

AN ABSTRACT OF THE THESIS OF

Jessica C. Cox for the degree of Master of Arts in Applied Ethics presented on April 18, 2011.

Title: Hospice Nurses as “Midwives to the Dying”: Guiding Life’s Important Journeys

Abstract approved:

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This thesis explores the metaphor of hospice nurses as “midwives to the dying” by applying philosophical inquiry to the field of hospice. I focus on the history of the movements, their professional approaches to caregiving, and the core commitments of both the modern midwifery and hospice movements. Although focused on different ends of the life cycle, the two professions share many similarities and a method of caring that are set against—and provide a critique of—the institutionalized care of the biomedical model. In addition, interviews with both midwives and hospice nurses allow the thesis to move beyond philosophical inquiry by examining how the metaphor is reflected in the approach to care of the hospice nurses. A better understanding of the dying process has the potential to change our attitudes and beliefs about something that has become taboo in Western culture. Hospice has played, and will continue to play, a role in this important change. Deepening the understanding of hospice care, for those both within and outside the movement, provides an important contribution to this attitudinal shift.

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Hospice Nurses as “Midwives to the Dying”:  
Guiding Life’s Important Journeys

by  
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A THESIS

Submitted to  
Oregon State University

in partial fulfillment of  
the requirements for the  
degree of

Master of Arts

Presented April 18, 2011  
Commencement June 2011

Master of Arts thesis of Jessica C. Cox presented on April 18, 2011.

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I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

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Jessica C. Cox, Author

## ACKNOWLEDGEMENTS

I would like to thank a number of people without whom this thesis would not have been completed. First and foremost, I would like to thank Dr. Courtney Campbell, who not only supervised the writing of this thesis, but provided incredible insights, challenges, and opportunities for me during my two years at Oregon State University. His desire to open doors for me to step through if I chose allowed me a number of opportunities that I would not otherwise have had. His guidance and mentoring have improved both this thesis and my education in ways too numerous to count. I also thank the members of my master's committee: Dr. Sunil Khanna, Dr. Kathleen Moore, and Dr. Carol Caughey.

I also owe my deepest gratitude to my family and friends, who provided encouragement and support throughout the process. Each time I answered the question "what is your thesis about," I was reminded of my intellectual curiosity about how our words and beliefs shape our actions and character. A special thanks to my parents, who provided insight and feedback on drafts, and to my fiancé, who provided support and encouragement.

I am indebted as well to the hospice nurses and midwives with whom I spoke, and without whom this project would not have been possible. Their insight and willingness to reflect on their important work made the task of exploring this metaphor interesting and relevant.

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Hospice Nurses as “Midwives to the Dying”:

Guiding Life’s Important Journeys

## Introduction

*A woman lies in bed, in pain and agony, wishing for the suffering to end. "How much longer?" she asks. "Make it stop," she pleads. Another woman gives her a hot compress, speaks to her soothingly. "Soon," she whispers. But the pain gets worse. It is the most powerful experience the woman has ever felt. "Trust your body," her guide says, "it knows what to do." At the peak of her pain, the woman gives in to her bodily instincts, because she knows nothing else to do. She is relieved, her body takes over. It begins to actively work, and the physical exertion causes her to moan. The ache does not subside, but she feels a connection with her natural urges as they navigate the waves of pain. And then, just when she thinks she cannot take it anymore, a release.*

The description above is likely to elicit ideas about childbirth. A woman lying in pain, actively laboring, and then a release as the pain subsides. Admittedly, the choice of a woman was purposeful, but the act of childbirth is not the only one to which this description could apply. In fact, for many who have experienced the death of a loved one, this may just as easily elicit memories of the last moments of life. There are strong parallels between the birthing and dying processes, and given these parallels, it should not be surprising that hospice nurses might use the metaphor of "midwives for the dying" to describe the extraordinary care they provide. This metaphor should not be taken lightly. It has serious implications for the kind of care provided to the dying person and also for the self-understanding of those who use it to describe their professional world.

Twentieth century anthropologist Margaret Mead once noted that "When a person is born we rejoice, and when they're married we jubilate, but when they die we try to



pretend nothing has happened."<sup>1</sup> Our death-avoiding culture perpetuates this attitude, and the quality of end-of-life care in our country suffers because of it. The modern hospice movement, which in North America began in the 1960s, aims to reverse this trend, to educate the public about death and dying, and to help dying patients through the process, in the hopes of achieving a peaceful and comfortable death. In addition, hospice strives to provide dying patients with opportunities for growth and reconciliation in the end stages of terminal illness. End-of-life care remains, however, largely a mystery to the general public. A misunderstanding of hospice by the public and dying patients contributes to its underutilization. It is important that accurate information about hospice and the services hospice professionals perform is available in order to provide these services to those who would benefit from them.

