certificates and notification of coroners.

Inconsistencies or interruptions in any of these material and social junctions facilitates sometimes markedly different dates and times in the agential cuts of death. In some cases of accidental or suspicious death, dislocations in timing and available resources can result in the impossibility of dying through brain death. Postmortem medical examinations, which are generally focused on the heart, may also render brain death pathologically unlikely (Timmermans 2006:59). Differences in enactments of legal death also have racialized and gendered components. Recent and historical work exploring coroners' reports of murder and rape victims demonstrates the potential for bias when reporting on autopsies of racialized victims (Kolsky 2010, 2020). When legally sanctioned institutions such as the police and medicine already view certain bodies as predisposed to weakness, official death reports may be more likely to emphasize the role of "underlying conditions" like heart disease rather than the direct physical results of police homicide

(Crawford-Roberts et al. 2020; Feldman et al. 2017). The criteria by which patients are determined dead may not matter for those who are dead either way, but it does have potential consequences for surviving family members and surrounding social contexts. In the end, there is a significant difference between a death due to homicide and one resulting from heart disease.

For some people, the legal agential cut determines whether their death occurs at a moment determined through neurological criteria (as per physicians at the bedside in the intensive care unit) or through circulatory criteria (as per the coroner's post-mortem assessment). This cut is enacted through interactions of the relative positions of power held by bedside physicians and coroners, alongside administrative, legal, and material constraints, all of which are shaped by pervasive structures of systemic oppression. The authority of scientific medicine has a strong influence on determining the agential cut of human death. However, as this example demonstrates, it is possible in some cases for the power of legal and administrative concerns to modify this determination.

Agential cuts: religious

Almost all historical research on cultural practices of human death refers to the role of religion in helping to determine the moment when death occurs. Early anthropological work in this area identified the role of the "rite of passage" as part of ritual processes delineating start and end points to dying, death, and mourning (van Gennep 1960). Ritual transitions surrounding death are based in social and cultural relations (Green 2008; Hertz 2004), however, ritual practices and religious rites also

provide some grounding to physical changes occurring in the body. Many religious traditions assign a physical moment at which the soul, the essential material essence of the living, departs from the body. What this moment looks like differs between cultures, ranging from the absence of a particular light in the eyes to a change in the quality of breath (Rinbochay and Hopkins 1981). Other groups believe the soul or spiritual presence remains with the body until or even after burial, resulting in specific attentions that must be paid to the corpse (Green 2008; Hertz 2004). The agential cut of death, from a religious position, is based on understandings of the material essence of the human body and the actions that can be taken (e.g., certain rituals) to facilitate its movement between one world or physical state and the next. Thus, in the absence of a particular ritual, some religions may find that the death of the person has not yet occurred, even if bodily signs and medical practitioners have declared death (Lott et al. 2021).

In Western European history, ascertaining the moment of death was historically the task of the priest, not the physician. Priests alone had the ability to distinguish when the human soul had departed from the body and thus when a person had died. This historical religious agential cut of death was made through the performance of religious rituals such as the last rites. As the authority of scientific medicine gradually solidified during and after the Enlightenment period, objective tests and tools for determining death replaced religious ministrations. Green (2008:46–47) outlines, for example, how early doctors placed mirrors over the mouths of dead bodies to look for the condensation of breath, or inserted pins under fingernails to verify that the patient had no response.

Despite improved technology for determining death, religion continues to be important for many in helping make sense of the process of dying (Orsi 1997), and many modern hospitals accommodate religious rituals. This partial sharing of authority over the rituals of death introduces interesting irregularities and conflicts about when exactly human death occurs. Specifically, it raises questions over what should be considered the essential material essence of human life. One of my interview participants made this discrepancy clear as we discussed the timing of the ritual of last rites in the context of brain-dead individuals:

... you wouldn't want to do the last rites before you've actually decided that the patient is actually brain dead, [...] because you want clarity of message going to the family, and this is where you run into troubles right. [...] ...from the family's point of view, the body's still there, right. So last, from a, if you're talking Catholic issues, yes, typically you would do the last rites before you withdrew on someone, right that wasn't an organ donor, you, the family might want the preacher or someone to come in and do that, [if the patient is] not likely to die for the next, likely to die for whatever reason for the next two days or something right. But no, [...] I wouldn't want the, I wouldn't suggest doing the last rites before we do a declaration. If you thought we were going to do a brain death declaration I wouldn't have the last rites done first, I would do the brain death declaration first. Yeah. Because I think the family kind of, they kind of see the last rites more as a, what happens to the body and the soul and that kind of thing. As opposed to the brain, right. (Interview #11)

From this conversation it appears that in usual practice (at least in the hospital where this physician practices) the declaration of brain death is treated differently than the more common case of determination of death using circulatory criteria. The declaration of brain death must be scheduled, requires the presence of two physicians, and is an event for which families are asked to gather *after* it occurs, rather than before or during.

Religious rituals such as the last rites, a Catholic ritual which must be performed prior to

death, are arranged to take place after the official determination of neurological death. To me, this seems to be in direct opposition to the claims of scientific medicine that brain death is equivalent to the death of the human.²⁰

There were exceptions to this pattern of family involvement after official declaration, with several participants stating that they liked to inform families before the declaration of brain death was performed. However, at least one also stated that this would be an unusual practice.

I always invite them to a death declaration so they can actually see it. I can imagine that maybe there might be situations where I wouldn't and I would do that assessment maybe when they're not there and then I can, you know, but provide them with a time of death, if they're determined to be brain dead. But I, you know, I just, I find that if they're able to watch, without interfering, that it's um, you know, they see, they see what exactly we're doing and how there's just no response. And, I think that that really helps them to accept the determination of death. (Interview #5)

Then, you know, in one particular example they, the, there was such limited trust that um, we actually offered the family to watch us perform the declarations, the clinical declarations, which is unusual... (Interview #6)

I ask them to say who would want to be present, I mean there is limitation just because of the room size as to how many people can actually be in the room, and, sometimes our families are quite large so, and sometimes having 30 people in the room and 30 people asking questions makes it impossible to actually do anything so, I tend to say you know, if there are people that want to be involved, sort of limiting it to a few people that are immediate family is reasonable [...] I think sometimes having too many people point out every little thing that they see slows it down and also just may complicate it sometimes because they perceive them to be moving when they're actually not and take that as a positive sign. (Interview #10)

²⁰ It also provides evidence of the ongoing tensions and uncertainties of *where* death is located in the body (e.g., is it best located in the “body and soul,” or in the brain?). Lock (2002) provides an extensive history and theoretical discussion of this issue.

While physicians appeared to welcome some family presence at the moment of death, the declaration of death using neurological criteria was viewed as more of a clinical procedure than a social or emotional moment. Families were perceived as potentially impeding this clinical procedure, and participant #10 complains that having to explain the complicated process to many people can take longer and introduce room for conflict over results. In contrast, the moment of circulatory death, which includes the brain-dead patient's last breath after they are disconnected from the ventilator, is an event for which families are usually called in to participate and witness. After the declaration of death using neurologic criteria, clinicians may provide the patient's family with hours to days in which to assemble family members for the moment of "pulling the plug."

I think on the third day we did an NDD [neurological determination of death] exam and confirmed brain death. [...] ...in the end it's not a negotiation. We just told them "we'll give you the next two hours to say your goodbyes and then the ventilator machine is being removed." And that's what happened. (Interview #4)

The whole family finally, because several family were from out of town, and when they finally arrived then it was decided to withdraw therapy at that time. And that was about six days after brainstem declaration. (Interview #1)

And, you know, sure we've had people say, yes I know he's dead but how do we, you know, what can we do, and that's why when, we'll say you know, if there's people that want to come and see him, and we'll give them that opportunity to do that, um, you know if they're not organ donors and we're not talking about all that kind of stuff. Then usually, you know, then, they would, someone might come for the last rites or other religious type things. Um, you know and usually that makes the families somewhat consoled, and a little more compliant. (Interview #11)

This pattern of family and patient management continues to place social, emotional, and religious emphasis on the moment of disconnection from the ventilator, rather than at the

moment at which physicians declare the patient to have died. It points to the continued importance to families and care providers of the moment of the last breath and the last heartbeat, rather than the moment during the clinical exam in which the brain has been determined to be functionless (though see Macdonald et al. 2008 for one contradictory account). And yet, the date and time of determination of neurological death absolutely remains as the authoritative moment at which the individual can be regarded as dead, the moment after which organ donation can ethically proceed, and the moment after which human rights legislation no longer applies (Ontario Superior Court of Justice 2018a).

Interestingly, the argument made for maintaining the primary authority of the clinical agential cut of death as the brain death determination, as compared to the religious agential cut enacted through last rites, is that it has the potential to be wrong. According to one participant, "...the clinical exam, it is so unreliable, in my opinion, right, it's so unreliable like pretty much everything we do in medicine" (Interview #9), a sentiment also expressed in published literature (Greer et al. 2008, 2016; Wijdicks 2002). Ongoing work to ascertain the most valid method of declaring death using neurological criteria support the concerns of participant #11, "you wouldn't want to do the last rites before you've actually decided that the patient is actually brain dead [...] because you want clarity of message." The hesitation here, as I read it, is that if last rites were organized in advance of a neurological determination of death exam and that exam happened to be inconclusive, the last rites would be performed in error. Taken in broader context, this juxtaposition asserts that declaration of death using neurological criteria is

valid enough to initiate and ensure the ethical practice of deceased organ donation and the revoking of human rights, but on the other hand, is too uncertain to permit the advance performance of religious rituals. Brain death appears to be an agential cut to be made by (certain trained and qualified) physicians, but one that should not be adopted by other trespassing practices such as religion.

On a theoretical level, I find it interesting to note that physician participant #11 found it necessary to outline that the agential cut of death configured through last rites and religion apply to "...the body and the soul and that kind of thing," seemingly implying that the declaration of death using neurological criteria applies to something else. Instead of the body or the soul, it is the rational conscious mind that becomes the material embodiment of human essence that is determined to be absent during a brain death declaration (Lock 2002). Although it is tempting to conclude that widespread belief in brain death is encouraged in more secular societies, research demonstrates that beliefs in individuality exert a stronger influence (Lock 2002; Setta and Shemie 2015). Societies which view individual rationality as the mark of humanness (a theme in the West from the Enlightenment onward), and which take the brain to be the seat of this rationality, are more likely to argue that the death of the brain indicates the death of the individual person (Bernat 2019). The finding that religious rituals usually preceding death, such as Catholic last rites, are encouraged to take place *after* the determination of brain death, appears to signify remaining practical discrepancies in clinically locating the boundaries of what constitutes a human life and when it has ended.

The three vignettes presented here, though anecdotal, provide illustration for thinking through three different agential cuts which can be made to signify the end of a human life. First, there is a clinical agential cut that can be made in the contexts of a well-resourced hospital intensive care unit and orchestrated through the prevailing authority of scientific medicine over the human body. This is the most commonly enacted, official, “determination of death using neurological criteria,” which asserts that human life has ended once two trained and qualified physicians have followed nationally accepted guidelines to test for the absence of brain function and potential for consciousness. This formulation of the threshold of human life assumes the presence of multiple resources, as well as the idea that consciousness is firmly located in the brain and not the spinal cord, digestive tract, circulatory system, or hormonal systems which continue to function after brain death has been declared. Importantly, this agential cut provides permission for more literal surgical cuts if the patient’s family consents to deceased organ donation.

Another agential cut of human death is illustrated through a specific legal framework. This cut is made in certain contexts of an accidental or criminal death and requires the presence of a medical examiner and an autopsy. In order for this examination to occur in a way in which the findings can be admissible in court, death is enacted using a circulatory definition and requires that all life-sustaining therapies are first disconnected. In this context, the clinical agential cut of brain death made through the power of scientific medicine is overruled by legal and administrative powers, and a new threshold of death is made certain. In some cases, it appears that the clinical

understanding and subsequent declaration that brain death has occurred can be interrupted by the material requirements of the legal system.

Finally, the introduction of religious and social rites again troubles the clinical agential cut of brain death. Healthcare providers encourage families to gather anyone who “wants to say goodbye” to assemble for the moment at which life-sustaining therapies are turned off, not for the declaration of death using neurological criteria. In contrast to circulatory determined death, loved ones are not always informed or permitted to be present at the bedside at the moment of clinical death determined by neurological criteria. Last rites and other ceremonies to honor the departure of the soul are conducted after brain death has been determined, essentially enacting a double threshold of human death and challenging conclusions already explained by clinical staff. Continued emphasis on the social and emotional importance of the moment of circulatory cessation once life-support has been withdrawn, and displacement of this moment to hours or days after the formal declaration of brain death introduces an element of ambiguity to understandings of when the end of a human life has been reached.

These vignettes provide just three examples of what could be multiplied into many different thresholds of death (Hadders 2009). My intention with this analysis is not simply to provide a description of the many different contextual situations but also to critically consider what it means to insist on a singular interpretation of the threshold of human life given the degree of variation and the possibilities for difference in how and why people die. In light of the exceptions and “grey zones” made for legal and religious

reasons, should we not take more seriously the suggestion that personal beliefs and perhaps social context be taken into account in establishing the thresholds of subjective death? How is it that only contexts relevant to the goals of scientific medicine and organ transplantation are permitted to count?

Must we believe in death in order to die?

