



More Than “Spending Time with the Body”: The Role of a Family’s Grief in Determinations of Brain Death

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Abstract In many ways, grief is thought to be outside the realm of bioethics and clinical ethics, and grieving patients or family members may be passed off to grief counselors or therapists. Yet grief can play a particularly poignant role in the ethical encounter, especially in cases of brain death, where the line between life and death has been blurred. Although brain death is legally and medically recognized as death in the United States and elsewhere, the concept has been contentious since its inception in 1968. Yet in most cases, families are not allowed to reject the determination of brain death. Apart from religious exemptions, families have no recourse to reject this controversial determination of death. This paper explores the role of grief in brain death determinations and argues that bioethics has failed to address the complexity of grief in determinations of brain death. Grief ought to have epistemological weight in brain death determinations because of the contested nature of the diagnosis and the unique ways in which grief informs the situation. Thus, I argue that, in some rare cases, reasonable accommodation policies should be expanded to allow for refusals of brain death determinations based on the emotional and moral force of grief. By drawing on ethnographic accounts of grief in other

cultures, I problematize the current procedural and linear understandings of grief in brain death determinations, and I conclude by offering a new way in which to understand the case of Jahi McMath.

Keywords Grief · Brain death · Reasonable accommodation · Anthropology · Jahi McMath

“Orders should have been immediately written to discontinue all life support. The family should have been allowed to spend some time with the body if they wished. And then her body should have been sent to the morgue.”

Laurence McCullough in response to Jahi McMath (Szabo 2014, ¶9).

In many ways, grief is thought to be outside the realm of bioethics and clinical ethics, and grieving patients or family members may be passed off to grief counselors or therapists. Yet grief can play a particularly poignant role in the ethical encounter, especially in cases of brain death, where the line between life and death has been blurred. In the well-known case of Jahi McMath, and in other diagnoses of brain death, the family is allowed to grieve in one particular way, as noted by bioethicist Laurence McCullough above: the family should be allowed to spend time with the body. However, this restricted, time-limited understanding of grief does not adequately address the role that grief can play in the clinical encounter. Because brain death is a contested determination, in which the loved one still appears alive—warm to the touch, chest rising and falling—time alone may not lead the family to the

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conclusion that their loved one is dead. This limited understanding of grief hinders providers and clinical ethicists from addressing the various manifestations of grief that are often present even before the determination of brain death.

Because grief informs the situation and influences the decisions that can be made, clinical ethicists need to recognize grief as an ethically and morally relevant factor in order to fully understand the situation and to provide care and guidance for the family. In this paper, I argue that clinical ethicists, and bioethics more broadly, fail to address the complexity of grief in cases of brain death. Because of the contested nature of the diagnosis and the unique ways in which grief informs the situation, grief ought to have epistemological weight in brain death determinations. Thus, I argue that, in some rare cases, reasonable accommodation policies should be expanded to allow for refusals of brain death determinations based on the emotional and moral force of grief.

I first show that there is sufficient disagreement in the brain death debate to warrant reasonable accommodations of objections to brain death. I then outline the ways in which grief is currently handled in brain death determinations by examining brain death policies and reasonable accommodation policies. In these policies, there is a time-limited, procedural understanding of grief that does not allow family members to truly engage with their grief and forces them to accept the determination of brain death. However, grief does not just occur after the death of a loved one. I explore the idea of grief and the myriad ways in which grief inhabits life. While grief counselors may help family members through their grieving, I argue that because grief counselors are enmeshed in the biomedical culture, they use a normative approach with a certain telos ultimately aimed toward getting the family to accept the brain death determination. I problematize this approach by arguing that a full understanding and appreciation of grief in brain death may not, in fact, lead to acceptance of the brain death determination. Because of the interdisciplinary nature of their work, clinical ethicists—more so than grief counselors—may be aptly situated to incorporate this holistic understanding of grief into brain death determinations. Then, by exploring ethnographic accounts of grief, I highlight the situatedness of grief and question the assumption of linearity in the grieving process. These anthropological accounts offer clinical ethicists new ways in which to consider grief in brain death. I conclude by discussing the unique ways in which a social and cultural understanding of grief might have impacted the difficult case of Jahi McMath.