At the same time, it is important for hospice professionals, like any other professionals, to continually seek to understand their own roles more completely. Doing so allows them to see their work in context, examine it from different perspectives, and continue to improve on the work they do. One way of understanding the role of hospice professionals more completely is to examine the metaphors they use to describe their own work. The metaphor of hospice professionals (and hospice nurses in particular) as “midwives to the dying” is used by hospice professionals, physicians, and patients; however, there is little serious exploration of its use or application. This thesis will explore the appropriateness and utility of the metaphor, and evaluate the prescriptive

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<sup>1</sup> Margaret Mead in Pamela Albert, “Grief and Loss in the Workplace,” *Progress in Transplantation* 11(3), 2001, 169.

value of the metaphor and its ability to provide insight to hospice professionals and the general public about their role in the dying process. Thus, my central question is whether the application of the metaphor of midwifery in hospice care is appropriate, useful, and insightful for hospice professionals and the general public. At the end of my analysis, I anticipate being able to argue that this metaphor is not only accurate, but that it illuminates essential roles of hospice professionals, particularly hospice nurses, in the dying process, that it could provide guidance to hospice nurses struggling to define their role for themselves or others, and that it could also potentially prove useful in helping patients understand their dying process.

In order to argue for these claims, I will first discuss the history of both the modern midwifery movement and the modern hospice movement, highlighting important similarities and differences in the way these movements have been shaped. In doing so, I will also contrast both models with the biomedical model of healthcare dominant in contemporary American medicine. Both movements are set in opposition to the biomedical model of care, and point out the harm of the highly technological role that biomedicine plays in the natural processes of birthing and dying. Following the discussion of the history of the movements, I will discuss the philosophy of professional identity as it pertains to midwives and hospice nurses as well as their counterparts in the biomedical world. By doing so, I will be able to draw further parallels between the work of midwives and hospice professionals, including the ways in which they view the body, their patients, their role, and the processes of birth and death, respectively. In a third chapter, I will test the scholarly analysis of the first two chapters with interviews I

conducted with midwives and hospice nurses to better understand whether this metaphor is applicable beyond the academic world. If it does not hold true with the nurses themselves, then its usefulness is immediately limited to the ivory tower of academics, and should be discarded if it does not correspond to the lived experience of those it is intended to describe. Finally, I will conclude by answering my question about whether the metaphor of hospice professionals as midwives to the dying is accurate and useful, or whether it can serve a prescriptive purpose in the hospice field. It is important, however, to say an initial word about the use and importance of metaphor in ethical discourse.

## **Metaphor**

Metaphors are widely used in the medical sphere, and, as with most metaphors, some prove more helpful than others. We can describe physicians as God, patients as consumers, disease as a war, medicine as a weapon, death as failure, or an illness as the enemy, among many others. In order to evaluate the usefulness of a metaphor, it is important to look at how it is used, what it illuminates, what it hides, and what it means. A metaphor compares two things, and, as linguist George Lakoff and philosopher Mark Johnson contend, its essence is “understanding and experiencing one thing through another.”<sup>2</sup> Thus metaphors strive to tell us more about one thing (generally, something that is more abstract) by comparing it to, and encouraging us to understand it through, another thing (generally something more concrete and accessible). Bioethicist James

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<sup>2</sup> Lakoff and Johnson in James Childress, *Practical Reasoning in Bioethics*, (Bloomington, IN: Indiana University Press, 1997), 4.

Childress argues that metaphors can be powerful tools in the medical field, as they “shape how we think, what we experience, and what we do by what they highlight and hide.”<sup>3</sup>

Before going further, it is important to distinguish between descriptive metaphors—those that endeavor to describe what is—from normative metaphors—those that describe what ought to be. For example, we could debate whether the metaphor of the physician as father (attached to the model of medical paternalism) aptly describes how physicians and patients relate to one another, or we could debate whether or not it *ought to* form the basis for the physician-patient relationship. We may, conversely, decide that while it accurately describes what physician-patient relationships are or have been like, it should not inform our model in a normative way. In addition, it is important to look at the implications of any metaphor for how they guide or direct beliefs or actions of those to whom they apply. Descriptive models have the potential to create similarities in addition to expressing preexisting similarities between the primary and secondary subjects of a metaphor. Metaphor, Childress argues, “does not merely compare two things that are similar, but rather enables us to see similarities in what would be regarded as dissimilar.”<sup>4</sup> I suggest that the metaphor of hospice nurses as midwives to the dying can be used both as a descriptive metaphor, because the similarities between midwifery and hospice care are striking, but also as a normative metaphor, one that directs the kind of care that the dying ought to receive.