The applicant submits that a determination of death requires not only an assessment of medical considerations but also of an individual's values and beliefs and that physicians have a duty to make inquiries of such values and beliefs before making a determination of death. If those values and beliefs include a belief that biological functioning of the body is life, even in the presence of brain death, that belief ought to be accommodated in the determination of that individual's death. (Ontario Superior Court of Justice 2018a:34)

The respondent's position is that the absence of capacity for consciousness, brainstem reflexes, and capacity to breathe is the medical and legal definition of brain death in Canada. The respondent submits that this definition of brain death has been accepted by courts in Canada, the United Kingdom, and the United States. (Ontario Superior Court of Justice 2018a:61)

"Every time I visited and touched her she would move to show us all I am a Life."
– Raquel McKitty [Taquisha McKitty's cousin]
(from Anon n.d.)

The proximity to death suspends life, not in transcendence, but rather in the radical immanence of just a life, here and now, for as long as we can and as much as we can take. – Rosi Braidotti (2006:211)

A central concern of the McKitty case hinged on whether or not personal religious beliefs should be taken into consideration as part of a medical determination of death.

The McKitty family did not actively contest the definition of brain death in court, and

they agreed that Taquisha was seriously neurologically injured. However, they did not believe that Taquisha's state of being, maintained on a ventilator and supported through invasive therapies in the intensive care unit, constituted human death. In support of their argument, the McKitty family presented observations and cellphone videos taken by friends and family members of Taquisha moving in her hospital bed. Physicians defended the declaration of death using neurological criteria, arguing that the diagnosis had been made by multiple medical specialists on more than one occasion and had followed nationally accepted guidelines. Ultimately, the court ruled in favor of the physicians, finding that the diagnosis was a sound and legally acceptable means of deciding Taquisha's death. Individual beliefs pertaining to when the moment of death should occur were not found by the judge to be substantive criteria on which to base the legal end of a human life. Instead, the overarching and institutionalized belief of neurological criteria for the determination of death prevailed.

While I see how this ruling made logical and practical sense for the current medical system in Canada, I remain troubled by the considerations and voices left out of the decision. To me, the argument that brain death is irrefutably the moment of death in all instances of similar devastating neurological injury because it has been defined as death and accepted legally seems circular. Read in light of the Tucker case 50 years earlier, this ruling appears to conclude again that legal death is the death in which physicians believe, at the time at which they find it prudent to apply the definition. This type of technocratic operationalizing of the concept of death precludes a more

collectively determined and inclusive discussion about reasonable limits to human life.

The conclusion that brain death is death because it is what physicians currently practice does not take into consideration the historically contingent manner through which the concept was introduced as a means of obtaining organs for transplantation. It does not take into consideration that challenges to the concept of brain death have not been particularly welcomed in the medical and academic community where questions about the validity of the concept are often met with sombre warnings about the potential loss of organs for transplantation and apocryphal claims that without brain death, intensive care units would be full of indefinitely incapacitated, ventilated, expensively maintained bodies (Ontario Superior Court of Justice 2018a). The conclusion does not take into consideration how the technological infrastructures of intensive care units are part of the material network that produces the brain-dead body in the first place. Finally, it does not accommodate the reality that many policy decisions, such as requiring seatbelts and helmets, are responsible for reducing organ availability, or that tragedies such as the ongoing opioid crisis are responsible for its increase (Kramer, Baht, and Doig 2017; Reynolds, Rittenberger, and Callaway 2013).²¹ The idea of brain death and its shadowy partner of deceased organ transplantation rest on a historically and materially contingent network of technical and scientific innovations, as well as political and economic

²¹ Interestingly, recent restrictions and stresses on North American intensive care units due to COVID-19 have all but ceased the practice of deceased organ donation and transplantation in some places. The surge in need for intensive care unit beds has restricted the ability to maintain bodies on ventilators long enough to facilitate testing required for deceased organ donation. In this period of uncertainty and public health crisis, organ donation and transplantation has not been deemed an essential or emergency service.

assumptions about which lives count. The failure to honestly account for these contingencies, both in recent court cases and published support of brain death, is a significant shortcoming which hinders the objectivity of the concept.

Vocal perspectives from the periphery are often most proficient at shifting conversations in the centre; the past decade has seen several formal legal challenges to the concept of brain death by religious minorities and racialized families (Lewis and Greer 2017; Ontario Superior Court of Justice 2018a, 2018b; Pope 2017). This observation fits within the historical finding that it was Black communities in the United States who first voiced concerns about a new mechanism of deciding death which appeared as yet another ploy to concentrate power in the hands of those with the potential to abuse it (Koretzky 2017). Given the underlying racism, sexism, classism, and other oppressions “baked in” to the very structure of scientific medicine (Harding 1993), it does not seem surprising that marginalized patients and their families would be the ones most likely to voice resistance to what have historically been devastatingly biased circumscriptions to the limits of life.

A concurrent exercise of power exists in the way in which racism around brain death operates at the bedside. With the 1968 JAMA committee report, “the location of life in the heart was made to seem primitive, sentimental, and obsolete,” (Giacomini 1997). These perceptions appear to be mapped onto minority families already labelled with the same derogatory descriptors (Cooper and Kierans 2015). My discussions with physicians about their experiences with families who contested definitions of brain death

revealed that “ethnic” families are often perceived as the ones most likely to have trouble accepting medical expertise on this issue.

Uh, well, people with certain cultural backgrounds have very different expectations and, uh, yeah, very different expectations whether they’re actually brought out in religion or not, I think it’s a cultural thing, that you know, whereas quite frankly you’re, you know the, more traditional White, farm-type population, they don’t have that expectation, and they would think it’s actually inhumane to be keeping someone alive or on a ventilator who’s not actually alive. (Interview #11)

I didn’t mention the cultural aspect of this particular case last year, but these were not people who were originally from Canada and so there may, and we try to look into that, but there may have been some cultural issues as well, in terms of their feeling that their child may not have been prioritized due to race factors. (Interview #7)

Yeah, I mean, they often fall under religious and sort of cultural kind of stuff. So, there are certain, I guess phenotypes, or different types of families that are more likely to challenge this [brain death] than others [...] Generally the more religious ones do, the ones that are perhaps slightly lower socioeconomic background do, in general. The ones that are more distrusting of the medical system, I think. (Interview #10)

As identified by these physicians, it is families holding less social capital who are perceived as potential threats or disruptions to the diagnosis of death using neurological criteria. In contrast, as pointed out by participant #11, the “more traditional, White, farm-type population,” is understood as more likely to agree with the prevailing views of the medical community that maintaining a brain-dead body on a ventilator is unethical. These perceptions are perhaps guided by assumptions that White, able-bodied, productive humans are more likely to hold what are more widely considered as rational perspectives. But limited research exploring this phenomenon has shown that White

families also voice concerns and face conflicts in accepting the concept of brain death.

The major difference identified by Cooper and Kierans in their work was that while working through these challenges, racialized families were more likely than White families to be considered “difficult” (2015). In conflicts over the validity of the concept of brain death, there may be a double feedback loop of racialized minorities identifying real reasons to resist the concept, while also being perceived by physicians as “difficult” and somehow hindered in their acceptance of brain death by “religious and ... cultural kind of stuff.”

Ultimately, challenging the concept of brain death involves challenging the epistemological authority of scientific medicine to define the end point of a human life, not exactly a small undertaking, and one that is almost certainly hindered by perceptions of “otherness.” The challenge involves not only contesting the historical and structural powers of the rationality of science and medicine but also thinking differently about what it might mean to reach the end of subjective life. Tied to the epistemological authority of scientific medicine is an inherent judgement about what constitutes “*a life*.” Is it enough to be just A Life, a singular instance of many, a temporary subject formation unfolding into new connections, or must one also be decidedly “alive” in a manner in which medical and legal systems judge acceptable? The ruling of the McKitty case appears to suggest that the later decision currently prevails. In the absence of sufficient “aliveness” (i.e., the presence of officially sanctioned signs taken to indicate an irreversible loss of the potential for consciousness), a person is considered dead. The life that is ongoing

through breath, blood flow, and in some cases the successful transfer of organs into waiting recipients, is considered not inherently valuable outside of its potential for organ donation. Although saving “a life,” saving lives, is deemed to be the overarching goal of intensive care medicine, as explored previously, application of the concept of brain death produces scenarios where this is no longer the case. Instead, saving lives in this context is interpreted to mean saving the lives of transplant recipients, since the human life of the brain-dead person is no longer considered salvageable.

What could it mean to think about life, and the end of human life, differently? What would happen if we chose to honor brain dead life? It could be that thinking differently about honoring all types of lives and differential subjective thresholds of death might help to move us towards a more just medical system. The current medical systems in most places in Canada and the United States permit people to make decisions (within limits and with discriminatory exceptions) about when life begins; why should we remain rigid in our universal beliefs about when it ends? Opening up this perception might permit communities and families with alternative viewpoints about the value of “just a life” to practice their own meaningful thresholds, instead of the present insistence on a single threshold based on neurological rationality. Permitting the option of ethical choice upholds a belief in the value of differently situated knowledges rather than insisting on the ongoing support of historically hegemonic systems of knowledge. The fact of brain death was once a belief with a purpose. The synthesis of scientific medicine and transplant technologies have rather smoothly moved the concept from suggestion at a

conference to indisputable medical fact (Fleck 1981). Opening up the threshold of human death to the potential influence of new subjective beliefs might allow new purposes and futures to emerge, new positive possibilities for valuing and honoring subjective life and its inevitable end.

On a practical level, it is likely that most families would continue to opt for disconnection of the ventilator and, if possible, donation of organs from brain dead patients (Bernat 2019; Truog and Miller 2008). Caring for a brain-dead body requires a great quantity of technology, expertise, and resources; it is an immense affective and costly responsibility. To imagine that families will choose this option without weighing their social, economic, and emotional obligations is to preclude their ability to make ethical choices. I draw a parallel to those who would argue that women given access to abortion will simply choose it as a form of birth control. This sentiment wrongly and quite insultingly positions women as unfeeling actors with no ethical potential, as well as devalues and disregards the intense emotional and physical strains involved in both pregnancy and its termination. There is always an affective aspect involved in potentially life-limiting choices. To assume that certain subjects (often unsurprisingly racialized, classed, and sexualized along usual lines of discrimination) make choices without thinking or without the capacity to be ethical denies the evolution of new ways of being and relating in the world and perpetuates systems of oppression. It also draws attention away from the broader social structures and inequalities shaping society which make

certain decisions such as keeping a baby or choosing to live with severe disability impossible even when they are desirable.

In many ways, deceased organ donation is one such new form of (potentially) ethical relating made possible through active family consent to different thresholds of death. Consenting for deceased organ donation often requires acceptance of delay in the moment of the patient's disconnection from the ventilator to permit testing and preparation of an organ recipient, and then acceleration of the actual moments surrounding death, since organs must be removed as soon as possible after the heart stops (or before, in the case of brain-dead donors) in order to be the best quality for transplantation. Donor families are provided with this information and make the decision to consent to changes in the choreography of death so that they and their loved one can participate in a greater good (Ralph et al. 2014). Deceased organ donation is therefore a way that families can facilitate connection and responsibility towards life, even in the face of catastrophe. However, this can only occur when they are given the option to willingly participate. Consent and integration of family perspectives and beliefs (e.g. the belief in charity) matter for deceased donation (Chandler and Gruben 2015), why should they not be included in general understandings of the threshold of human life?

Permitting individual nuance to the threshold of human death need not eliminate the concept of brain death entirely. Instead, as advocated by the McKitty family and by some scholars, brain death could continue to exist as a way to describe the state of irreversible loss of consciousness (Ross 2018). An opening up of alternative perspectives

would simply entail that this loss of consciousness does not necessarily signify the absolute end of a human life. In contrast, each subject would have the capacity, if desired, to outline their own ethical threshold for how much they could take. In the absence of such information, it would be up to the patient's family to decide. The transplant industry has already created administrative infrastructure to capture healthy people's consent to become organ donors through registration on a driver's license; an addition could be made to request input as to what extent individuals wanted to be maintained on a ventilator should they become incapacitated. Indeed, these two decisions are inseparable, since deceased organ donation requires that patients are maintained on invasive life-sustaining support prior to organ procurement. Rather than usurping the position of brain death as a practical concept for use in facilitating organ transplantation, opening up the potential for multiple thresholds of death appears to have the potential to allocate a higher degree of power to families and individuals in designating subjective limits, as well as to reaffirm the ethical value of deceased organ donation.

Several interview participants pointed to potential downsides to a shift in power around the determination of death, suggesting that families do not want to have to decide the point at which to disconnect life support therapies. In these cases, some physicians advocated, it was easier to determine brain death and thus be able to provide families with the information that a concrete and irreversible end point had been reached.

Often times in those situations I think our experience has been that for whatever reason cultural, religious, personal, who knows, individuals like family members of patients often feel that they have an obligation to say, 'do everything.' You know like 'I'm not allowing you to stop the machines, I'm not allowing you to turn

off the whatever', right [...] I think I can generalize and say that when you take the responsibility for making those very, very, heavy decisions off of somebody's family members, they have an obligation to put up a bit of a fight. But in the end, they actually feel relieved that somebody else has made this very difficult decision for them. (Interview #4)

Interestingly, these arguments hark back to the Harvard committee's original reasons for defining the concept of brain death, that of helping grieving families faced with a permanently comatose loved one. More information is needed about the perspectives of families, including whether and when families require assistance with grief and/or desire more control over helping to determine the subjective end of a particular life. Ideally, future research would seek to communicate directly with diverse groups of families about what they desired when faced with these types of situations.