A Case for Grief: Jahi McMath

The highly contested case of Jahi McMath may be one of the most public displays of a family's grief and the failure of the medical establishment to carefully consider and understand that grief. On December 9, 2013, thirteen-year-old Jahi McMath went to Oakland Children's Hospital in California for a tonsillectomy and adenoidectomy to alleviate her sleep apnea. After a seemingly routine procedure, Jahi began to bleed profusely from her mouth. Suddenly, Jahi suffered cardiac arrest because of the massive loss of blood volume. Following extensive CPR and administration of blood, blood products, and fluids to try and restore Jahi's blood volume, her heart started to beat again. She was placed on a ventilator to help her breathing, but because of the prolonged period in which Jahi's brain was not receiving oxygen, she suffered a severe brain injury. Three days later, Jahi was declared brain dead.

After Jahi was declared brain dead, the hospital moved to withdraw ventilator support. Her family strongly objected. As devout Christians, they believed that as long as Jahi's heart continued to beat, she was alive. Jahi's mother, Nailah Winkfield, said: "Her heart is beating, her blood is flowing. She moves when I go near her and talk to her. That's not a dead person" (Onishi 2014, 6). Despite the family's objections, the hospital issued a death certificate listing December 12, 2013 as the date of death. The family took the hospital to court to stop the unilateral withdrawal of ventilation, and the court issued an injunction barring the withdrawal of ventilation, allowing the family time to find another facility that would be willing to take Jahi. Jahi resided in a facility in New Jersey until her "death"¹ as a result of complications from liver failure in June of 2018 (Goldschmidt 2018).

The contentious case of Jahi McMath generated a plethora of scholarly and public attention. Apart from the debate over whether or not Jahi was really "alive" after her initial cardiac arrest, the rhetoric became deeply personal: one author describes Jahi as an "obese black girl" whose family is "large, passionate, and black" (Luce 2015, 1145). In questioning why Jahi's family

¹ I have placed "death" in quotation marks here, as some scholars would say Jahi was dead on December 12, 2013, after being declared brain dead. However, the aim of this paper is not to posit whether or not Jahi was dead or alive. Rather, I aim to highlight the complexity of grief in brain death determinations and offer new understandings of grief in brain death.

members might want to continue with life-sustaining treatment, McCullough said, “Their thinking must be disordered, from a medical point of view.... There is a word for this: crazy” (Szabo 2014, ¶10). These characterizations of a “crazy” black family reveal not only the biomedical but also the racial tensions that were at play in this case, highlighting the myriad other factors that might have been impacting the situation. But was the family “crazy” for thinking their daughter was still alive? Theoretical and scholarly disagreement about the concept of brain death itself suggests that the concept might not be as settled as the medical personnel in this case made the family to believe.

Disagreement in the Brain Death Debate

Since its inception in 1968, the concept of whole-brain death has been contentious. Although it is legally and medically recognized as death in the United States and elsewhere, there is significant “medical, moral, and philosophical” disagreement (Johnson 2016, 106). In 1968, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death developed criteria for determining death in response to two developments in medicine: advances in intensive care technology that could maintain life in individuals with severe brain injuries, and improvements in the success of organ transplantation (Ad Hoc Committee 1968). The committee justified this definition of death based on these instrumental reasons, but they did not explain why brain death actually constituted death. This task was taken up by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1981, in its report *Defining Death*. According to the commission, death is the moment where there is a loss of “the integrative unity of the organism as a whole.” Because the brain is the central integrator of the whole organism, death occurs when the brain ceases to function (Johnson 2016, 107).

Yet as neurologist D. Alan Shewmon points out, most of the integrative functions of the body are not brain-mediated (Shewmon 2001). Moreover, the diagnostic criteria for determining whole-brain death do not establish the absence of integrative brain function, but rather “loss of consciousness, of cranial nerve functions and of spontaneous breathing”

(Shewmon 2001, 465). The commission bolstered its conclusion by claiming that brain dead bodies ultimately deteriorate to cardiovascular collapse within a few days. However, as philosopher L. Syd Johnson aptly notes, this is less proof that brain death is a *diagnosis* of death than it is a *prognosis* of imminent death (Johnson 2016, 107).

In response to ongoing criticism of the whole-brain definition of death, the President’s Council on Bioethics published a white paper in 2008 seeking to establish a new rationale for equating brain death with death. According to the council, “total brain failure can continue to serve as a criterion for declaring death—not because it necessarily indicates complete loss of integrated somatic functioning, but because it is a sign that this organism can no longer engage in the essential work that defines living things” (President’s Council 2008, 64–65). According to the council, that essential work includes “self-preservation” and “need-driven commerce with the surrounding world,” both of which are conducted in two critical ways: breathing and consciousness (President’s Council 2008, 60).