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<sup>3</sup> Childress, *Metaphor*, 5.

<sup>4</sup> Childress, *Metaphor*, 17.

Some critics argue that metaphors mask true meaning, particularly in ethical discussions, and that moral points should be made more directly.<sup>5</sup> “According to the traditional substitution view,” Childress writes, “a metaphorical expression is merely a substitute for some equivalent literal expression... [and] are dispensable ways to express what could be expressed differently.”<sup>6</sup> In contrast, Childress claims that metaphors serve to elicit the moral imagination—we must imagine medicine as war in order for that metaphor to serve as an illustration of anything. Critics argue, however, that their use in ethical discourse is limited and points should be made without appealing to them. While they might prove compelling in bioethical debate, critics claim, they are dispensable ways to express things that “equivalent literal expressions or comparisons” could express more accurately.<sup>7</sup>

Many critics also argue that metaphors ought not be central to bioethical discourse because they are unrelated to the principles, rules, or theories that guide bioethical discussion and decision-making. In contrast, Childress claims that metaphors exist in close relation with these foundations of bioethical discourse. Metaphors help us to see and understand the moral problems in medicine, while principles, rules, virtues, and moral reasoning generally help us to solve those problems. He argues that our health care discussions and policy “need the vision provided by metaphors, analogies, and symbols, as well as...principles, rules, and theories.”<sup>8</sup> Metaphors also ought not serve as

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<sup>5</sup> Childress, *Metaphor*, 12.

<sup>6</sup> Childress, *Metaphor*, 4.

<sup>7</sup> Childress, *Metaphor*, 4.

<sup>8</sup> Childress, *Metaphor*, 4.

conversation-stoppers. Medical ethicist Edmund L. Erde contends that the phrase “playing god” does just that. He argues that any activity labeled “‘playing god’ carries the implication that it is clearly wrong.”<sup>9</sup> Instead of allowing for more fruitful discussion, the use of the metaphor “playing god” hides several relevant moral features of the acts to which it is applied, and is employed to end the discussion, rather than to enrich it.

Despite the problems that arise from employing metaphors in ethical discourse, few ethicists wish to do away with metaphors altogether, and instead work to demonstrate what distinguishes a good metaphor from a bad one. Metaphors contribute to constructive ethical discussion when they do any of three things—(1) provide new insights, (2) contribute meaning or depth, or (3) provide a tool for normative prescriptions. In health care, then, a metaphor is constructive when it empowers or explains things in a way that improves a patient’s health or welfare in its many forms, including emotionally, psychologically, or spiritually. A metaphor is unhelpful, on the other hand, when it fails to do those things, clouds the conversation with emotions by hiding relevant moral considerations, or unfairly highlights others. In addition, they are unhelpful when they are so vague that they cannot be understood. Statements such as “doctors should not play god,” Erde asserts, cannot give relevant moral guidance because they are so unclear that moral agents cannot act in accordance with them.<sup>10</sup> Thus, good metaphors not only accurately describe or prescribe beliefs or behaviors and fairly highlight moral

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<sup>9</sup> In Childress, *Metaphor*, 15.

<sup>10</sup> In Childress, *Metaphor*, 15.

considerations, but must also be clear enough to guide (or describe) the beliefs or actions of moral agents.

In reality, many medical metaphors may do more harm than good. For example, as Childress points out, military metaphors, such as those about disease as the enemy or medicine as war can stigmatize illnesses and those who are ill. While military metaphors can, in some circumstances, elicit courage and hope for a patient, these same metaphors can prove detrimental for other patients. Those who cannot “beat” the disease or who choose to “give up the fight” can be seen as weak. While such metaphors can provide inspiration to “fight cancer” or “beat the disease,” they can also distort the nature of the disease or make one feel as if he or she is fighting themselves. In addition, this metaphor focuses on “combating” disease through the use of technology rather than preventing diseases, which can distort our discussions about health care priorities. Childress also points to the potentially problematic nature of other metaphors, including business metaphors, which envision patients as consumers, physicians as providers, and health care as a commodity. These metaphors also distort health care priorities, focusing on consumer choice, rather than medical necessity. Critics of business metaphors “worry that the language of efficiency will replace the language of care and compassion for the sick and equity in distribution of health care.”<sup>11</sup> Particularly when used prescriptively, or when descriptive metaphors do not resonate with a patient’s lived experience, metaphors can be detrimental to the experience of a patient. Metaphors are unhelpful if they prove

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<sup>11</sup> Childress, *Metaphor*, 9.

disempowering to any individual, particularly one who is in a position of vulnerability, such as a patient.