Resistance to the concept of brain death within specific religious communities, such as Orthodox Jewish populations, has led to amendments of legislation in some US States allowing for a modification in the definition of death in the presence of strongly held opposing religious or moral beliefs (Ariane Lewis, Varelas, and Greer 2016b). Arguments against such amendments, as made by the judge in her ruling on the McKitty case, claim that permitting exceptions would result in an overflow of brain-dead bodies in intensive care units and a significant loss of available organs for transplantation. However, requests for exceptions to the determination of brain death have thus far not overwhelmed the health system nor significantly impacted the transplantation industry in "exception states." In addition, it appears that families who do not believe that brain death is the end of human life are not likely to be interested in deceased organ donation

anyway. As one participant pointed out to me, “if the family remains unwilling to accept a diagnosis of death, organ donation is almost never a conversation that they can have. And so, really one begets the other [...] they always sort of travel together,” (Interview #2). Thus, it seems an unlikely argument that permitting families an exception to neurological determination of death would significantly reduce the number of available organs. Nonetheless, merely allowing exceptions may not be sufficient to redistribute who has a say in the declaration of thresholds of death. Physicians in “exception states” continue to hold the power to determine the validity of patients’ moral and religious beliefs, resulting in ambiguity about which beliefs qualify for exceptions, and how these exceptions should be operationalized (Lewis and Pope 2017; Ariane Lewis et al. 2016b; Olick, Braun, and Potash 2009; Smith and Flamm 2011). The approach to permit exceptions to the declaration of death using neurologic criteria has also been criticized as introducing the possibility for legal ambiguities surrounding the timing and mode of death, for example, when the date and time of death are connected to the release of life insurance policies (Ontario Superior Court of Justice 2018a).

Another suggestion for a mode of opening up new possibilities for thresholds of human life is presented by Muramoto (2016), who proposes a policy of obtaining family consent prior to the formal assessment for neurologic criteria for the declaration of death. In this way, the universal endpoints of either circulatory or neurologically determined death remain constant, but families are given the choice between the two. Muramoto proposes that this arrangement could uphold the Uniform Declaration of Death Act and

would prevent development of pluralism in the threshold of death (2016). While I agree that there is certainly a need to improve the counselling and support provided to families prior to any declaration of death, particularly in the context of traumatic deaths, I find that this approach again concentrates too much power in the hands of bedside practitioners. If we are to creatively imagine an ideal scenario it would be one in which subjects are able to participate in advocating for the limits best suited their particular mode(s) of existing and relating. In theory, this could fall anywhere between assisted death (now increasingly legal) and intensive artificial and technical support of the body until cardiocirculatory collapse or bodily decay (an option presently pursued by the very rich through their multi-million-dollar investments in anti-aging research). The task will be to determine a way to ensure that all subjects have the opportunity and economic and social potential to advocate for the thresholds of life that best fit with their ethical capacity to endure.

Conclusions

Thinking through the case presented at the beginning of this chapter with the understanding that the neurological determination of death is materially shaped through social, technical, and historical influences helps to highlight the continued powerful role of scientific medical authority in deciding human death. Ontario courts accepted the scientific medical belief in a neurological threshold of death as indisputable fact, while deciding that the McKitty family's insistence on the presence of remaining life was held to be simply a cultural or religious belief. While the biomedical evidence presented made

logical sense, a consideration of the genealogy of the concept of brain death highlights how “belief” in brain death and “belief” in ongoing bodily life after this state has been established may have more in common than initially thought. In addition, it highlights the discriminatory tone and potential for abuse that the application of the concept of brain death has held throughout its history.

Whether or not Taquisha should have continued to be maintained on ventilators is a moot point, as the appeal judge found, since her heart stopped while she remained on a ventilator on December 31st, 2018. By pursuing the formal legal challenge, the McKitty family was able to achieve their goal of maintaining Taquisha on somatic support technologies until her heart stopped beating. In Taquisha’s case, a sustained belief that brain death did not constitute the end of her life was sufficient enough to delay the moment of bodily demise. On one level, belief in a certain threshold of death may not modify when the physical body inevitably fails, but rather the perception of whether the ethical limits of a subjective self were reached voluntarily, or whether this ending was forcibly orchestrated through the actions of larger and more powerful forces. The difference could mean hours, days, or even a year, as in Taquisha’s case. On another level, permitting differences in belief in the moment of death is about the freedom to determine the inevitable “when” of our thresholds of subjective existence. Perhaps there are those who would prefer to live in a society where these endings are universal and prescribed. Likely those are subjects without any doubt as to their righteous inclusion in the category of “human” (White, male, property-owning, able-bodied). For those with a

shorter or not yet existing history of being included in this category, it seems more likely that power to determine our own limits would be preferable. The ongoing production of new life-sustaining technologies and the capacity for revival of and resuscitation of life, not to mention new technologies of organ transplantation, should be cause enough for continued focus on ethical and open debate of the belief in subjective thresholds of death and what it means to die.

CHAPTER 7 | Collective responsibilities and individual endings: toleration of the other within

It is more or less widely accepted that death is an inevitable endpoint to human life that functions as a definitive limit to the physiological capacities of the human body. However, it is also accepted by most that serious illness, severe disability, even losing all vital signs does not necessarily equate to the permanent loss of life – intensive technologies for saving and sustaining life in many forms are available.²² It is entirely likely that technologies for lifesaving will continue to be developed and that the definitive end point of bodily death will be pushed back even farther. Nevertheless, all sustainable forms of life must include a stage of dying, and how we approach and cross the last thresholds of our existence is an important ethical and political question that requires attention *before* sustained bodily immortality is technologically feasible. We cannot take death for granted – there is too much at stake in this complex process through which the power of life is transposed. Over the past two chapters I have drawn from fieldwork, interviews, and one publicized legal case to analyze two different aspects of the apparatus of the intensive care unit that influence how and when death can occur within present contexts of medical technology: the logic of lifesaving and the

²² A recent newspaper headline reads, *Hiker lost in Mount Rainier whiteout dies in ER – and is brought back to life*. The article describes the case of a 45-year old American outdoorsman whose heart remained inactive for 45 minutes during CPR attempts and was finally revived through extracorporeal membrane oxygenation (ECMO) support (Associated Press 2020). The physician who administered treatments comments, “He died while he was in the ER, which gave us the unique opportunity to try and save his life by basically bypassing his heart and lungs, which is the most advanced form of artificial life support that we have in the world.”

epistemological power involved in defining and registering the moment of death. In this chapter, I return to the intensive care unit and draw from a different set of legal challenges to grapple with a more theoretical exploration of the implications of this work, including how we might ethically approach, acknowledge, and potentially reimagine how and when death can occur amidst advanced life sustaining technologies.

In Chapter 4 I considered cases of what I called denied bodily endings, exemplified by the story of an elderly woman who is admitted to the intensive care unit despite a documented “Do-Not-Resuscitate” order and a “Category Status” form indicating a wish for no invasive therapies. Though this type of case is not typical of the intensive care unit, which more often encounters people who deeply desire to live, it is not altogether uncommon, and highlights the presence of an underlying logic of lifesaving which orients pragmatic and patient-centered decision-making to err towards the side of saving and sustaining life. Patients who express wishes for a desired death run directly counter to logics of lifesaving (especially when life-sustaining technologies are available, and recovery seems likely) and are considered deviant and unable to advocate appropriately for their care. In these types of cases, I observed how the underlying social, technical, and material structures of the intensive care unit embodied through the logic of lifesaving operate to push admitted patients towards the point at which medical innovation has presently reached the feasible end of bodily existence.

Juxtaposed against this story, I presented in Chapter 5 what appears as the opposite case: a young Black woman who appeared to friends and family to be alive, but

whom the technological and clinical apparatus of the intensive care unit deemed as dead. In the McKitty case, the technology and expertise of critical care medicine was mobilized in the form of the determination of death using neurological criteria to establish that Taquisha McKitty no longer had any possibility for regaining meaningful human consciousness. McKitty's family insisted that she would not consider this imposed threshold of death to be valid, but the evidence they presented of Taquisha's movements and her religious belief in the death of the heart was not sufficient to undo the deadly categorizations applied through the authority of medicine and law. The life force of this young Black woman and the opinions and beliefs of her family ran directly counter to judgements about what counts as a "salvageable" human life in the intensive care unit, leading to a court case in which the legal system aided physicians in ultimately pronouncing bodily death. Interviews with intensive care physicians about instances in which brain death is refuted revealed how underlying assumptions about what counts as truth and what gets labelled as merely belief help shape how the logic of lifesaving applies only for certain types of life. In the McKitty case, the fact that Taquisha's body could feasibly be maintained through life-sustaining technologies was not sufficient to justify continued treatment; the scientific medical practice of the intensive care unit determined that she no longer met the conditions for human life.

These two narratives, though different, bring forward fundamental questions inherent in negotiating life and death amidst the technologically sustained thresholds of bodily existence present in the intensive care unit. Rendering these narratives as a

comparison or diffraction of perspectives permits new lines of inquiry to come forward. In the first perspective we are faced with the question: is the human being maintained on machines really *alive* if they are sustained beyond their personal subjective threshold of bodily existence? From the second perspective, the central concern becomes: is the being maintained alive on machines really *human* if they fail the central criteria of consciousness? At the basis of both questions remain persistent concerns with what it means to be alive, what it means to be human, and whether or not these two concepts must always intersect, especially given growing medical and technical capacity to modify assumed traditional definitions of both.

In this chapter I return to observations from the intensive care unit to consider when and how subjects are considered to be alive, and when and how they are considered to be human. From here, I move into an ethical and theoretical consideration of the question of how posthuman, subjective thresholds of bodily existence might be navigated and respected within the contexts of lifesaving technologies. My goal is to imagine a perspective for thinking about the tensions between life and death amidst life-saving technology that relegates neither disability nor death as ultimate end points to be avoided, and one that does not ignore the larger social processes through which certain lives become inherently more valued. I want to contend with what happens to ethical imaginings when we consider living and dying in all forms in cyclical and inseparable relation, rather than as morally opposed states of bodily existence.

To begin, I present fieldwork vignettes to help illustrate the various relations through which patients in the intensive care unit come to be recognized as meeting conditions for aliveness and/or humanness as part of everyday practice. Drawing on Mel Chen's (2012) critical insights around queer animacy and further integrating insights from posthuman theory, I aim to explore how socio-technical relations of the intensive care unit serve to trouble inherent assumptions of purity within categories of alive/dead, and human/non-human. To move forward with ideas of ethical responsibility, I introduce Mary Rawlinson's (2001) suggestion of the figure of pregnancy and Lynn Margulis' (1995; Sagan 1967) theory of symbiogenesis as feminist, posthuman models for imagining an ethical understanding of the thresholds between life and death and what it means to be human, testing out these concepts against limit cases of "posthumous motherhood" (Spike 1999). Further developing Rawlinson's concept of "toleration of the other within," and relating this to Braidotti's Spinoza-inspired theories of Life as unending and un-stoppable force, I explore the implications of understanding states of life and death as intimately relational and ethically inseparable, especially within the contexts of advanced scientific medicine. This chapter concludes with a contribution to the posthuman reimagining of death in technological spaces and a rethinking of collective responsibilities, including how doing so might lead to the creation of more inclusive and sustainable futures.

Life, non-life, and posthuman subjects in intensive care

The patient in bed 3 is receiving hemodialysis today. The machine is comprised of a rounded rectangular prism on wheels, about 4 feet tall, with a color in the same soft blue of medical scrubs. It has a big screen on the top front side, and two plastic cylinders about the width of an arm attached to its body in a vertical orientation below the screen. Thin plastic tubes (smaller than a pinkie finger in diameter) travel about a meter's distance from the machine up under the bedclothes and into the patient's body. Each tube does a loop or two before meeting its connections. The loops of tubing are suspended in mid-air between the machine and the bedside. Dark red blood pulses through them. The tubes vibrate and dance with each of the patient's heartbeats. The patient is also very gently moving their head from side to side, head resting on the pillow. Later, at rounds, the team notes this patient is doing much better and now "tolerating hemodialysis" quite well.

(Fieldnotes, Apr. 3, 2019).

What does it mean to be a living human subject in the intensive care unit, where life can be maintained by machines and most patients do not display characteristics of independence, rationality, and consciousness so celebrated in traditional humanist formulations of Man? In place of the independent human subject, the intensive care unit centres subject positions distributed across technological and social relations. Here, "existence is not an individual affair" (Barad 2007:ix). Subjects are not independent, free-floating and always already formulated positions as Enlightenment philosophy might contend. Instead, positions of subjectivity are relational – the position of the subject is always in relation to one or more others and is something that is sustained and continuously modified through our ongoing, historical, and ever-changing relationships with the world around us (Viveiros de Castro 2015). Specific worlds, certain sociocultural and nature-cultural conditions enable certain subject positions to come into being and to be sustained, while others are ignored or actively suppressed. In the

intensive care unit, patients' bodies and subject positions are sustained and continuously modified through a vast array of interpersonal and material connections which directly challenge the idea of the discrete, universal human subject. Posthuman subjectivities are relational and nomadic, as Braidotti (2006) argues, drawing from the philosophy of Deleuze (1987). Posthuman subjects are not static entities based on affiliation and identity but are instead flexible "becomings" that always have the potential for ongoing change. Finally, posthuman subjectivities are sustained through relationships made possible with other subjects, including nonhuman subjects such as the material and affective environment (Braidotti 2006). The weakening or cutting of these relational ties changes and can destroy the subject. As Deleuze (1987) has argued, cutting relational ties changes the whole composition of relations that the particular severed relation was part of, in the same way that losing a member of a group changes the group as a whole, even if the group itself sustains. For posthuman scholars, then, individual subjective life is a distributed concept, something that is collectively produced and sustained, and something that always has at least two subjective elements, due to the need for a relation. It is a function of having the capacity to enter into life-sustaining connections with other subjects, and the capacity to exercise power in a positive sense as well as to be affected by power in a negative sense.