Critics were quick to point out that anyone in a coma would be considered dead by this line of reasoning. According to Miller and Truog, because neither unconsciousness nor lack of spontaneous breathing alone constitutes death, the conclusion that having both characteristics constitutes death is “a *non sequitur*” (2009, 189). Shah and Miller call the council’s reasoning “fallacious” and point out the legal fictions in determining brain death (2010, 550). Furthermore, several studies provide evidence that whole-brain death is not indicative of a completely dead brain (Halevy 2001; Truog 2007; Halevy and Brody 1993). As Engelhardt laconically puts it, brain dead bodies “appear to be alive because they are in fact alive” (1986, 209).

Reasonable Accommodation Policies: A Temporizing Approach

Because of this considerable disagreement concerning brain death, and the unlikelihood of resolving this moral dilemma through scientific or legal means alone, Johnson argues for a universal adoption of “reasonable accommodation” policies, like those of New Jersey and New York, in which families can reject the determination of brain death based on religious and moral

objections (Johnson 2016).² Most states define death in accordance with the Uniform Determination of Death Act (UDDA) as either “(1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem” (UDDA 1980, 5).

Reasonable accommodation policies in New Jersey and New York, however, allow families to reject the neurological determination of death based on religious objections. These laws were passed to accommodate Orthodox Jews and other religious groups who believe that death only occurs with the cessation of circulatory and respiratory functions. While these reasonable accommodation policies strive to respect cultural and religious diversity, they do not go far enough in embracing the moral variation that may arise in cases of brain death determination. Specifically, these reasonable accommodation policies (and other policies pertaining to brain death) do not adequately address the complexity or moral weight of grief in brain death determinations. Like the position evinced by Laurence McCullough above, many policies and position statements imply a time-limited recognition of familial grief and mourning *after the determination of brain death*, but they do not explicitly state the need to consider grief or the need to support families before the determination has been made.

In California, where Jahi McMath was treated, the Accommodations & Brain Death Act, enacted in 2009, mandates a “reasonably brief period of accommodation” of the family following death, defined as “an amount of time afforded to gather the family or next of kin at the patient’s beside” (Cal. HSC. Code 1254.4).

In New York, the reasonable accommodation statute requires hospitals to establish written procedures for addressing the accommodation, but the law does not mandate what those procedures or policies must be (NYSDOH 2011). The New York City Health and Hospitals Corporation Ethics Network interprets the law to mean that religious and moral objections “should be respected to the extent of making an effort at reasonable accommodation,” which might include a “short, specified period of time” during which ventilation, nutrition and hydration, and other medical support might be

continued, but this does not mean “that the now dead individual must continue to be treated as a patient” (HHC Ethics 2016, ¶4).

In 2014, the Neurocritical Care Society (NCS) published an online toolkit on brain death to help hospitals modernize and accelerate the pace of policy updates in accordance with the American Academy of Neurology Practice Parameters for determining brain death. In this online toolkit, the NCS included a sample determination of brain death policy that hospitals could implement. The last section, “Communication with the Family,” reads:

The family should be informed that evaluation for neurological death is taking place, and also when the determination has been made. The family is then informed that even though the patient has spontaneous cardiac activity, the patient is legally dead. Family permission is NOT required for the removal of the ventilator when a determination of death by neurological criteria has been made. However, a *reasonable amount of time* should be allowed for the family to visit the patient and *come to terms* with the diagnosis prior to the removal of the ventilator (Neurocritical Care Society 2014, 3 [emphasis added]).

While these statutes and policies do not specifically mention the word “grief,” there is an implied understanding that grief is properly handled by allowing the family to spend “time” with their loved one in order to “come to terms” with the diagnosis. This notion of “coming-to-terms” and “reasonable amount of time” reveals the inherent normative telos of the NCS and state accommodation laws: grief should have a logical end-point—namely, the acceptance of the brain death determination. There is no question of whether or not this determination is right or true but only a question of when the family will sufficiently process their grief in order to arrive at the “correct” linear end-point.