On the other hand, some metaphors are useful. Historically, the metaphor of nurses as advocates for their patients has moved them from a passive role in medicine to a more active one. Nurses, who previously were taught to be loyal and obedient to *physicians*, are now expected to be dedicated to their *patient's* well-being, even if their ideas about treatment differ from that of the physician. This historical shift, which took place in the 1970s, gave patients another ally in the often-confusing medical establishment.<sup>12</sup> In addition, it served to empower nurses, who often felt conflicted between their duties to the medical establishment and their duties to their patients. Gerald R. Winslow detailed this shift in his 1984 article "From Loyalty to Advocacy: A New Metaphor for Nursing." Winslow argues that metaphors are not simply "niceties of language," but rather "they interact with the more explicit features of nursing ethics, such as stated rules and principles, in ways that tend to be either mutually supportive or productive of change."<sup>13</sup> When military metaphors dominated not only medical discourse in general, but nursing in particular, the virtue associated with their profession was loyalty and the norm obedience to those of a higher rank. In contrast, the contemporary metaphor of nursing as advocacy "is associated with virtues such as courage and norms such as defense of the patient against infringement of his or her rights."<sup>14</sup>

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<sup>12</sup> Childress, *Metaphor*, 13.

<sup>13</sup> Gerald Winslow, "From Loyalty to Advocacy: A New Metaphor for Nursing," *The Hastings Center Report* 14:3 (1984), 32.

<sup>14</sup> Winslow, *From Loyalty*, 32.



Not only are these two contrasting metaphors linked with different virtues, Winslow contends, they have been purposefully used to direct the behavior of nurses. The military metaphors placed this purpose within the confines of loyalty primarily to the physician, and often meant nurses were expected to follow physicians' orders even when they believed the orders would cause serious pain to the patient. They were taught to be "good soldiers" and trained in military values like obedience. Nurses were taught that a patient's faith in the physician was an important healing element, so that "even if the physician blundered, the patient's confidence should usually be maintained at all times."<sup>15</sup> In 1929, however, the gradual shift to a more active nursing role was helped along by a Supreme Court ruling that found a nurse guilty of manslaughter because she had followed physicians' orders that resulted in the death of a patient.<sup>16</sup> While the physician was acquitted, the nurse was convicted based on her failure to question orders she believed would bring harm to the patient. Nurses who had formerly looked down upon any nurse who questioned physician's orders now began to examine their own role in patient care.

The ways in which people, including nurses, think about themselves shape the beliefs they have about their jobs and dictate their actions. For example, Sarah Dock, in an article in the *American Journal of Nursing* in 1917, wrote that "...The first and most helpful criticism I ever received from a doctor was when he told me that I was supposed

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<sup>15</sup> Winslow, *From Loyalty*, 34.

<sup>16</sup> *Somera Case*, G. R. 31693 (Philippine Islands, 1929).

to be simply an intelligent machine for the purpose of carrying out his orders.”<sup>17</sup>

Contrasting this with advocacy language implies different actions nurses are expected to take. Nursing codes now require nurses to protect “the client” from the “incompetent, unethical, or illegal practices of any person,” including the physician.<sup>18</sup> In order to be a good advocate, nurses provide information, prevent harm, and actively protect the patient. A shift in metaphor, in this case, both reflected and contributed to a shift in nursing behavior.

Childress also points to the more direct role that a metaphor can take for a patient. He argues that sometimes the individual chooses a metaphor that in turn assigns meaning to his or her illness.<sup>19</sup> This creative act might allow a patient to view their illness in a different way, and this could be an empowering act. While in some cases the military metaphor might help a patient through his or her illness, perhaps a gentler metaphor of journeying is more appropriate for other patients or at other times. He claims, however, that the military metaphor is “generally more prevalent than the journey metaphor because it better fits the experience of modern medicine.”<sup>20</sup> Whether the use of the military metaphor is positive for a patient or not then serves as an important tool in evaluating its usefulness in that situation.

We ought not do away with metaphors, Childress and others argue, because they form an important part of bioethical debate, at the very least because no matter what

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<sup>17</sup> In Winslow, *From Loyalty*, 34.

<sup>18</sup> Winslow, *From Loyalty*, 37.

<sup>19</sup> Childress, *Metaphor*, 7.

<sup>20</sup> Childress, *Metaphor*, 7.

priority is given to them within bioethics, everyday people are still going to use them to inform their understanding of their illness or their relationship to the medical establishment. Because people use them to understand their own situations, bioethicists must seek to understand them if they hope to understand the experience of being a patient or physician or any other health care actor. Critics who call for the removal of metaphors from ethical discourse “miss the role of imagination,” he claims.<sup>21</sup> He points to the fact that opponents of particular metaphors rarely argue that the metaphor should be thrown out altogether, but rather supply other alternatives that they think better describe—or ought to direct—the way physicians approach their work as moral agents.