In the vignette presented above, direct relations with the hemodialysis machine extend the bounds of the subject outside of human skin. The dialysis machine processes human blood and in a way is an extension of the human body – connections between

plastic and skin both enhance the subjective power of this human-machine assemblage by quite literally maintaining life, as well as introduce new forms of subjective vulnerability (Oudshoorn 2016) such as the threat of losing the life-sustaining machine implied by what could happen should the patient's body cease to "tolerate" intervention.

But it is not just the extension of material boundaries that works to trouble the assumed structure of humanist subject positions. In the example provided above, connections to the hemodialysis machine not only physically sustain the patient's life but also modify perceptions of life and aliveness. Here, tubes of blood render the patient's pulse and heartbeat, their literal "lifeblood" or "life force" as a material presence, a reminder of the patient's animacy. Mel Chen (2012) advances queer animacy theory, a mode of considering hierarchies of "aliveness," as an additional perspective for exploring when, how, and why certain bodies or objects are at times considered more "alive" and thus afforded greater degrees of subjective power than others. For Chen, understandings of being "alive" have more to do with social, political, and material forces than they do with more traditional categories of whether or not something breathes or has a heartbeat. Using the example of the 2008 oil spill in the Gulf of Mexico, Chen demonstrates how media attention to an undersea oil well becoming "dead" starkly contrasted with limited attention to the ongoing destruction of human and fish life in poor, racialized fishing communities. For Chen,

This occlusion of life over marginal life speaks, ... to the inadequacy of lifely notions as a framework for governance, medicine, and vernacular affect and makes room for a concept like animacy, which encodes forces without being beholden to failing categories of life and nonlife. ... [A]nimacy permits an even

more thorough registration of the role of racial, geopolitical, affective, and sexualized politics therein. (2012:227)

Animacy as a concept helps to think beyond clear-cut distinctions between alive and dead, or life and non-life, and is a helpful tool for exploring how and where the everyday activities of the intensive care unit produce conditions for rethinking the human. In the intensive care unit, aliveness is not a biological quality inherent within patient bodies but rather occurs in relation to connections with various life sustaining interventions. These connections, in turn, do not necessarily occur in the same way for all subjects – treatments are dependent on the decisions of individual physicians, availability of technology and the expertise required to monitor it, and the capacity of the patient’s body to accept (“tolerate”) or reject treatment.

Thinking through a posthuman perspective of distributed subjectivity, interconnections with non-human others extend the subject’s capacity to act on relations as well as their capacity to be affected by them. The concept of animacy hierarchies allows for consideration of how perceptions of liveliness also influence subjective capacities and relational power, as well as how these perceptions are formed through ongoing interactions of prevailing social conditions of which types of lives, bodies, and liveliness matter. These two concepts allow for a more precise consideration of whether and how categories of alive and dead, and human and non-human are troubled through the everyday practice of intensive care.

Thinking through concepts of distributed subjectivity and animacy hierarchies also helps to illustrate ongoing tensions between categories of alive/dead and

human/nonhuman present in intensive care spaces. The following observation of a patient case provides an example.

The RN at bed 10 is explaining that her patient remains on oxygen therapy. She tells the physicians, “I’m treating the monitor, I’m not treating her... Without oxygen, she goes down to 80,²³ but she’s asymptomatic, I think this is normal for her.” The attending asks the resident taking charge of this case to look at the patient and asks, “Do you believe the monitor, or do you believe the patient? Try not to look at the monitor while you look at the patient.” The resident looks into the room and reports back that the patient “seems fine.”

The RN tells us that the patient wants to go home and is requesting that she be discharged. The fellow says, “I think we can let her go home but I wouldn’t be surprised if she comes right back.” The attending asks, “What amount of O2 is she on at home?” The fellow and the RN respond that this patient is not on any oxygen at home. The attending looks surprised and then recommends they take away the O2. “Let’s de-medicalize her - get everything off, let her have one quiet day and then we can discharge her home first thing in the morning.” The RN shakes her head. She does not think this plan will work, “She’s going. She’s going to sign herself out.”

(Fieldnotes, May 21, 2019).

Similar to the previous example of the hemodialysis machine, this patient’s connections to life-supporting therapies provide both an extension and distribution of her subjective self as well as an indication of relative liveliness. First, connections with the O2 monitor and with the oxygen therapy extend the boundaries of the subject into a format which can be easily measured and monitored by the healthcare team. Indeed, in this case, the extension of the subject through oxygenation levels displayed on the monitor appears at first to be more trustworthy to the nurse than the patient’s verbal and physical expressions. As a result, the nurse explains how she is “treating” the oxygen

²³ Here the RN is referring to a reading on a pulse oximeter device which is estimating a blood oxygen (O2) level at 80%. Average blood oxygen levels in individuals without chronic illness usually range between 95-100%. Readings below 88% are considered abnormally low, even in individuals with chronic disease (Abdo and Heunks 2012).

values on the monitor rather than looking for cues from the patient who seems eerily asymptomatic in comparison. Using the concept of animacy hierarchies, one might say that the numbers displayed on the bedside monitor are perceived by healthcare practitioners to have a higher degree of animacy and liveliness than the expressions of the living, chronically ill patient. Nevertheless, the patient actively subverts this assignment and advocates through her own subjective potential the desire to leave the hospital, which she successfully did less than an hour after this observed interaction.

Whether this is a clinically appropriate approach or not is besides the question here. What is interesting is how perceptions of the liveliness of monitor displays and physiologic values alongside the ability for healthcare workers to act on these extensions of the distributed subject reveal the importance of extra-human relations and connections. In addition, this case draws attention to how subjects can and do actively resist categorizations of animacy. As argued by Chen, such observations point to the “inadequacy of lifely notions” for making decisions (2012:227), as was clearly exemplified by the contradiction between this patient’s dire oxygenation level values and her ability to otherwise “seem fine.” I would also add to this the inadequacy of the traditional idea of the human as a point from which to move forward with decisions, either about individual treatments or on a larger economic or political scale. As demonstrated over and over again in the intensive care unit, the rational, conscious, human subject is an idea imposed through social relations, not an inherent quality of any body. In reality, most critically ill subjects do not fit into this idea of the “normal human,” and

are instead distributed across connections with life support machines, monitors, and relations with healthcare workers and family. As a result, defining human characteristics of individualism and independence become a farce (Clare 2017). Patient futures are determined through the interactions of relative power of various distributed parts, rather than through some centralized, standard source of independent rational control as might be assumed from a traditional humanist perspective.

Observations of the relative liveliness of numbers and machines over human expressions of pain or comfort, rather than pointing to error or inadequacy in intensive care practices, suggest a disutility of the traditional understandings of what it means to be alive, and what it means to be human. The intensive care unit demonstrates that these categories are not equivalent, nor are they imperative to holding subjective power. Rather than setting up systems of evaluation and categorization in which one is alive and through loss of life and humanness (i.e., rationality, consciousness, independence) becomes dead, we need new models for thinking creatively about how both axes of evaluation are flawed. In the next section, I present a novel analysis of a mode of ethical reasoning using the concept of “toleration of the other within,” as a mode of thinking through new relations of liveliness in clinical spaces.

Posthumous reproduction & pregnant ethics

Four years prior to Taquisha McKitty’s overdose, Marlise Muñoz, a young Latina woman, collapsed on her kitchen floor. Muñoz was rushed to hospital but physicians were unable to reverse the systemic damage caused by the blood clot in her lungs, and

she was declared brain dead two days later (Ecker 2014). Marlise's family and her husband Erick were distraught. Marlise had been a paramedic and had made clear to her loved ones that she did not want to be maintained on life sustaining therapies. Newspaper reports and interviews do not specify whether Marlise had agreed with the prevailing medical opinion that loss of consciousness is fundamentally equivalent to human death, only that she had decided and advocated prior to her death that her personal, subjective limit to existence ended at the moment she required permanent connection to life-sustaining machines: she did not want to be maintained in such a state. This clinical case could have ended with the withdrawal of the ventilator and perhaps arrangements for organ donation prior to transportation of her body to the morgue. But relational and material specificities here interrupt the narrative: Marlise was 14 weeks pregnant, and she happened to be declared brain dead in Fort Worth, Texas.

Texas is one of several jurisdictions in the United States with specific legislation outlining that a person's advanced directives about medical care are suspended or considered invalid while they are pregnant (Burkle, Tessmer-Tuck, and Wijdicks 2015). As a result, a person's decision to decline life-sustaining care or to forego life-saving treatments like chemotherapy are considered legally and medically unacceptable if they are pregnant. In line with conservative norms regarding abortion, this type of legislation outlines that a person's right to determine their own thresholds of existence are trumped by the requirement to maintain the life of a fetus. The Muñoz case tested the limits of this law. After learning of the pregnancy, the hospital in which Marlise remained supported

on a ventilator refused to withdraw life-sustaining interventions (Fernandez and Eckholm 2014). Physicians maintained Muñoz's body for two months against her and her family's wishes while Erick brought the case before the state court. For Erick and Marlise's family, the case was fundamentally about, "[Marlise's] wishes not being honoured by the state" (Fernandez and Eckholm 2014). Muñoz's lawyers accused the hospital of conducting a macabre science experiment with Marlise's body (Fernandez and Eckholm 2014). For the hospital and supporting clinicians, the case was about "protecting the unborn child against the wishes of a decision maker" (Ecker 2014). And for some commentators in the media, the biggest concern came down to who should pay for the exorbitant costs associated with maintaining an undesired post-mortem pregnancy and caring for the resulting infant, who was likely to be born premature and possibly disabled (Solomon 2014; Wickline 2014). The Muñoz family eventually won their court case, and Marlise's physicians were ordered to remove organ support in January 2014. Both the court and the family agreed that Marlise was brain dead, and the judge ruled that prohibitions about restricting life-sustaining treatments during pregnancy could not apply to someone who was already legally dead (Lavandera, Rubin, and Botelho 2014).

This case provides just one example of rare but possible situations in which brain-dead people are maintained on life-support for the purposes of sustaining a pregnancy (Breitwieser 2019; Pikto-Pietkiewicz et al. 2019; Spike 1999). During the same time in which Marlise Muñoz was maintained in a Texas hospital bed, a young, White, pregnant woman named Robyn Benson was declared brain dead in Victoria, British Columbia

(CBC News 2014). In the Canadian case, Benson's partner Dylan advocated for her to be maintained on ventilator support until the baby was born, a request with which the hospital complied. In contrast to the Muñoz case, the Benson case involved no legal disputes and no public conversations about the cost of medical care or science experiments gone awry. The media instead reported touching accounts of how Dylan's community rallied in his support while he simultaneously mourned his wife and prepared for his new child (CBC News 2014).

The juxtaposition of these two cases of pregnancy in brain death demonstrate the complex nature of posthumous reproduction, which Hashiloni-Dolev and Schicktanztz (2017) define as, "the intentional application of advanced medical technologies to achieve conception, pregnancy and childbirth in a situation where one or both parents is declared dead." As these two cases exemplify, posthumous reproduction can take on different meanings depending on medical, legal, and social contexts and on the specific desires of the actors involved (Burkle et al. 2015; Hashiloni-Dolev and Schicktanztz 2017). In some American states, local guidelines explicitly prohibit declaration of brain death in pregnant patients in instances where a "fetus can be preserved," but in most cases specific guidance about these types of situations is ambivalent or missing altogether (Ariane Lewis, Varelas, and Greer 2016a). Posthumous pregnancy completely blurs physiologic boundaries between life and death and disrupts the prevailing medico-legal narrative asserting that a permanent absence of consciousness infers an absence of any meaningful functions or future potential for the human body (Bernat 2019). Posthumous pregnancy

also disrupts any remaining vestiges of a “natural” separation between life and death in the contexts of advanced medical technologies against which moral decisions might be made, and troubles reliance on a medical “standard of care.” Posthumous pregnancies must be sustained through active, attentive, intensive, full-time organ-support therapies required for both pregnant person and fetus (Pikto-Pietkiewicz et al. 2019). Maintaining pregnancy in irreversibly unconscious, certifiably brain-dead people is an entirely intentionally technologically supported endeavour that nevertheless leads quite literally, when successful, to the emergence of new life forms.

Pregnancy as a model for ethical relations of life and death

Rather than brush posthumous pregnancy aside as a rare exception or uncommon inconsistency to the concept of brain death, I wish to consider on a theoretical level how the pregnant and brain-dead person might serve as a model for rethinking and reimagining ethical responsibilities surrounding human death and disability in the contexts of technology. I am aided in this undertaking by philosopher Mary Rawlinson, who in a 2001 paper in the *Journal of Medicine and Philosophy* suggests the figure of pregnancy as a new possibility for thinking about ethical relations. Rawlinson draws on the feminist ethics of Irigaray (1996, 1997) to suggest how pregnancy, as “toleration of the other within,” can provide a framework for ethical relations (2001:413). She explains how pregnancy, “...is a relation which has as its aim neither mastery, nor reduction of the other to the same. The mother, rather, cultivates the difference of the other and delivers

the other into its own independence” (Rawlinson 2001:413). Toleration of the other within is a recognition of intimate connection and relation despite and across pain, hardship, and difference. It is a relation with a logic not of *salvation* or savior to some imagined state of “normal,” but rather one of *liberation* in which the other is supported and tolerated so that they might reach their full subjective potential, whatever that might turn out to be.