This time-limited approach to grief can be characterized as “temporizing,” in which one assumes that grief, trauma, or emotional pain will fade over time. The goal of temporizing, commonly used when treating burn victims or other patients who have sustained severe traumatic injuries, is to maximize patient autonomy (Volpe et al. 2015). Physicians believe that giving patients time to understand their injuries and their current situation will allow them to make the most informed decision. While this temporizing approach seems to account for patient

² Linda Emanuel also argues that families should be allowed to determine whether a family member is dead because of the overlapping nature of life and death and the ways in which dying is a process rather than a state. She argues for the creation of a bounded zone of life cessation, within which moral variation on deciding what constitutes death would be tolerated (Emanuel 1995).

autonomy, it in fact may deter the patient from making a decision until that decision aligns with the wishes of the providers or family members (Volpe et al. 2015).

Likewise, the temporizing approach in brain death is ultimately aimed at getting the family to accept the determination of brain death. The temporizing approach assumes that time will heal the grieving family and will allow them to autonomously conclude that their loved one is dead. However, time alone may not resolve a family's grief or lead them to believe that their loved one is dead. In fact, the goal of temporizing in this context is not really to help the family at all; the main goal is to limit the amount of time that the brain-dead patient will receive ventilator support. Rather than care of the grieving family, the goal of temporizing in brain death determinations is proper resource allocation. This temporizing approach—while disguised as a method to help families—fails on its own terms, and clinical ethicists must recognize that grief is still present even after a certain amount of “time” has passed. In order to care for these families and to resolve moral conflict surrounding the situation, clinical ethicists need new understandings of grief and new ways in which to incorporate that grief into the ethical encounter.

The Need for New Understandings of Grief in Bioethics

In order to understand the morally significant role of grief in brain death, we first must understand grief, as the experience of grief and bereavement represents one of the major challenges facing people (Payne et al. 1999). Sheila Payne traces three distinct understandings of bereavement that have been particularly influential in the last century: intra-psyche, interpersonal, and social approaches (Payne 2007). The intra-psyche models, or “phase and stage models,” focus on psychological processes and the “grief work” necessary to overcome one's grief. Elizabeth Kübler-Ross's (1969) five stages of grief model has played a key role in loss and bereavement understanding, and this staged model is reflected in the reasonable accommodation policies described above, in which the grieving family is expected to “come to terms” with the loss and arrive at the “correct” linear end-point.

However, these staged models of loss and bereavement have been critiqued and challenged because they assume that the experience of grief involves a linear, time-limited

progression through phases from which there is an eventual outcome where grief or distress is no longer experienced (Wortman and Silver 1989; Stroebe et al. 2005). Newer interactional perspectives of grief and bereavement draw on the stress and coping literature and emphasize how the grieving individual interacts with others and construes the situation (Payne 2007, 28). Stroebe and Schut propose the dual process model, in which people oscillate between “restoration-focused” coping (e.g., dealing with everyday life) and “grief-focused” coping (e.g., expressing their emotions) after the death of a loved one (1999). Because people move between these two forms of coping in different ways and interact with others differently while grieving, this model helpfully points out individual diversity and the necessity of interaction while grieving.

The third perspective—social approaches to bereavement—includes the understanding that grief not only impacts how people think and feel or the interactions they have but also recognizes that grief is a fundamentally social process (Payne 2007, 30). Field and Payne have argued that medical professionals have failed to account for the ways in which grief changes people's positions in society because they tend to focus on individual reactions to loss, especially psychological reactions (2003). However, “grief is not merely a set of psychological responses which are largely biologically determined (as presented in the intra-psyche approaches) but patterns of grief and possibilities for its expression are largely influenced by social and cultural factors” (Payne 2007, 31). Contemporary sociological accounts of grief and bereavement, such as Klass and colleagues' continuing bonds approach, challenge the assumption that successful resolution of grief necessitates “letting go” of the relationship (Klass et al. 1996). Even though the physical relationship may be lost, these theories posit the importance of maintaining feelings of continuity with the deceased by incorporating some aspect of their relationship into the individual and collective memory.

While Kübler-Ross and others presenting the intra-psyche models started an important conversation about grief, popular conceptions of grief have not moved past this linear, stepwise narrative. Many people still consider grief an emotion that occurs after death, as one has to “deal with” and “learn to let go of” their lost loved one. This formulaic language highlights Anne Cheng's deduction that as a nation, we are unequipped to deal with grief (2001). We turn away from grief, averting our eyes, willing the grieving individual to “get over it.” This ideology is reflected in the brain death policies noted

above, allowing only a limited time for the family to “come to terms” with the diagnosis; these policies do not account for the interactional or social perspectives of grief as outlined by Payne (2007). Furthermore, grief does not just occur at the death of a loved one. Especially in cases of brain death, grief can occur in the midst of the patient’s life, and new models of grief and bereavement have begun to explore this phenomenon.