What makes a good metaphor, then? In using a metaphor, we presume that comparing what Childress calls the “principal subject” to another thing highlights certain of its features, while hiding others. A good metaphor, then, is one that highlights and hides features in a fair way, and through which we can come to a better understanding of the principal subject. Childress contends that “for each use of metaphor, we have to ask whether, through highlighting and hiding features of subjects, it generates insights about what is or about what ought to be.”<sup>22</sup> Having considered the use of metaphor and the ethical standards by which they should be measured, I now want to apply some of these insights about metaphor to assist in understanding the metaphor of midwife to the dying in hospice care.

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<sup>21</sup> Childress, *Metaphor*, 12.

<sup>22</sup> Childress, *Metaphor*, 16.

## **Chapter 1: The History of Hospice Care and Midwifery**

In order to begin to understand the intricate similarities between the modern hospice and midwifery movements, it is essential to understand how each came to be. Each model is at least in part about returning to an older, historical practice of caregiving, and finding and embracing in that older model a new way of caring for people. I will first discuss the history of hospice care, including the relocation of dying and death from the home to the hospital, and the hospice movement's response to this context for death. Second, I will discuss the history of midwifery, including the transfer of birthing from the home to the hospital and the rise of obstetrics, as well as the recent advancement of the "natural birth movement." Once I lay out the roots of each movement, I will then discuss how hospice care and midwifery contrast with the biomedical model of institutionalized care, and why that contrast is central to the model of care practiced in both fields. Each movement defines itself not only on its own terms, but also in contrast with what it is not, and what it sees as harmful in the modern medical world. Both midwifery and hospice care are wary of the medicalization of processes (birth and death) they see as natural, and are concerned about the idea of the loss of personhood through technologization. By this, critics of modern medical care mean the overuse of technology to "assist" processes that need no such technological intervention, or at least very limited technological intervention. When technology is applied to natural processes as is common in modern medical care, they argue, the person who receives treatment becomes a secondary factor to the disease and the focus of medical care is on the disease rather than the patient.

## History of Hospice Care

Although hospice is often seen as a response to the medicalization of death and the impersonal and lonely nature of death in a hospital (and in large part, the rebirth of hospice can be seen in this light), it is important to understand its roots, which go back at least as far as the 3<sup>rd</sup> century B.C.E.<sup>23</sup> Historically, the terms hospice, hospital, hotel, and hostel were used interchangeably, all derived from the Latin root *hospe*, meaning hospitality. Along with care of the dying, ancient hospices offered care to those who were sick or traveling, providing care not for those who resided near them, but rather for travelers who lacked family and support when they encountered trouble on their journeys. For many religions, most notably Christianity and Islam, care for the sick and dying was seen as a sacred duty. Christianity's emphasis on love and piety for the poor, sick, and homeless led to the church's control of Western medical care by the end of the fourth century.<sup>24</sup> At the same time, Muslims built many hospices throughout the Islamic world, sustaining and adding to Greek medical knowledge.<sup>25</sup> These early hospices emerged out of a sacred worldview where love and commitment to God translated into service to others. Thus, the typical medieval hospice "was a blend of guest house and infirmary where all comers were given food, shelter, and care until they died or set out again,

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<sup>23</sup> Cathy Siebold, *The Hospice Movement: Easing Death's Pains* (New York: Twayne Publishers, 1992), 13. A special facility for the dying was recorded in India around 225 B.C. for religious pilgrims who came to the Ganges River in order to have their ashes scattered in the river when they died. Separate houses for the sick, travelers, and the dying, which were related both to modern-day hospices and hospitals, were built as early as 1134 B.C.E.

<sup>24</sup> J. Q. Benoliel in Siebold, *Hospice Movement*, 14.

<sup>25</sup> Siebold, *Hospice Movement*, 16.

refreshed and renewed, on their journeys.”<sup>26</sup> Hospices continued to grow throughout the medieval centuries, with an especially intense period of growth during the Crusades. Beginning in the 11<sup>th</sup> century, institutions were built to cater to travelers on their way to and from the crusades, and crusading knights often contributed to the building of such structures. By the 13<sup>th</sup> century, there were 750 hospices in England, 40 in Paris, and 30 in Florence.<sup>27</sup>

Health care in these early hospices was largely provided by religious workers, and was thus relatively ineffective at controlling or treating diseases. Sociologist David Wendell Moller argues that from the 5<sup>th</sup> through the 19<sup>th</sup> century:

an attitude of acceptance and unconcerned familiarity with death and its artifacts was socially widespread. The traditional patterns of human death reflected an intimacy of ongoing involvement between human living and human dying.<sup>28</sup>