Rawlinson does not provide much further flesh to this image, leaving unexplored the tensions and aberrations of pregnant relations such as when people are made to sustain or end pregnant relations against their will. I also see the need for a queer, posthuman reconfiguration of this image, one in which the physical and emotional work of gestation and the work of “mothering” are not always connected, and in which people who are pregnant are not always women, not always “human” in the traditional humanist sense, and perhaps not always lively in the ways we might assume life to be (Green and Lee Pelletier 2015). From a posthuman perspective,

Pregnancy is between an act and a state, it is conscious and unconscious within an intimate involvement with the world to come. *Being with* child is being with the always not-yet of the world. It is the search for the world after the promise of engagement, after the affirmative choice for the world. (van der Waal 2018:369, emphasis in original)

From this perspective, toleration of the other includes an ongoing choice for engagement despite the absence of knowledge of what is to come. As van der Waal notes, toleration of the other as the act/state of pregnancy includes both an active choosing as well as an ongoing acceptance of states of intimate involvement. Further, any ethical

model of pregnancy must contend with the fact that this embodied relationship always occurs within a social, political, and temporal context in which certain lives are made out to be more desirable at specific times and in specific places than others.²⁴

Inserting these additional nuances to the affective and relational aspects of pregnancy helps to expand the potential of this ethical figure and to imagine how many different types of actors can be involved in supporting or troubling relationships of “toleration of the other within.” The act/state of pregnancy confirms that caring and growing for/with the Other is possible despite difference, while at the same time never devoid of affect and often host to conflicting desires (Ellis, Wojnar, and Pettinato 2015). The mapping of this ethical model onto situations of death and dying in the intensive care unit is not meant to be a literal translation, I am not suggesting that all dying patients are somehow pregnant. Instead, I introduce the ethics of embodied pregnancy as conceptual framework that can help to elucidate ethical issues and highlight power dynamics beyond more mainstream bioethical perspectives of the individual rational human subject that ceases to exist or to be alive with the end of consciousness.

Using this concept of “toleration of the other within” to think through the ethical dilemmas of death in the intensive care unit could take on multiple forms. We could imagine the life-sustaining therapies that sustain patients’ bodies and provide signs of life as akin to the material, physiological structures and connections that link pregnant person

²⁴ For a recent and vivid example, see Bui et al.’s powerful piece on the effects of Texas governor Greg Abbott’s temporary suspension of abortion access during the COVID-19 pandemic (Bui, Pike, and Mirk 2020).

to developing fetus. This would position the intricate apparatus of the intensive care unit as complex, distributed, nonhuman actor with some degree of ethical responsibility towards sustaining and eventually liberating the potential, as opposed to saving the body of the dependent, disabled patient. Within a model of toleration of the other within, the aim of the intensive care unit is not “cure” or salvation of perceived disability to return some standard of “normal,” nor is it mastery over death such that this undesirable “other” state of being cannot occur. Instead, toleration requires relations of care and communication to understand the subject’s desires and then making careful steps towards liberation in that direction – whether that is facilitating extended intensive care support or a dignified death.

The figure of pregnancy enables some ethical consideration of affective desires inherent in the apparatus of the intensive care unit when sustaining patients’ bodies. Pregnancy as an act/state involves becoming other than the self; in entering into physical connection with the other, the boundaries, desires, and identities of the self are modified (Shanner 1998; van der Waal 2018). Some existing mechanisms of action of affective relations of the intensive care unit appear to include the medical-industrial logic of lifesaving, as discussed in Chapter 5, and maintaining the epistemological authority of assigning declarations of death, as discussed in Chapter 6. The culture of the intensive care unit also includes healthcare worker’s desires for professional prestige, after all, this is the location of “cutting edge” medical practice. These objectives can be in conflict with patients who have expressed desires to live despite being assigned as dead, or who desire

to end life sustaining therapies and heroic intervention against medical advice. Clinical signs of liveliness and subjective patient perceptions of feeling well or unwell can also be in conflict, as explored earlier through the vignette of the chronically ill woman with low oxygen.

An ethical model of toleration of the other within might call for consideration of potentially conflicting professional objectives alongside and in relation to patient desires, as well as the broader contexts which bring these desires into being. For example, this might include contemplation of pharmaceutical and device manufacturing industries positioned to acquire financial gains from sustaining life at all cost, staffing restrictions due to funding shortages, the patient's potential eligibility for ground-breaking clinical trial participation, and other issues influencing relations between patients and the apparatus of the intensive care unit. In addition, it should consider how certain aspects of material care and particular forms of social relation emphasize elements of liveliness (or its opposite). Ethical critique seeking to situate modes of toleration of the other within would need to consider the role and social context of the medical-technical network that is the intensive care unit, and not only individual situations of care providers and patients involved.

Cases of posthumous reproduction trouble any simple application of this model of "toleration of the other within" by introducing a question vital to the intensive care unit: What happens to the pregnant person-fetal relationship when one party is considered legally dead? Should a determination of death shift the balance of power of ethical

consideration such that one party's objectives would take precedent? Cases of brain-dead motherhood, like instances of fetal death and anencephaly,²⁵ demonstrate that the relationship between pregnant person and fetus can be physically and emotionally maintained in the absence of measurably conscious, rationally integrated humanist life. Similarly, patients in the intensive care unit can be technologically maintained after death, a strategy which helps to facilitate end of life rituals and medical practices such as organ donation. Given these technical and medical capacities, what is the responsibility of the pregnant person to continue to sustain and support a fetus that has died? Or, the reverse, what are the conditions in which brain dead or otherwise unconscious pregnant people are required to support a fetus?

The determination of death of either pregnant person or fetus appears presently to displace the ethical viewpoint of pregnancy as an ongoing and transcendent relationship in favor of reversion to privileged individual autonomy and rational consciousness (Farragher and Laffey 2005). Whether it is the presumed autonomy of the fetus or the mother that is privileged appears to depend on perspective. For example, some pregnant people who learn that their fetus has died feel compelled to carry the pregnancy to term, and consider the stillborn baby a member of the family (Yamazaki 2010). Others desire abortion as soon as possible, which can require navigation of financial and administrative

²⁵ A neural tube defect in which the fetus does not develop a cerebral cortex or full scalp, in other words, is missing most of the brain. Some have claimed that this state is morally equivalent to brain death (Truog and Fletcher 1990).

hurdles²⁶ in regions with restrictive abortion laws (Levin 2019). As comparison of the Benson and Muñoz cases demonstrates, decisions about whether to maintain or terminate a posthumous pregnancy can vary depending on whether the relative moral value of pregnant person or fetus is leveraged. Imposing mainstream, humanist ethics and moral values overlooks the idea that pregnancy involves a transcendent relationship between subjects whose ethical boundaries of tolerance are not standardized (Braidotti 2006:242–43).

The application of a feminist perspective of embodied “toleration of the other within” invites consideration of the tangled and affective relationship(s) of pregnancy beyond a focus solely on individual rational actors. That the pregnant, material, ethical relationship of toleration and support of bodily difference (not to mention ongoing circulation of fluids, nutrients, and affect) persists between “dead” and “live” bodies provides reason to pause. Despite our social and cultural perceptions of an irreconcilable and recognisable gap between states of deadness and aliveness, we have evidence of a relationship of care and material support maintained beyond accepted categorizations of death (with sufficient invasive and continuous technological and medical intervention). Such cases seem to provide evidence for the “toleration within” of death within life – the possibility of a lower position on the animacy hierarchy that is present within all subjects, depending on perspective and available technical and social supports (Chen 2012).

²⁶ In some places in the United States, women have been prosecuted with criminal charges for delivering stillborn babies, with the legal and moral assumption that they should have somehow prevented what is a tragic and unpredictable event (The Editorial Board 2018).

Returning to the context of the intensive care unit, foregrounding the continued ethical relationship between pregnant person and fetus despite categorizations of death places a renewed focus on the need to consider the deliberate decision-making that is always involved in bringing this relationship to an end. Instead of an obvious and universal point at which life ends or liveliness ceases, the model of posthumous pregnant embodiment shows us that relationships of ongoing life and “intimate involvement with the world to come” can continue in situations of technologically supported bodily death (i.e., brain death) unless a deliberate decision to terminate supportive relational connections is made. Further, this framework highlights how such decisions about terminations, as with the case of abortion, are socially and culturally contextual and require ethical considerations that take into account available possibilities for action within these relational and embodied states.

An immediately obvious critique of using the framework of posthumous pregnancy to argue that relationships of life can be sustained through death is that pregnancy has a pre-determined temporal duration. There is a loosely defined physiologic point at 9 months post-conception after which the relationship of human pregnancy comes to an end. But a posthuman, post-anthropocentric position might consider how 9 months is hardly the norm, with mammalian gestation ranging from less than 20 days in small rodents to over a year and a half for African elephants. Thinking beyond or outside of the relatively small family of mammals, one might also consider how sexual reproduction through spores can permit the perpetuation of life across large expanses of

space and time. These non-human examples provide potential conceptual models for expanding the possibilities for tolerating, or living with death within life for longer periods of time and through different relational patterns than the more circumscribed instance of human pregnancy. Current research into the mechanics of cryopreservation (e.g., preserving the body and/or brain of a deceased person for future revival) renders this sci-fi comparison with pregnancy closer to “science fact” than one might think. A video promoted on the main website of Alcor Life Extension Foundation (a cryonics company funded by billionaires), suggests that, “cryonics is, in fact, simply an extension of critical care medicine” (Alcor 2020). The increasingly non-human technological capacity to sustain, maintain, store, and revive human bodies beyond accepted thresholds of death calls for deliberate thinking about relations of reproduction, life, and death that go beyond the narrow limits of humanist traditions.

Symbiogenesis and coevolution as models for ethical relations of life and death

Evolutionary biologist Lynn Margulis provides one such opportunity for stepping outside of anthropocentric perspectives in her discussions of symbiogenesis (1995). Margulis upended the field of evolutionary biology by producing evidence that certain structures of animal cells (mitochondria) emerged not as inherent parts of the animal but as free and separate living entities that were taken up at some point in history by animal cells in a symbiotic relationship (Lazcano and Peretó 2017; Sagan 1967). On a conceptual level, Margulis’ findings underscored that instead of thinking about the development of

life through narratives of competition and domination, we would do better to explore how life as we know it has prevailed through processes of cooperation and mutual development. Like the idea of “toleration of the other within”, models of symbiogenesis insist on a recognition of the mutual co-constitution, rather than individual domination, of self and other.

Margulis’ work also presents another point which helps to bridge concepts of death and pregnancy, which is that death and sexual reproduction, rather than disparate events, formed through a process of coevolution (1995). Sexual reproduction, which involves a special cellular process for propagating genetic material, requires as a consequence that animal cells have limits to the number of times they can successfully replicate. As a result, death, along with sex, is an evolutionary strategy that has helped animal cells and multicellular beings to rearrange into many creative and highly successful forms (Margulis and Sagan 1995:137). Death and sexual reproduction are intricately connected – the death of one cell or one organism may occur as a direct result of genetic material being passed on to a new generation.²⁷ But this death is only death from one perspective – the genetics of the individual can continue into the future through offspring which are at once self and other. Likewise, the materials that make up the body do not suddenly vanish – they are broken down, reused, and reformed into new creatures, new bodies, and new possibilities in the ongoing endless cycle of the biosphere. The possibility of continuity of life through death has been recognized for millennia within

²⁷ Explicit recognition of the connection between death and sexual reproduction is also present in some social rituals surrounding death, for example, in Hindu traditions as outlined by Green (2008:36–39)

ritual death practices in many cultures. For example, the ritual burning of the deceased on the banks of the Ganges river in Varanasi represents an important and celebrated moment of transformation in the energies of the universe rather than an individual loss (Green 2008:36–38).

There are theoretical connections here with Rosi Braidotti's philosophical proposal that death is not always an ending but can also be thought of as a new beginning into something otherwise, an opening for the continuation of Life itself (2006). Theories of symbiogenesis and death as evolutionary strategy render death as ultimate ending of an individual subjective life as an entirely cultural and political event, rather than a biological reality. Human death involves considerations of what constitutes a body and what constitutes the end of that instance of that body – two conceptual points which are politically and culturally determined. Our desire to fix the moment of human death as a “natural” or purely “biological” phenomenon only serves to do away with the need to confront the always embedded cultural and political values through which we allow death to occur.

Death for nomadic, collective, multi-cellular animals is built into our very materiality – over the course of a week, it is normal for many cells in our bodies to die. This process allows new cells to form. On a social level, it is reasonable to expect that intimate interpersonal connections with other subjects will change or cease to exist, allowing new modes of relation and intersubjective connections to issue forth. The failure of this process of programmed death at a cellular level results in catastrophic disease such

as cancer and autoimmune disorders (Robertson, LaCasse, and Holcik 2009). On a social level, inability to let go of personal connections or to process emotional attachments can lead to neuroses and anxieties. Death as an expected threshold of ending is part of our lives; it is one of the many nonhuman “others” that we must nurture within ourselves and tolerate within society if we are to flourish. Complete elimination of this process is neither desirable nor advantageous. Indeed, attempts to stall or foreclose possibilities for transformative change and transcendent becomings have been criticized as symptoms of a capitalist ideology intent on accumulation of wealth and material resources (Deleuze and Guattari 1977, 1987). In refusal of a concordant practice of hoarding and prolonging life, posthuman subjects can learn to live in mutual relationship with death as the other in new and creative ways, acknowledging that the ultimate end point, though unavoidable, may be quite different from what we imagined.