The Power and Possibility of Grief in the Midst of Life

For many people, grief can occur before the death of a loved one. Psychiatrist C.K. Aldrich discusses the concept of “anticipatory grief,” in which family members grieve for the impending death of a loved one (1955). Even if family members still hope for recovery, grief can begin to shape their experiences with their loved one. Sociologist Pauline Boss also recognizes grief in life and describes a type of loss that can lead to unresolved grief: ambiguous loss. There are two basic kinds of ambiguous loss. In the first kind, people are perceived by family members as physically absent but psychologically present because it is unclear whether they are dead or alive. Missing soldiers or kidnapped children illustrate this type of loss in its most dramatic form. In the second type of ambiguous loss, a person is physically present but psychologically absent, as illustrated by people with Alzheimer’s or severe brain injury (1999). In both cases, the family must live with “unresolved grief” because there is no official verification of death, no possible closure, and no formal rituals to recognize their loss (Boss 2010). This “frozen” grieving process can leave family members feeling isolated and alone, especially when therapists or other trained professionals do not know how to engage with the family.

This unresolved grief might also become “disenfranchised grief,” in which the family’s loss and grief are not recognized or validated socially (Doka 2002). Grief experienced as disenfranchised or unresolved can often be turned into action; it is not merely an emotion that is experienced individually and passively nor a static event or process that occurs only after someone has died. Grief has the power to do things in the world, impacting people and the decisions they make. According to Martha Nussbaum in her seminal work *Upheavals of Thought: The Intelligence of Emotions*, emotions are forms of judgment. Because emotions are “suffused with intelligence and discernment,” we must consider emotions as “part and parcel of the system of ethical reasoning” (2001, 1). In

examining the grief felt at the death of her own mother, Nussbaum shows the cognitive aspects of grief: “Internal to the grief itself must be the perception of the beloved object and of her importance; the grief itself must estimate the richness of the love between us, its centrality in my life” (2001, 44). Grief is not just a raw emotion felt at the death of a loved one, but rather an evaluative form of perception and judgment, an “upheaval of thought” that impacts our understanding of and involvement with the world around us. Grief is thus an emotional marker of a deeply held belief.

The grief of Jahi McMath’s family was not simply a disordered emotional or psychological reaction, but rather a marker of their deeply-held cognitive belief that she was still alive. However, because the family’s grief was immediately dismissed as inappropriate within the medical and bioethical communities, the family was not given the opportunity to explore the interactional and social implications of their grief or incorporate their loss into their system of ethical reasoning. Because their grief was not recognized or validated socially, the family turned their disenfranchised grief into legal action to stop the hospital from withdrawing ventilator support, thus creating a stalemate between the family and the medical providers. However, if the family was given the opportunity to express their grief both socially and interactionally instead of being dismissed as “crazy,” the ethical and decision-making tensions might have been eased or avoided. Thus, a clinical ethicist who understands these various manifestations of grief can play a particularly important role in a determination of brain death.

The Clinical Ethicist’s Role in Understanding Grief

While grief counselors may seem aptly situated to recognize and understand the various expressions of grief described above, they fail to address the complex and varied contexts in which families grieve and the ethical impact of grief on clinical decision-making. Although grief counseling can help many families process their grief, counseling can also impose a certain worldview onto the clients, forcing them to come to a conclusion that fits within Western biomedical culture. Because grief counselors are enmeshed within Western, biomedical notions of grieving that draw heavily on linear, phase, and stage models of bereavement, the ultimate telos of their counseling in cases of brain death is getting the family to accept the brain death determination.

Clinical ethicists, however, may be more aptly situated to offer a context-specific, interdisciplinary approach to grief in the ethical encounter that takes seriously grief's impact on decision-making. In many cases of brain death, the medical team may request guidance from a clinical ethicist. The clinical ethicist may thus be the first person outside of the medical team to talk with the family and may serve as a first-line grief counselor, assessing whether the family needs a religious leader, a grief counselor, or other resources.