While the nature of this attitude had changed, death remained an integral and ever-present part of life. Similar attitudes toward death were prevalent in colonial America. The Puritans in the United States lived with the ever-present fear of death in light of the likelihood of eternal damnation, and rural Americans continued to care for the dying without the assistance of professionals. In rural America, death was often seen as an “inevitable dimension of human destiny and an integral part of the life of the individual and the community. People died at home with family and friends around them... and the

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<sup>26</sup> Anne Munley, *The Hospice Alternative: A New Context for Death and Dying* (New York: Basic Books, Inc., Publishers, 1983), 28.

<sup>27</sup> E. G. McNulty and R. A. Holderby in Siebold, *Hospice Movement*, 16.

<sup>28</sup> David Moller, *On Death Without Dignity: The Human Impact of Technical Dying* (Amityville: Baywood Publishing Company, Inc., 1990), 13.

family doctor...came to the house to minister to both patient and family.”<sup>29</sup> Beginning with the 19<sup>th</sup>-century Romantics, dying was transformed into what historian Anne Munley refers to as “a peaceful and beautiful deliverance.”<sup>30</sup> Death was seen as a key to salvation, and thus remained an integral part in the daily lives of 19<sup>th</sup>-century people. While motivations differed among these groups and across time, death was nevertheless familiar and accepted, whether that meant begrudgingly acknowledged as inevitable, or welcomed with open arms as the grace of salvation.

Even while these attitudes remained pervasive, particularly in rural America, a shift was taking place in the kind of care given not only to the dying, but to sick people in general. The Protestant Reformation, which began in 1517, marked the beginning of a transfer of medical authority from churches to secular institutions.<sup>31</sup> Institutions that formerly resembled what we would consider hospices were renamed hospitals and many began to specialize in the treatment of specific illnesses. As medical knowledge increased, physicians—now the main caregivers for the ill—worked to improve their status. According to Cathy Siebold, a historian of the modern hospice movement:

Before the 1800s, medicine was a natural art performed by apothecaries, midwives, barber surgeons, and diploma physicians. Diploma physicians were not viewed as experts or accorded high status; midwives, apothecaries, and lay healers were their equals, and the public received health care from their preferred healer in their own home. Those who sought medical care in hospitals were often poor and unable to afford other services.<sup>32</sup>

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<sup>29</sup> Moller, *Without Dignity*, 10.

<sup>30</sup> Munley, *Hospice Alternative*, 8.

<sup>31</sup> Siebold, *Hospice Movement*, 17.

<sup>32</sup> Siebold, *Hospice Movement*, 18.

With further development of knowledge in anatomy and physiology, physicians applied a scientific approach to treating disease that moved away from the supportive services for the dying that had previously been the domain of religious health care. Hospitals became the center of treatment, even though death remained a common outcome and the general public remained wary of their success.

More scientifically-based medical care developed in response to control exercised in early hospitals by physicians. In order to improve their status, physicians started to regulate who could be treated in hospitals, discouraging treatment for patients “with chronic, incurable, or terminal conditions,” whom they perceived to be outside of the medical realm.<sup>33</sup> Death for the first time became the enemy, not a reluctant inevitability, but a threat to the work of physicians.<sup>34</sup> The changes that had taken place as medical authority was transferred from religious leaders to secular physicians were compounded in the early twentieth century, when new technologies like X rays and radiation placed medical authority almost completely in the sphere of modern science.

With the rise of scientific medical care that placed death as the enemy, death and disease became something that was dirty and needed “cleaning up.” No longer was death an inevitable part of daily life; it had become feared and intolerable. With a shift in perception of death to something dirty and evil, some hospices that had reemerged in Europe, and even some new early hospices that had been built at the turn of the 19<sup>th</sup> century in America, were viewed negatively, and were even referred to as “death

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<sup>33</sup> Munley, *Hospice Alternative*, 19.

<sup>34</sup> Siebold, *Hospice Movement*, 21.



houses.”<sup>35</sup> These early hospices returned to the religious roots of hospice care, and generally cared for people dying from cancer. Although these hospices remained through the beginning of the modern hospice movement and persist today, they are generally not seen as part of the movement, and are often completely forgotten by the modern hospice movement.<sup>36</sup> When the modern hospice movement began with Cicely Saunders, these religious hospices saw their work as different from those in the movement (and vice versa) particularly as it related to family involvement in the hospice process.<sup>37</sup> Nevertheless, it is important to note their presence in order to understand how the modern hospice movement viewed itself.