Thinking through these figurations of pregnancy and symbiogenesis allows for a conceptual reimagining of the process of dying as an embodied practice of negotiating a relationship with “the other within,” the death that is already always occurring as part of life. The project of a life well lived involves navigating an intricate balance between processes of life and death. At first this appears wholly abstract, until one considers the socially acceptable process of becoming completely unconscious at least once daily as part of the normal practice of sleeping. The commitment to eventually waking up again is what Braidotti (2006) refers to as an “addiction to life,” something that is innately present for some but a task that others must work at. Rather than positioning death as a once-in-a-

lifetime event to be avoided at all costs, a perspective of embodied dying that is informed by physiological models of symbiogenesis and programmed cell death can appreciate bodily ending as an ongoing, negotiated process that occurs at different speeds and qualities for different subjects in different contexts. Instead of Bauman's (2013) deconstructed mortality or everyday immortality, this perspective does not consider the death of the human as always inherently terrible or undesirable. Instead, balancing the threshold between life and death is an ongoing task and a collective responsibility for all living posthuman subjects.

Thinking about death through the figure of pregnancy provides an additional focus on the social and political contexts in which this act/state is always negotiated. Certainly, each subject encounters a personal threshold of life and death, but the social and material environment in which this intimate relationship is sustained or denied is an important part of the context required for ethical decision making. Subjects learn the everyday practice of living and dying based on the norms, expectations, and resources that surround them. Thus, attention to the social processes which render certain lives or certain types of life more desirable or salvageable than others are required, while still respecting the immediate specific personal limits through which subjects negotiate relational boundaries between states of living and dying. Present focus on whether individual decisions about the moment of death are morally correct takes away from a broader, relational view of how any specific threshold of death is negotiated against a historically contingent process of embodied dying.

The ethical approach that I have described, one of affirmation and respect for the relational and embodied practice of dying, includes a respect for interdependent yet personal ethical limits along with a strong focus on the contexts in which the final threshold of death is encountered. This position stems from a belief that it is not ethically possible to choose thresholds of acceptability for other subjects. The moment of, “*I can’t take it anymore!*” is ultimately determined by each relational subject in each specific context (Braidotti 2006). In order to repudiate an apathetic relativism, this ethical position also insists on an awareness and accountability to how social and environmental contexts inherently shape the contours of individual limits. Subjects do not maintain their addiction to life, or their process of embodied dying, in isolation, but rather through the cultivation of meaningful relationships and within contexts in which certain materials and certain subjects are perceived as more “lively” than others (Chen 2012). As a result, ethical responsibility lies in building and sustaining meaningful relationships with others along with fostering political and social climates for flourishing. In other words, ethical responsibility to life requires broader projects of anti-oppression in all forms. Ethical responsibility also requires interrogating how and why particular subjects reach their limits of existence in different ways. Instead of assuming that the desire to live forever is the most rational aspiration, this ethical approach of respected, embodied, subjectively determined living and dying aspires to achieve sustainable states of interconnection and toleration which promote positive potentials of all subjects in a way in which lives can be lived well in many configurations.

Toleration of the other within – rethinking ethical approaches to life, death, and technology

What happens to the intensive care unit when we no longer locate death or disability as enemies to be avoided? What happens to the logic of lifesaving and the medical power to define the moment of death when we fundamentally rethink our relationships to life and death? What types of futures are produced by an ethical approach that positions death and disability as integral, valuable parts of lives lived well?

Revising the assumption that death and disability are inherently undesirable has repercussions for the practice of medicine. In the intensive care unit, an approach which upholds toleration and acceptance of death and disability upends the logic of lifesaving which seeks to save and return patients to an imagined “normal,” and instead focuses on how material and affective connections of lifesaving transform patients’ lives into radical interdependence. The ethical focus here is not on arbitrary quality of life assessments but on understanding the limits and capacities of existence desired by patients. Similarly, the traditional authority of medicine to apprehend and define the moment of death is replaced by a respect for patients’ desired thresholds of bodily endings. Instead of saving lives and delineating the moment of death, the practice of intensive care becomes one of deliberate and careful stewardship around which types of life are technically and clinically possible, determining subjects’ preferred thresholds of existence, and finding ways to honor and respect different choices.

This ethical approach seeks to redistribute power in a technologically intensive part of the medical system in which the arbitrary limits of acceptable life and allowable death remain veiled. Modern intensive care units already have the capacity to suspend and animate bodies beyond imagined limits of “natural” human life. What I am proposing is that both medical practice and patients become accountable in the decisions to continue or circumscribe life, as well as the broader social, political, and legal conditions which make these decisions necessary.

I want to return to the case of Marlise Muñoz, brain dead, pregnant. A mainstream, humanist bioethics approach might compare the individual claims to autonomy of mother and fetus, weighing the fetal right to life against Muñoz’s right to make informed advanced treatment decisions about her body (Aas 2020; Burkle et al. 2015; Persad 2019). Physicians might argue that treatment focused on the still “salvageable” fetus is required due to a professional obligation for saving lives (Farragher and Laffey 2005; Paola 2015). Neither approach accounts for how the material and affective relationship of pregnancy – the act/state of embodied caring and toleration required in order to produce and deliver new life into its own subjective interdependence – is inherently complicated by changes in states of liveliness, nor how this embodied relationship came to be so drastically interrupted in the first place.

A posthuman ethics focused on foregrounding relationships, respecting subjective ethical limits of existence, and critical analysis of slippages between perceptions of alive and dead might consider the continued connection between mother and fetus as evidence

of intent to persist against the pre-stated desire of Muñoz not to be “kept alive on machines.” But it would also take a step back to consider the contexts of the situation in which Muñoz ended up in the intensive care unit, the social circumstances in which she articulated her personal threshold of existence to friends and family, and the opportunities for fulfillment of potential for the baby once it was born. This analysis would identify how Black and Latina women are much more likely than White women in the United States to suffer complications during pregnancy, such as the blood clot which killed Muñoz (Bornstein et al. 2020; Hirshberg and Srinivas 2017). It would consider that private healthcare insurance in a country without universal healthcare might not cover the expenses of continued life support needed to bring the pregnancy to term, and that widowed Erick was already in the socially marginalized position of single parent (the couple had an existing 2-year-old child). It would explore further the ableist arguments made on both sides of the dispute that the fetus was “not viable.” It would take into account the costly and invasive technologies and ongoing medical attention required to manage a successful posthumous pregnancy. This ethical position considers lifesaving technologies and the expertise present in the intensive care unit not as neutral resources to be employed on bodies but as part of the very conditions that make manipulation of the life/death threshold possible. Finally, this position would analyze the subjective ethical threshold which Muñoz had expressed, not with the intent to make moral judgements but rather to explore how different subjective limits are products of social relations.

Where a standard bioethics approach might help to inform the moral nuance of a discrete decision, this affirmative, embodied, and relational perspective takes a broad and future-oriented position. Toleration of the other within, in this instance, becomes a concept allowing for medical acceptance of Muñoz's death despite her pregnancy. This is a difficult position for healthcare providers who are capable of supporting the pregnancy to viability. Permitting death goes against the logic of lifesaving since "saving" the fetus is medically and technically possible. Toleration of the other within requires acknowledgement that death is not always undesirable, and that it is not a finite ultimate endpoint but a greater part of sustainable, collective life and thus an imperative component of medical practice. Leaving the personal decision about whether or not to continue a posthumous pregnancy up to Muñoz (in this case represented by the people in her life who knew her best), this analysis considers the social and political contexts in which this decision became possible and necessary in the first place. In particular, the power imbalances which shape how individuals come to determine personal ethical thresholds of life. A posthuman ethics helps to outline how a move away from consideration of the figure of the rational individual and application of moral principles can better account for the configurations of power that shape individual endings.

Centering death and disability as parts of sustainable life removes them from the position of being in opposition to life, and thus makes them viable options for a caring practice of medicine, rather than an enemy to be thwarted or an evil to be "cured." When death and disability are no longer oriented as in opposition to life and thus as unwanted,

and when medicine is imagined as a practice that centers patient liberation to difference rather than salvation to sameness, the intensive care unit emerges as a site of important negotiation of relational responsibilities of aliveness and deadness, rather than one solely for heroic lifesaving or application of standardized practice. Acceptance of death and of disability as parts of life to be respected and tolerated might help to shift the focus of medical intervention from one of saving idealized normal human lives to one of enabling lives well lived, and of respecting subjects' desired thresholds of death, in whichever forms they arrive.

An approach which views the embodied practice of dying as an inevitable but personal threshold does not conceive of death as an inherent moral wrong. Instead, it investigates instances in which this threshold is resisted or enforced as moments indicating unequal social power imbalances. A version of utopia involves at every death the understanding that each life, however long and however lived, was lived well. Unfortunately, in the present world, undue and unfair influences abound, and an ethical position of embodied dying must be wary of supporting or encouraging death in ongoing conditions of unequal access and unequally valued lives. A posthuman ethics seeks to first locate these instances of resistance and imbalance and to understand how broader disparities in power impact our capacities for coming to terms with a life well lived.

In the intensive care unit, such an approach requires a broader consideration of the social patterns that drive admissions, and critical reflection of how and for whom medical standards are derived. The perspective of posthuman ethics helps to underscore how

medico-technical spaces such as the intensive care unit provide the location in which it becomes possible to question and contend with thresholds of death in the first place. This implicates the designers, builders, and users of lifesaving technology as ethical actors in a larger practice of tinkering with boundaries of life and death. It also suggests that advanced technologies such as magnetic-resonance imaging and deep brain stimulation might be used not only to stave off dying and impose cure but also to enhance communication with those in unconscious states so that we may ascertain subjective wishes (Owen et al. 2006). Finally, on an individual level, this novel approach involves careful attention to the subjective desires of patients and the social and political environments that shape and sustain addictions to life.

Based on the relational idea of pregnancy, which has as its aim not salvation to a life of the same but rather embodied toleration with the aim of delivery unto unknowable difference, and grounded in an understanding of death as biological innovation, a posthuman ethical approach seeks to imagine death not as an absolute loss or ending of the rational subject but as a relational project and a subjective choice. Further, this perspective does away with the exclusive category of the human and takes as a starting point the reality of subjective interdependence. How each subject navigates their intricate involvement with death as “the other within” is as intimate and affectively charged as how a pregnant person forms a relationship with a fetus over time. It is at once both deeply personal and intimately related to broader social, economic, and cultural contexts. The goal of a posthuman ethics approach is to account for these personal subjective

thresholds of existence and to consider how they are both shaped by and act on larger social structures, such as the lifesaving technologies of the intensive care unit.

Conclusions

In this chapter, I have considered the interconnections and analyzed the ethical and political repercussions of taking seriously the everyday tensions between life and death as observed in the intensive care unit. I have taken up Haraway's (2016) methodological advice to "stay with the trouble," returning to difficult cases such as that of pregnancy in brain death and the accompanying uneasy feelings inspired by accusations of futile care, enforced intervention, and circumscribed vitality (Breitwieser 2019). In this chapter I have demonstrated how patient subjects in the intensive care unit trouble both categories of humanness and aliveness, and I have then grappled with the pervasive tension of how to let life go despite the capacity to sustain. I have built on Braidotti's (2006) concept of subjective ethical thresholds to imagine how technology and medical practice could convene to focus on the particular identification of these thresholds, rather than their presumption. The figure of the brain-dead pregnant person helps to illustrate the ethical potentials of imagining death in this way. I have also cautioned against universal acceptance of subjective thresholds of death in the absence of honest and in-depth interrogation of the broader social, economic, and political power imbalances in which the values of life and liveliness are made real.

In this discussion, I have been interested in going beyond normative expressions of the "good death" or the "scientifically valid" death to explore how thinking beyond or

outside of the bounded human subject might allow for new creative figurations that open up possibilities for living and dying. Understanding existence as relational subjectivity changes how we understand death. Making a broader perceptual shift away from humanistic individualism requires accounting for the material implications and possibilities already enacted in everyday practices of living and dying.

CHAPTER 8 | Conclusion

Spaces of life sustaining therapies hold the possibility for preserving and transforming lives alongside the epistemological and material power to dictate life and death. As I have explored, this unique configuration results in complex paradoxes: people maintained alive despite desiring to die, people declared dead who are not acknowledged by their families as having died for months afterwards, and healthcare workers tasked with the difficult role of “saving” patients through transforming the very limits of patients’ subjective selves. While it might seem like an admirable goal to employ advanced life sustaining therapies to eliminate the need for human death, a closer look reveals how distinctions between life and death may be both more necessary and more complicated than an assumed natural or socially constructed transition would have us believe. How these distinctions are made, reshaped, and resisted is a concern of increasing importance as the quest for immortality continues to gain powerful investors.²⁸

In this project I have taken a unique approach to studying how boundaries between life and death are made in spaces of advanced life sustaining possibilities. Using ethnographic methods and concepts from feminist new materialism and founded on an in-

²⁸ Hedge fund managers and tech company billionaires— those with money to last more than a lifetime — continue to invest heavily into anti-aging research and life-extension technologies (Warner 2018). Examples include The Breakthrough Prize in Life Sciences, a \$3 million prize for discoveries that extend human life funded by Mark Zuckerberg (Facebook), Priscilla Chan (Facebook), Sergey Brin (Google), Yuri Milner (tech venture capitalist), and Anne Wojciki (23andMe); the anti-aging drug company Unity Biotechnology backed by Jeff Bezos (Amazon) and Peter Thiel (PayPal); the SENS research foundation for anti-aging, with substantial contributions from Peter Thiel (PayPal) along with other Silicon Valley CEOs; and Calico Labs, an anti-aging research subsidiary of Google. Much of this research is aimed at developing consumer products to extend the lives of individual bodies.

depth understanding of posthuman theory, this work contributes novel analyses of how death happens, and how our perceptions of it could be different. I contrasted cases of patients who were denied their deaths and sustained on technologies beyond their limits with those of individuals declared as dead against their beliefs. A final analysis of cases of people who continue to produce life through pregnancy despite being categorized as dead helps to reconfigure assumptions about life, death, and life sustaining technologies into a new understanding of how bodily endings, alongside perceptions of liveliness, are always a product of ongoing social and technical relations. Specifically, I suggest that life sustaining technologies and their extended capacity to maintain vitality allow us to appreciate how death is already always a part of life, a perhaps unwanted “other” that we can learn to tolerate and accept, a personal ethical threshold of existence with the potential to transport us into different futures. I build on the concept of toleration of the other within, initially used to think about pregnancy, as a secular model for imagining how our bodily endings are a relational aspect of our subjective selves.