While I do not expect all clinical ethicists to be grief counselors, their role as gatekeeper to other services may be just as important. Furthermore, clinical ethicists are aptly situated to attend to grief in three specific ways. First, if one of the goals of clinical ethics consultation, broadly understood, is mediating a disagreement between medical providers and patients and family members (Dubler and Liebman 2011), clinical ethicists can consider grief in the larger context of the disagreement. Questions they may ask include: what role does grief play in this disagreement? How might understanding or acknowledging this grief resolve the conflict or open up different conversations? What assumptions about this particular family's grief and bereavement are the medical providers bringing to this experience? How is the family's experience of grief impacting their decision-making processes?

Second, because clinical ethicists do not focus exclusively on grief like grief counselors, they can incorporate a more holistic understanding of grief into the larger social context of the patient and family. They may be more attuned to the ways in which the loss changes social roles and relationships or creates a need for interaction. Lastly, because clinical ethicists often draft and implement hospital policies, they can incorporate an understanding of grief at a policy level. Although policies are not explicitly drawn upon in each individual patient encounter, introducing an awareness of grief at the policy level can move grief from the emotional realm of therapists and private life to the normative, cognitive realm of policy and practice.

Allowing Room for Grief: Anthropology in Bioethics

In order for an attunement to grief to shape the ways in which families interact with the medical community, and vice versa, clinical ethicists—and bioethics more broadly—need a more nuanced, situated, context-specific understanding of grief that incorporates both interactional and social perspectives of bereavement.

Anthropology, as a discipline that is devoted to shedding light on the ways in which people live and understand their lives in certain places at certain times, is aptly situated to offer bioethics new understandings of grief. Furthermore, anthropology is committed to disrupting linear narratives and highlights the harm of imposing linear narratives on people's unique lived experiences. Ethnographies, as the methodology of anthropologists, often make important normative claims and judgments about “inequalities, injustices, and abuses of power” (Turner 2009, 38). Ethnographers are “called into the stories and lives of others by the moral process of engaged listening and by the commitment to witnessing” (Kleinman 1999, 89). By engaging with two specific ethnographies of grief, I explore the myriad ways in which grief can shape and inform a family's story, and I offer clinical ethicists a new lens through which to consider the situatedness of grief in brain death that goes beyond the temporizing approach.

Maternal Love and Minimal Grief

In her seminal ethnography *Death Without Weeping: The Violence of Everyday Life in Brazil*, anthropologist Nancy Scheper-Hughes explores the nature of grief and mothers' love for their infants in the shantytown of Alto do Cruzeiro. In the extreme poverty of the Alto, malnutrition and disease ran rampant, taking their toll on the most vulnerable populations—infants—who died at an astonishing rate of almost one per day during Scheper-Hughes's fieldwork (Scheper-Hughes 1992, 15). In response to this “everyday violence,” Scheper-Hughes argues that shantytown mothers practice emotional distancing from their children during the first year of life when their survival is most uncertain, and they do not grieve or mourn the death of their children in “natural” or “appropriate” ways (Scheper-Hughes 1992, 354). She argues that “mother love is anything other than natural and instead represents a matrix of images, meanings, sentiments, and practices that are everywhere socially and culturally produced” (Scheper-Hughes 1992, 341). These Alto mothers push against the assumption of Western psychology that all mothers should immediately attach to their infants and instead offer an alternative way of responding, given their circumstances. Scheper-Hughes seems to suggest that rather than blame these women for their “disturbed” or disordered mother love and grieving process, blame should be laid on a

society that considers these women “marginal and inconsequential” (Engle 1994).

While this seeming lack of grief may seem callous and even abhorrent, Scheper-Hughes posits that this grief response must be considered in its wider social context in order to be understood. Likewise, rejections of brain death based on grief must be considered in their wider social context. What forces are acting (or not acting) on the family to spur their rejection of the brain death determination? In what ways are the cognitive aspects of the emotion dismissed by providers as disturbed or disordered? In the case of Jahi McMath, the family was immediately characterized as “crazy” for thinking their daughter was still alive, but would their reaction have been so hastily dismissed as “crazy” if they were an affluent white family? Might their refusal to accept the determination of brain death be influenced by a long history of (well-founded) mistrust of the medical establishment?

Thus, clinical ethicists should not prioritize or affirm only one grief reaction as “natural” or “appropriate” when reacting to brain death determinations. Rather than characterizing a natural or appropriate grief reaction to brain death as “spending time with the body” and dismissing other conceptualizations of grief out of hand, clinical ethicists can turn a critical eye to the society that formulated such circumscribed understandings of grief and can challenge the biomedical model of accepting a brain death determination.