In the 1930s through the 1950s, the increasing medical knowledge held by physicians and in hospitals, combined with an attitude of fear and avoidance of death which will be described further in the third part of this chapter, led to the relocation of death and dying to the hospital. As death moved from the familiarity of the home to the confines of the hospital, some observers noted that this process was harmful for dying persons, particularly because these patients were often left to die when nothing further could be done to treat their disease. These patients often felt abandoned. At the same time, rejections of this tendency to abandon dying patients for whom nothing could medically be done sometimes led treatment too far in the other direction, causing overtreatment of patients for whom further treatment was futile.

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<sup>35</sup> Siebold, *Hospice Movement*, 23.

<sup>36</sup> Siebold, *Hospice Movement*, 22. One of the religious hospice groups, began in the 1890s, is the Dominican Sisters of Hawthorne. Some of their seven original facilities exist.

<sup>37</sup> Siebold, *Hospice Movement*, 24.

The modern hospice movement is generally viewed as a response to two extremes, excessive treatment of dying patients even when such measures are medically futile, and the threat of euthanasia and hastened death. It is also largely a response to what people in the early modern hospice movement saw in regard to how dying persons were treated. The void in modern medical care in treatment of the dying, hospice professional Judith Kohn states, exists because acute care hospitals are not designed to meet the needs of dying patients. “Such institutions,” she argues, “are geared instead to cure patients and send them home as quickly as possible and to give efficient rather than individually optimized care.”<sup>38</sup> This gap was also clearly demonstrated in the lack of knowledge physicians had regarding care for the dying. Until the 1950s education about caring for this population was generally nonexistent for physicians.<sup>39</sup> Modern hospices are a response to a perceived social need, a conviction that people who are dying need a different kind of care than that provided under the dominant biomedical model. “If dying obliterates the dignity of the self,” says Moller, “the societal movement toward total development of human potential is thwarted.”<sup>40</sup> If, on the other hand, dying can be transformed into a process of growth and enrichment, then our desire to develop as individuals can continue through the dying process. The desire to transform the experience of dying—to create a way of dying “meaningfully,” formed the root of the modern hospice movement.

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<sup>38</sup> Judith Kohn, “Hospice Movement Provides Humane Alternative for Terminally Ill Patients.” *Modern Health Care (Short Term Care Edition)* 6:3 (1976): 26.

<sup>39</sup> Siebold, *Hospice Movement*, 19.

<sup>40</sup> Moller, *Without Dignity*, 10.

The modern hospice movement initially consisted largely of scholars and non-physician health care workers who were concerned that hospitals and nursing homes were not prepared to care for the dying, and worse, that the dying were often mistreated or abandoned when institutionalized medicine concluded that nothing more could be done for them. While nothing more could be done to cure these patients, hospice caregivers knew there were still ways to provide care for them. The concept of the modern hospice first emerged with Cicely Saunders, a former nurse who trained first as a medical social worker, then as a physician. Upon seeing how the dying were treated, she committed herself to creating a space that could better meet their needs, and opened St. Christopher's Hospice in London in 1968. She defined hospice as a cross between a hospital and a home, "with the skills of one and the hospitality, warmth, and time available of the other and beds without invisible parking meters beside them."<sup>41</sup>

The emphasis is on control of pain, and advanced comfort measures when curative measures are no longer deemed appropriate. Importantly, the focus of pain control in hospices is not on controlling pain after it occurs, but rather on preventing it from occurring, eliminating, when possible, the fear about whether pain will or will not come, and the degree to which it will affect the patient. In addition, it includes the family in the unit of care, rather than an exclusive focus on the individual patient, and on providing a variety of services that not only meet the patients' physical needs, but emotional, spiritual, and psychological needs as well. Other early leaders of the modern hospice movement included psychiatrist Elisabeth Kübler-Ross, who conducted extensive

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<sup>41</sup> Cicely Saunders in Munley, *Hospice Alternative*, 30.

research about how to communicate with dying patients, and nurse Florence Wald, the main organizer of the movement.<sup>42</sup>

Leaders of the movement saw themselves as disconnected from the older, religious programs. Because they viewed their work as a response to the perceived mistreatment of the dying, and not as a religious or spiritual calling, they were uninterested in these earlier hospices. Similarly, while these earlier hospices were interested in the expansion of hospice care, they did not see themselves as involved in the new hospice movement. In addition, the early hospices saw themselves as the end of treatment, while these new hospices wanted to change current treatments and add new ones focusing on pain control.