Observing and reimagining death amidst technology

Where previous work has sought to study death through a focus on cultural factors (e.g., anthropological work on rituals of death and dying), poststructuralism (e.g., theoretical work on biopower, necropolitics), or social constructivism (e.g., sociological inquiry focused on technologies of life and death), my work has taken a different tack. Through a combination of my existing position as a medical researcher working on projects of death and dying in the intensive care unit, a close reading of theories of

posthumanism, and methodological concepts borrowed from feminist new materialist scholars, I described the practical aspects of death amidst technology alongside ongoing philosophical reflection on the diffractions between death as a conceptual state, and death of the human subject as a particular symbolic and social event.

The focus of my work has been the intensive care unit, a specific location in the hospital in which the boundaries of life and death are materially enacted in everyday clinical practice (Hadders 2009). As I described in detail in Chapter 3, modes of caring and relating in the intensive care unit emerged from a particular history of social, technical, and medical advances, and are largely built upon the power and unfolding possibilities of cutting-edge scientific medicine. The diagnostic revolution, for example, saw the movement of power to know the body away from individual patients and into the hands and diagnostic tools of medical practitioners through the development of the clinical gaze (Foucault 1973). The intensive care unit, I argued, represents one particular form of the continued concentration of this power culminating in the intensive gaze, an intensive care physician's current ability to access intimate knowledge of bodies without even having to be in the same room as patients. Far from painting these highly specialized professionals as somehow untrustworthy or uncaring, I have been concerned in my analysis to consider how it is overarching cultural, social, and material structures that shape the way that medicine is practiced and how death is defined in highly technical, clinical spaces.

My explorations of the ways in which medicine operates in intensive care units are founded on an original methodological approach. Seeking to move beyond the confines of traditional anthropological ethnography and Actor Network Theory, I turned to the materialist work of Barad (2007) and Viveiros de Castro (2015), as described in Chapter 4. At the core of both scholars' foundational work on social science methods is a commitment to seeing things differently. For Barad, this is exemplified through her methodological concept of diffraction, the process of thinking concepts and observations through each other, rather than accepting at face value and merely reflecting on or about what already exists. In Viveiros de Castro's work, seeing differently is embodied through his concept of perspectivism, the idea that observation is based on relation, and that the same phenomena can be different depending on where one is standing. Both scholars refuse positivist assumptions of an objective and universal truth, instead insisting on the need for grounded and responsible accounting for the social and material aspects permitting phenomena to occur in a specific time and place. I found this approach particularly useful for studying the contours of life and death amongst life sustaining technology as it insists on foregrounding the processes through which certain configurations of reality become "thinkable" while others remain unspoken or unimagined. Describing and exploring these processes then permits an applied ethical reckoning as questions arise regarding which realities should be taken seriously, and what can be done to encourage the emergence of different worlds and futures.

A driving concern within this project has been my curiosity to employ applied qualitative research methods such as ethnographic observation and secondary data analysis of semi-structured interviews to pursue difficult questions about death. For example, is death ever acceptable? If yes, how, when, and for whom? Could death ever be desirable? To what extent should individuals be able to determine their own bodily endings? Throughout my work, I have made a point to frame my analyses as applied ethical questions concerned with what we should do and how we should act in the contexts of ongoing uncertainty and against a background of continuing social oppression and inequality.

What and when is death?

What is death and how do we know when it occurs? This dissertation has demonstrated how the answer to this question is neither straightforward nor stable over time, an observation in line with other social science work surrounding human death (Green 2008; Lock 2002). In keeping with the objective aims of scientific medicine, establishment and negotiation of human death in advanced capitalist societies has become dependent on the implementation of medical technologies. But it has also become dependent on a particular entrenched idea of what it means to be a living human. Attempting to think outside of this category, as I have done throughout this project, leads to novel ways of considering what it might mean to die. One such argument stemming from a posthuman perspective in which people are interconnected subjects is that death is a unique form of social relation, a negotiated but subjective limit that occurs when

subjects reach the boundaries of their ability to act and to be acted upon within the current constraints of their social, political, and material environment. At a certain point, all subjects lose their capacity to form meaningful connections with others and at that time, may desire to become other than themselves, essentially, to die. Death, as a social relation, is a transformation, rendering subjects into new forms and marking the end of one form of subjective power for the beginnings of others. The capacity to imagine death as relation requires acknowledgement that it occurs through a culmination of subjective perspectives and experiences. No one universal definition can apply here, since all subjects will reach different thresholds of bodily existence and, in the intensive care unit, different moments at which connection to life-sustaining interventions are no longer subjectively desirable. This decidedly posthuman perspective does away with the terror of human death and instead places focus on how the power and consequent responsibility to establish subjective endings can be best distributed.

The deduction that the boundary of death is subjective and relationally constituted is not surprising, given that the boundary of the beginnings of life meets a similar fate. What is interesting, and what I have attempted to do in this project is to consider some of the conditions through which the concept of human death has persisted as a relatively inflexible theoretical categorical assignment even within contexts of technologies and practices which serve to lengthen, enhance, and trouble the limits of human bodily life in clinical spaces.

In Chapter 5, I investigated this practice of lengthening and enhancing the limits of bodily life using technology through an analysis of the culture of “saving lives.” Specifically, I aimed to consider how a logic of lifesaving produces ethical norms of enforcing cure and salvation right up until the end of feasible existence. Though medical “lifesaving” has roots in religious traditions focused on salvaging the soul, this has now mostly transformed into a secular emphasis on the economic and political power of liveliness and vitality (Chen 2012; Haraway 1997; Rose 2009). While some have found this focus on vitality results in healthcare systems which strive to save particular types of life such as previously healthy individuals and young people (Timmermans and Sudnow 1998), I focused my observations on how an overarching logic of lifesaving almost appeared to surpass considerations of patient concerns altogether in the name of establishing “signs of life” such as stable breathing and blood pressure (Macdonald et al. 2008). After observing and analyzing several instances of patients admitted to intensive care and maintained alive seemingly against their wishes, I proposed that material practices of routine lifesaving interventions, discursive labelling of desires for death as deviant, and strategic deployment of the concept of patient autonomy converge to deny, delay, and devalue subjective desires for death. When contrasted with a posthuman consideration of life and death as inherently relational and death as subjectively determined, the trend towards saving life in the intensive care unit appears all-consuming, based more on restoring a cultural ideal of individual human liveliness than establishing conditions for collective flourishing. This analysis provides impetus to consider the

possible need for technology to facilitate better communication so that subjective thresholds of endings might be respected. It also points to the need for a broader consideration of the social and relational importance of the threshold of death in the lives of individual subjects. The intensive care unit has the potential to become a space for the cultivation of respect for such a transition, rather than simply a location for its denial.

In contrast to patients desiring no resuscitation, there are also cases in which patients would appear to desire life and yet the practice of scientific medicine decides that they are dead. In Chapter 6 I explored the case of Taquisha McKitty, a young Black woman who was declared brain dead but whose family indicated that she would not have accepted this threshold of bodily ending. In this analysis, I sought to emphasize and outline the complex tensions that arise when the desire for a unique and subjective threshold of existence conflicts with the idea of a universal boundary of human death. At the core, this type of conflict hinges on an epistemological disagreement about which types of knowledge count, and which types of subjects hold the power to know. In this chapter I considered critiques of brain death and organ donation against less well explored but implicated questions of race and social privilege. My analysis focused on how the inherent exclusivity of the category of human renders acceptance of a universal definition of human death problematic. From this position, conceiving of death as a subjective and individual ethical threshold is not just a philosophical approach but also a point of justice, a perspective which uplifts and empowers those whose lives continue to be socially and politically circumscribed to regain control over the contexts of subjective

endings. This position also makes clear the need to take into account the role of broader social relations when apprehending moments of individual endings. Death, as a relation, does not exist in isolation but is always a product of a bigger picture, a greater movement, a larger conception of what it means to live and what it means to die in a particular location and time (Bauman 2013).

A strange exception to the concept of death occurs when fetal life is sustained in brain-dead, pregnant patients. This type of case, discussed in Chapter 7, pushes limits even in spaces where technological support of life is feasible. Though I did not observe any cases of posthumous reproduction in my fieldwork, I used publicized cases to compare this relation of life-in-death and found it related to patterns that I did observe between life and death amidst life-sustaining technologies. Posthumous reproduction, and posthumous pregnancy in particular, is a site for creative rethinking of ethical relations and moments in which the idea of toleration of the other within, or acceptance of death within a continuum of life, is stretched to its limit. The capacity to sustain life within a person who is considered dead highlights contradictions in persistently emphasized universal boundaries of human death, as well as opens possibilities for new ways of thinking. The clinical examples and media cases I presented in Chapter 7 demonstrate how death-in-relation is based on perspective, how some subjects desire to persist while others desire to transform into something new, and how these positions are always located within larger social milieus of molar and molecular power structures.

At the heart of ongoing puzzles about technological death I have located a tension between the fundamental category of “human,” its assumed connection to particular qualities of independence, vitality, rationality, and consciousness, and the increasing medical and technical capacity to obfuscate any semblance of reproducible “natural” or “normal” boundaries to human life. Throughout this work I have argued for the need for a posthuman perspective that does not shy away from complexity and creativity when thinking through these problems. The posthuman perspective that I have employed starts from the position that the idea of a “normal” or “natural” human has been a falsity from the very beginning, an exclusive and oppressive category flawed in its conception. Critical race, disability, and feminist scholars have demonstrated over and again how the imposition of the category of the “normal human” inscribes patterns of ableism, masculinity, and Whiteness, alongside a false ideal of independent rational objectivity which is rarely if ever actually achievable (Barad 2007; Braidotti 2006; Clare 2017). De-centering the concept of the normal human allows for a perspective of bodily death which is not located in the demise of the human (a flawed concept to begin with), but is rather construed through a pattern of relations, a particular variance of enhanced and limited potentials which ultimately results in the cessation of subjective relational power and the ceding of vital connections to other, ongoing life forms (Braidotti 2006).

With the aid of these conceptual tools, I argued in Chapter 5 that the choice of deciding when to continue and when to cease forming new bodily connections is a subjective ethical limit, an interdependent threshold which each subject nevertheless has

the responsibility to define for themselves. In making this argument, I also acknowledged the fundamental necessity of advancing societal conditions of flourishing for all persons in order to encourage all subjects to cultivate sustainable addictions to life, rather than “opting out” early due to social patterns of oppression, persecution, and exclusion. In Chapter 6 I developed this argument further, suggesting how expanding the ability to determine subjective thresholds of life is a means through which historically marginalized and excluded populations might safely exercise both the ability to exist and the responsibility to determine differently meaningful bodily endings. Subsequently, Chapter 7 contends with the ethical permissibility of choosing one’s own ending, demonstrating how such a move does not sit easily within traditional modes of reasoning based on Western, humanist principles of the independent rational self. Advocating for subjective ethical limits to life foregrounds collective, rather than individual, ethical responsibilities, both for communication and for attending to relational responsibilities of enhancing each other’s power and potential. Accepting death as a state to be tolerated within life has the potential to be macabre from some perspectives. But viewed another way, it is also one that makes possible the radical potential of living just a life, to the extent that one desires, and of living it well.

The future is a product of particular endings

In a world in which matter can neither be created or destroyed, it is imperative for certain configurations of life to end in order that new forms can emerge and begin. The so-called “cycle of life” still remains as an indefatigable sign under which we operate.

But ongoing advancements and developments of scientific medicine increasingly make the idea of death into a fiction for certain subjects and an untimely enforced reality for others. How death occurs, how it is organized, how we determine that it should and can exist matters for understanding the ways in which certain subjects will continue on and others will be denied a future. I have explored some perspectives of how life and death operate through the specific material site of the intensive care unit and as a result, propose possible changes and modes of re-thinking within this site that might contribute to different futures.

The intensive care unit provides a location for the support of disability and the production of new relations of death. Here, I argue that processes of saving, sustaining, and letting go cannot ethically occur in the absence of innovation through which we might ascertain subjects' wishes and thus work to respect their subjective thresholds of existence. Promoting and uplifting disabled lives is an action in which the intensive care unit already actively participates, and thus there is a potential for this site to become a champion of the rights of people with disabilities. One of the first steps to establishing this more equal future is to recognize the importance and equal value of disabled subjects through apprehending and supporting responsibilities to life at the same time as finding new ways to respect the desire to die. Here, responsibilities to disabled life encompasses more than a drive to save life in a curative, normative fashion. It requires commitment to understanding disability as an integral part of life, rather than its opposite. It requires a shift from perceiving intensive care as a heroic practice of saving lives to one of

respecting and valuing the important collaborative work of patients, care-workers, and life-sustaining technologies to enable new interdependent modes of liveliness.

Recognizing intensive care as a location for troubling the idea of independence and moving beyond the prototypical human subject opens space for a posthuman future in which interdependence is central to sustainable existence.