The Emotional Force of Rage in Grief

In stark contrast to the lack of grief seemingly exhibited by the women of the Alto, anthropologist Renato Rosaldo explores the cultural force of rage in grief in his study of Ilongot headhunting practices (1980; 2014). The Ilongot, a people who number about 3,500, live in the upland area of the Philippines. During the course of his field research from 1967 to 1969, Rosaldo became interested in the salient cultural practice of headhunting, in which Ilongot men kill an innocent stranger to express their anger in grief. When asked why they participated in headhunting, the Ilongot men simply claimed that the force of their rage in bereavement compelled them to headhunt. Rosaldo, however, was not satisfied with this one-line account. He thought there must be a deeper explanation for the men’s desire to kill another human being. He brushed aside the Ilongot accounts as

“too simple, thin, opaque, implausible, stereotypic, or otherwise unsatisfying” (2014, 118).

It was not until the tragic death of his own wife that Rosaldo could understand the simple yet profound force of grief. Before his own loss, Rosaldo notes that he was “naïvely equating grief with sadness” in trying to understand the Ilongot practice of headhunting (2014, 118). He was looking for another level of analysis that could provide a deeper explanation for the men’s desire to headhunt, ignoring the powerful “emotional force” of their simple statement. According to Rosaldo, “emotional force refers to the kinds of feelings that one experiences on learning, for example, that the child just run over by a car is one’s own and not a stranger’s” (2014, 117). He goes on, “One must consider, in other words, the subject’s position within a field of social relations in order to grasp their emotional experience” (2014, 117). A simple statement taken literally can be just as powerful, if not more so, than a deeply theoretical analysis.

In many ways, bioethicists search for a deeper meaning behind objections to brain death. They talk about religious exemptions, legal issues, and medical naiveté, but they overlook the simple yet potentially most important issue: grief. They fail to take into consideration the family’s own position within their field of social relations, thus effectively negating their experiences and circumscribing their role to that of the “inappropriately-grieving family.” Instead of seeking to explicate or theorize the family’s response, the biomedical community would do well to simply accept the family’s grief at face value, recognizing the cognitive force that grief can have in the situation. While grief may seem to be at odds with the bioethicist’s goals of objectivity and rationality, a case without grief is an empty, distorted shell of the full, messy, and complicated picture of human life.

Even while anthropology can inform a more situated, context-specific understanding of grief, the goals of bioethics and anthropology still diverge in fundamental ways. While Rosaldo, as an anthropologist, explores the myriad ways in which grief can be felt and expressed, bioethicists must take up the task from there and question the moral *rightness* or *wrongness* of the action. Rosaldo purposely withholds judgment as he begins to understand the Ilongot experience of grief after the death of his own wife. This is not to say that he condoned their practices or also felt compelled to kill an innocent stranger, but he did not pass judgment either way. However, bioethicists are called to a different standard. We

must be sensitive to specific situations while at the same time upholding moral ideals and values. A bioethicist in Rosaldo's position might strive to withhold judgment in order to better understand the Ilongot and then work with them to express their grief in ways that do not involve killing innocent strangers.

Bioethicists can validate the power and emotional force of grief while setting appropriate moral limits to its expression. Thus, bioethics needs anthropology in order to identify and understand the unique experiences, needs, and beliefs of particular people in particular places at particular times, and anthropology needs bioethics in order to address those experiences, needs, and beliefs in morally and ethically appropriate ways.

A Return to Jahi McMath

What would a morally and culturally sensitive attunement to grief look like in case of Jahi McMath? How might a social and cultural understanding of a family's grief change the way in which the situation unfolded? First and most importantly, when working from an anthropological point of view, the particular needs of this marginalized and non-elite family would be identified and prioritized. Once this foundation has been established, other services could be more readily identified and offered. While I do not know if the hospital ethics committee or pastoral care were involved in this case, these services could have been offered to the family immediately after Jahi suffered cardiac arrest. A clinical ethicist can serve as an important gatekeeper to these services that may help the family cope during this difficult time. Second, the family would have been treated with dignity and respect. In a meeting with Jahi's family, the chief of pediatrics said, "What don't you understand, she is dead, dead, dead" (Dolan 2013, 11). Instead of this staunch approach to divulging the determination of brain death, the medical team would have been considerate of the delicate situation, answering all questions thoughtfully and patiently.

Furthermore, instead of moving to withdraw ventilator support immediately after determination of brain death, the hospital would have given the family time to be with Jahi, without setting a definitive end-point of that time. Unlike the temporizing approach currently deployed by many brain death policies, allowing time in a socially and culturally appropriate manner is not aimed at getting the family to "accept" the

determination. Rather, time would allow the family to interact with others and navigate their changing social roles and relationships, as necessary.

Third, the family's religious values would have been incorporated from the beginning of the patient encounter. Rather than viewing the family's faith as a detail that needed to be handled or dismissed, the medical team would recognize the ways in which the family's faith shapes and informs their worldview. An attunement to grief in this case may also have prevented the stereotypical characterizations of Jahi's family in the media and scholarly literature. Whether Jahi was dead or alive after her cardiac arrest, her family lost the little girl they once knew, and they should be able to grieve without judgment. Most importantly, a holistic incorporation of grief is not merely giving the family "more time" to "come to terms" with the brain death determination. Rather, it is recognizing the pure emotional and moral force of the grief in its specific social context without trying to rationalize or justify the response.

In "The Will to Believe," philosopher William James (2010) argues that in some circumstances, where there is sufficient ambiguity, our passions may justify our beliefs. Arguing in support of religious faith, James states, "our passional nature not only lawfully may, but must, decide an option between propositions, whenever it is a genuine option that cannot by its nature be decided on intellectual grounds" (James 2010, 24). While critics of Christianity claim that there is insufficient evidence to rationally hold to this religion, James retorts, "Objective evidence and certitude are doubtless very fine ideals to play with, but where on this moonlit and dream-visited planet are they found?" (James 2010, 27). Similarly, as evidence has shown, cases of brain death will not be decided on intellectual grounds alone. Even with our advances in technology, we still live in a moonlit and dream-visited planet, where objective evidence and certitude are as elusive as ever in helping us to resolve moral conflicts.

In cases of brain death, where there is certainly ambiguity and families have so much at stake, perhaps a family's grief is truly enough to justify their belief that their loved one is alive. Unlike the Ilongot practice of headhunting, keeping Jahi on a ventilator was a morally viable option precisely because of the ambiguity and contested nature of the diagnosis. Only in cases of brain death, where there is moral, scientific, and legal uncertainty, can grief hold such moral weight. By expanding reasonable accommodation policies to allow for refusals

of brain death determinations based on grief, families can express the powerful moral and cognitive force of their grief. Providers might then have realized that a “good” outcome for Jahi and her family was simply accepting the family’s conclusions that she was not dead. Although Jahi has now been removed from ventilator support due to complications from liver failure, this argument remains salient for many other families who may face a determination of brain death. Will their experience of grief be dismissed out of hand, or will clinicians and bioethicists learn from the mistakes of the past?

Conclusion

One may be tempted to ask why grief merits such particular attention in determinations of brain death. Certainly, there are other emotions at play such as hope, fear, anger, and love, and I believe further research is warranted to explore the role of these emotions in brain death determinations. Yet grief is one of the few (perhaps the only) emotion explicitly attended to in policies for determining brain death. As shown in the policies above, there seems to be an implicit understanding of what grief is and how it should be handled in determining brain death. According to reasonable accommodation policies, time alone will resolve the grief and bring the family to accept the determination of brain death. However, this temporizing approach fails to address the complexity of grief in brain death determinations and does not recognize the variety of morally valid conclusions that can be drawn in these situations. Thus, I argue that in some rare cases, reasonable accommodation policies should be expanded to allow families to reject the determination of brain death.

Even for those who balk at my conclusion that an incorporation of grief may lead to rejection of the brain death determination, I hope I have shown that clinical ethicists, and bioethics more broadly, need to pay attention to grief in the clinical encounter in order to better care for the patients and families with whom they work. Indeed, most of my recommendations for attuning to grief in the case of Jahi McMath may seem moderate, but these small changes could have greatly improved the experience for Jahi’s family. Only by understanding and addressing the various manifestations of grief that impact the situation can clinical ethicists fulfill their

professional capacity to help family members work through these difficult situations.

And perhaps, at its core, grief encompasses other emotions that we so heartily want to embrace and recognize in the ethical encounter. As Martha Nussbaum poignantly articulates, emotions have close connections with one another: “as hope alternates uneasily with fear, as a single event transforms hope into grief, as grief, looking about for a cause, expresses itself in anger, as all of these can be the vehicles of an underlying love” (2001, 22). I hope that by offering new ways to think about grief in brain death, I have also shown new ways to think about a family’s life, a family’s love, and a family’s unique way of being in the world.

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