The technology present in the intensive care unit also serves presently to shift death from a social and ethical to an objective and technical responsibility. Through framing death in terms of the epistemology of scientific medicine, the practice of intensive care removes death from its place as a collective social and ethical decision and positions it instead as a purportedly objective and irrefutable moment orchestrated through the use of neutral technologies. Of course, technical devices are not neutral, and the technologies of life support contain specific material histories which shape the ways in which lives can be sustained or curtailed (Timmermans 1999). Granting the power to make death to technologies of life-sustaining overshadows the social and relational importance of death as a part of life. Part of this overshadowing, I have argued, is the ontological impetus to understand death as a universal biological event rather than a subjective and ethical threshold. As a result, alternative approaches and ways of knowing are discredited as less valid “religious” and “cultural” beliefs. To establish space for more ethical futures, I argue that one of the roles of healthcare workers, especially in spaces of high mortality such as the intensive care unit, should be to find ways to work with patients and families in order to help establish patients’ personal thresholds of ethical

sustainability. In other words, to more explicitly and consistently understand patients' desires to live and to die.²⁹ This would require meeting all patients and families where they are with their own limits, rather than imposing an idea of when bodily death should or could occur. For some patients, such as those who desire to donate organs after death, this approach may mean the establishment of thresholds of death far in advance of bodily decay.³⁰ It may mean the provision of medical assistance in dying to more patients who request it after several days of life-sustaining connections. For others, it could mean maintaining technical and medical relations of life-sustaining beyond the point at which consciousness is deemed to be "irreversibly lost." This ethical approach to death insists on transparency for the epistemological underpinnings that assist with determining death and creates space for the recognition of alternative ways of knowing and relating. Rather than a call to individualize death, I envision this as a push for the need to cooperatively reimagine bodily endings. It is a part of our collective responsibility, rather than a right, to establish subjective ethical thresholds and to ascertain the wishes of others about when they have had enough.

Instead of a world in which life-sustaining technologies swoop in to save and sustain us through critical illness in service to some underlying medical logic, I imagine a future in which medical technology and social organization coalesce to ensure that each

²⁹ Work on integrating such concepts of palliative care into intensive care spaces is ongoing (Hamdan Alshehri et al. 2020; Jennerich, Jöbges, and Slabbert 2020)

³⁰ Some scholars have proposed that pre-mortem kidney donation may be acceptable to willing donors and may also have the potential to substantially reduce organ wait list times (Denu, Mendonca, and Frost 2018; Morrissey 2012).

subject reaches their full potential. In this world, interdependence and disability are accepted as part of life, and subjects (with the help of proxies and the assistance of advanced communication devices) maintain the responsibility to determine the point at which they have reached their limits of bodily existence. Social policies of redistribution and collaboration ensure that all subjects have equitable access to the resources needed for interdependent flourishing, and with the imposition of untimely death a rare and unlikely event, people can relate to their deaths and tolerate their inevitability without fear. In a world in which relations to life are positive, fulfilling, and open to possibility, the threshold of subjective death becomes yet another opportunity for creative ways to become otherwise. Death is not a problem to be solved by humanity, and certainly not by an Enlightenment-era, transhumanist movement that would see the production of immortal Man. Instead, death is a wound that we move through, an extolment of our collective ability to endure and to heal, a reminder that we remain connected through suffering in our travels towards different futures.

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APPENDICES

APPENDIX A: Ethics approval from OHSN-REB



The Ottawa
Hospital | L'Hôpital
d'Ottawa
RESEARCH
INSTITUTE | INSTITUT DE
RECHERCHE



*Ottawa Health Science Network Research Ethics Board (OHSN-REB) / Conseil
d'éthique de la recherche du réseau de science de la santé d'Ottawa (CÉR-RSSO)*

Date: March 14, 2019
Principal Investigator: Dr. Amanda van Beinum, TOH/OHRI
Protocol ID: 20190109-01H
Study Title: Recognizing dying and orchestrating death in the intensive care unit: an ethnographic investigation
Submission Type: Initial Application
Review Type: Delegated
Date of Approval: March 14, 2019
Approval Expiry Date: March 14, 2020

Dear Dr. van Beinum,

Thank you for submitting the above referenced study. The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the application and granted approval for your study. This approval is granted until the expiration date noted above. This research study is to be conducted by the investigator noted above.

The **OHSN-REB ethics approval** is applicable only for The Ottawa Hospital, University of Ottawa Heart Institute and University of Ottawa Faculty of Medicine.

An **Institutional approval (OHRI and/or UOHI) letter is required prior to the conduct of the study** at this site. The institutional approval letter is an indication that you have satisfied ethics, contracts, departmental notifications, as applicable.

Documents Approved:

Document Name	Document Version Date
Informed Consent Form - Observation	March 4, 2019
Informed Consent Form -Interview	March 4, 2019
Interview Script	January 23, 2019
Protocol	January 10, 2019

No deviations from, or changes to, the protocol should be initiated without prior written approval of an appropriate amendment from the OHSN-REB, except when necessary to eliminate immediate hazard(s) to study participants.

REB members involved in the research project do not participate in the review, discussion or decision.

Civic Campus, Box 675, 725 Parkdale Avenue, Ottawa, Ontario, K1Y 4E9
613-798-5555 extension 16719 Fax: 613-761-4311 <http://www.ohri.ca/ohsn-reb>

APPENDIX B: Ethics approval from Carleton University

Office of Research Ethics
503 Robertson Hall | 1125 Colonel By Drive
Ottawa, Ontario K1S 5B6
613-520-2600 Ext: 2517
ethics@carleton.ca

CERTIFICATION OF INSTITUTIONAL ETHICS CLEARANCE

This document is an administrative clearance corresponding to approved protocol **#20190109-01H** from the **Ottawa Health Science Network Research Ethics Board**. The Carleton University Research Ethics Board-A (CUREB-A) has granted administrative clearance for the research project described below and research may now proceed. CUREB-A is constituted and operates in compliance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2).

Ethics Protocol Clearance ID:Project # 110612

Research Team: **Amanda Van Beinum (Primary Investigator)**
Carlos Novas (Research Supervisor)

Project Title: Recognizing dying and orchestrating death in the intensive care unit: an ethnographic investigation

Funding Source (If applicable):

Effective: **March 21, 2019**

Expires: **March 31, 2020**

Restrictions:

This certification is subject to the following conditions:

1. Clearance is granted only for the research and purposes described in the application.
2. Any modification to the approved research must be submitted to CUREB-A via a Change to Protocol Form. All changes must be cleared prior to the continuance of the research.
3. An Annual Status Report for the renewal of ethics clearance must be submitted and cleared by the renewal date listed above. Failure to submit the Annual Status Report will result in the closure of the file. If funding is associated, funds will be frozen.
4. A closure request must be sent to CUREB-A when the research is complete or terminated.
5. During the course of the study, if you encounter an adverse event, material incidental finding, protocol deviation or other unanticipated problem, you must complete and submit a Report of Adverse Events and Unanticipated Problems Form, found here:
<https://carleton.ca/researchethics/forms-and-templates/>

Failure to conduct the research in accordance with the principles of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2nd edition* and the *Carleton University Policies and Procedures for the Ethical Conduct of Research* may result in the suspension or termination of the research project.

APPENDIX C: Interview guide, Canadian physicians' experiences with requests for continued organ support after a declaration of death using neurological criteria

Physician Interviews – Experiences with Family Requests for Continued Life-Support after NDD

INTRODUCTION

- Thank you for answering the online survey and setting aside the time to speak to me today about your experiences
- Interview should take about 30-40 minutes
- Value of participation – to get more detailed and contextual information about this phenomenon of families requesting continued life-support after NDD
- Reminder that you are being recorded for accuracy of our conversation
- Reminder that no identifying information will be used in any analysis or resulting publication
- Reminder that you can choose not to answer certain questions or to end the conversation at any time
- Reminder that I don't have access to the responses they entered online since that survey was anonymous and cannot be linked with their name (apologies if some of the questions are repeated, but this is a chance to provide more detail)

Q1 What is your experience with declaring death using neurologic criteria?

- For background info to provide context to answers:
 - o Practice specialty
 - o Number of years of service
 - o Experiences with organ donation (frequency?)
 - o Type of hospital you work in (community, university, etc.)

Q2 Do you have any personal experience(s) with a family or families that requested continued organ support and/or refused withdrawal of organ support following a declaration of death using neurologic criteria?

- If YES: please describe the (most memorable) case
 - o When did you realize there was a conflict over NDD? How soon after the NDD diagnosis did the conflict appear? What were the first signs of conflict? How did the family make the request for continued support?
 - o What is your sense of why the family had difficulty with the NDD declaration?
 - o Who was involved in the case? (Clinical & hospital services)
 - o Did you ever offer the family ancillary testing? If yes, which ones?

- What was the outcome of the case/how did it end? (clinical, emotional, policy?)
Are there ongoing legal challenges? Did the patient die on full support or was the ventilator removed in ICU?
- Did you feel well supported during this conflict?
- What would you do differently/the same if a similar conflict came up during your next clinical shift?
- **If NO:** have you heard about this issue or discussed it with colleagues?
 - What is your sense of the frequency of this type of conflict?
 - What is your sense of the character of this type of conflict from the physician's perspective?
 - What is your sense of the impact of this type of conflict on ICU care?
 - What do you think are the reasons for this type of conflict?
 - What do you think we can do about this type of conflict?
- Q3 How do you think physicians could or should manage the challenge of family requests for continued organ support and/or refusal to withdraw of organ support following a declaration of death using neurological criteria?**
 - How have you managed it or heard about/seen it being managed by others?
 - Requests for additional support?
 - Moral distress?
 - Resulting burnout? How much do you see this as an issue for yourself and your colleagues?
 - Suggestions for the future?
- Q4 Is there anything else you want to share with us about your experiences or thoughts surrounding family requests for continued organ support following a declaration of death using neurologic criteria?**

CONCLUSION

- Thank you again for your time
- Please let me know if you'd like to be sent a copy of the results of this study
- Don't hesitate to reach out if you think of anything additional to add or if you have any questions for the study team

APPENDIX D: Copy of ethics approval from William Osler Health System



Research Ethics Board
 William Osler Health System
 2100 Bovaird Drive East, Room S.3.907
 Brampton ON L6R 3J7, Canada
 Tel: (905) 494-2120, Ext. 50448
 Fax: (905) 494-6769

Study Approval

Date: 06 November 2018

To: Dr. Andrew Healey
 William Osler Health System
 2100 Bovaird Drive East,
 Brampton, ON, L6R 3J7

From: Ronald Heslegrave

REB File No. 18-0072
Study Title: Canadian physician experiences of situations in which families object to discontinuation of organ support after the determination of death using neurological criteria

Approval Date: 06 November 2018

Expiry Date: 06 November 2019

The Research Ethics Board of the William Osler Health System has conducted a Delegated Review of the research protocol referenced above and approved the involvement of human subjects on the above captioned date.

Documents Approved:

- WOHS Application for Human Subjects Research Review by REB, Dated: 02 November 2018
- Study Protocol, Version 1.0, Dated: 02 November 2018
- Informed Consent Form, Version 1.0, Dated: 02 November 2018

Documents Acknowledged:

- Dear Physician Letter, Version 1.0, Dated: 02 November 2018
- Questionnaire, Rec. 06 November 2018

Study continuation beyond one year requires submission of a renewal form prior to the expiry date or a study completion report must be received to close the file with the REB.

All REB approved studies may be subject to review by the William Osler REB and, as Principal Investigator, you are responsible for the ethical conduct of this study. If, during the course of the research, there are any serious adverse events, changes in the approved protocol or consent form, significant deviations or any new information that must be considered with respect to the study, these should be brought to the immediate attention of the Board.

On behalf of the William Osler Health System Research Ethics Board,



Ronald Heslegrave
 Chair, Research Ethics Board
 William Osler Health System
 Brampton Civic Hospital
 2100 Bovaird Drive East, Room S.3.907
 Brampton ON L6R 3J7

The Research Ethics Board of William Osler Health System operates in compliance with the Tri-Council Policy Statement (TCPS), the International Conference on Harmonization (ICH) Good Clinical Practice (GCP) Guidelines, Part C Division 5 of the Food and Drug Regulations of Health Canada, the Provisions of the Ontario Health Information Protection Act (PHIPA), Part 4 of the Natural Health Product Regulations, and Part 3 of the Medical Devices Regulations.

APPENDIX E: Copy of ethics amendment approval from Carleton University



Office of Research Ethics
 4500 ARISE Building | 1125 Colonel By Drive
 Ottawa, Ontario K1S 5B6
 613-520-2600 Ext: 2517
ethics@carleton.ca

CERTIFICATION OF INSTITUTIONAL ETHICS CLEARANCE

The Carleton University Research Ethics Board-A (CUREB-A) has granted ethics clearance for changes to protocol to the research project described below and research may now proceed.

CUREB-A is constituted and operates in compliance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2).

Ethics Clearance ID: Project # 110612

Project Team Members: Amanda Van Beinum (Primary Investigator)
 Carlos Novas (Research Supervisor)

Project Title: Recognizing dying and orchestrating death in the intensive care unit: an ethnographic investigation

Funding Source (if applicable):

Effective: **March 04, 2020**

Expires: **March 31, 2020**

Upon reasonable request, it is the policy of CUREB, for cleared protocols, to release the name of the PI, the title of the project, and the date of clearance and any renewal(s).

During the course of the study, if you encounter an adverse event, material incidental finding, protocol deviation or other unanticipated problem, you must complete and submit a Report of Adverse Events and Unanticipated Problems Form, found here:
<https://carleton.ca/researchethics/forms-and-templates/>