In 1974, Hospice, Inc., America's first hospice, was created in New Haven, Connecticut.<sup>43</sup> In 1975, out of the momentum of this modern hospice movement, an international task force set forth guidelines for hospice programs.<sup>44</sup> These guidelines emphasized giving control to individual patients, incorporating personal lifestyles into treatment plans, providing care to family, who also suffer stress, and controlling patients' physical symptoms, as well as providing support to staff members. Hospice is not only a word used for a facility that provides such specialized care for the dying, but reflects a mode of care that can be provided in a variety of locations.<sup>45</sup>

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<sup>42</sup> Siebold, *Hospice Movement*, 87.

<sup>43</sup> Paul Dubois, *The Hospice Way of Death* (New York: Human Sciences Press, 1980), 85.

<sup>44</sup> Siebold, *Hospice Movement*, 2.

<sup>45</sup> Siebold, *Hospice Movement*, 105.

## History of Midwifery

Until the 18<sup>th</sup> century, “midwife” (literally mid, meaning with, and wif, meaning wife, or woman) referred to anyone who provided care to a woman during childbirth, regardless of the person’s level of training.<sup>46</sup> The English word midwife was used as early as 1303, although the practice of attending women’s births goes back much further. As a part of the everyday lives of women, many attended only a few births, but some became particularly skilled and often attended many births, usually out of their own homes. In these early days of attending births, women who were particularly good at providing comfort and encouraging others, and who were able to most often attend successful births were highly esteemed and often asked to attend future births.<sup>47</sup>

Men did not attend births, excluded from the practice due to religion and standards of sexual propriety; additionally, they had no particular expertise that was valuable to the childbirth process.<sup>48</sup> It was not until medicine progressed that physicians became interested in childbirth, and even then their interest was limited to abnormal pregnancies. The care of normal pregnant women, historian Judith Rooks says, “was beneath the dignity of early physicians.”<sup>49</sup> This does not mean that early midwives were free from scrutiny, however. During the fifteenth and sixteenth centuries, the church in Europe controlled midwifery, and many midwives were accused of offering babies who

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<sup>46</sup> Judith Rooks, *Midwifery and Childbirth in America* (Philadelphia : Temple University Press, 1997), 3.

<sup>47</sup> Rooks, *Midwifery*, 4.

<sup>48</sup> Rooks, *Midwifery*, 4.

<sup>49</sup> Rooks, *Midwifery*, 11.

died in childbirth to the devil.<sup>50</sup> Between 1450 and the mid-1700s many midwives were accused of witchcraft. The combination of increasing medicalization of birth and accusations of witchcraft meant that the once necessary practice was often driven underground.

At the same time midwifery faced increased scrutiny, medicine was advancing, and male physicians were seen as having far more authority, even though they lacked anything but a theoretical knowledge of childbirth. When midwifery was accepted by the Catholic Church in 1703, it was limited to women who had particular experiences, including having taken a class given by a physician, and these women had to pledge to call a physician if they encountered a difficult birth. Midwives, with far more extensive experience in attending childbirth, were for the first time placed under the authority of physicians, who had for the most part gained their knowledge from midwives and other untrained caregivers themselves. In addition, this led to a difference in the experience of childbirth by physicians and midwives, with midwives experiencing hundreds of normal births throughout their practice, and physicians encountering many complicated or dangerous labors.

Physicians, while lacking the hands-on experience with normal childbirth that midwives had to offer, did have other technological advances that allowed successful births that would otherwise probably have resulted in the death of the child, the mother, or both. In the early seventeenth century, the invention of forceps by Peter Chamberlain, a British surgeon, made it possible for a surgeon to deliver a healthy baby from a labor

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<sup>50</sup> Rooks, *Midwifery*, 13.

that would previously have resulted in the death of the baby, and potentially the mother.<sup>51</sup> Although Chamberlain kept his invention secret for over one hundred years, he and his family became “man-midwives” to the royal family in England. When the tool became more widely used, midwives generally could not afford them and were untrained in how to use them, resulting in the common practice of calling a physician when forceps were needed. Physicians began to feel superior to midwives and wished to intervene with most births in order to create successful birth experiences. At the same time, midwives began to be critical of what they perceived as too-frequent use of intervention by male physicians in what they considered a normal and natural process rarely needing such intervention. Obstetrics (a word derived from the Latin *obstare*, meaning “to stand by,”) became a medical specialty taught in medical schools by the end of the 1700s.<sup>52</sup>

Physicians began to form a larger part of the birth process throughout the 18<sup>th</sup> and 19<sup>th</sup> centuries, but midwives began to receive more formal training, often because of increased governmental regulations, and continued to attend the majority of births. Midwifery in England served as the model for midwifery in the colonial United States. Midwives were responsible for almost all childbirth experiences from 1620-1870.<sup>53</sup> In America, midwives were held in high regard, in part because few university-educated physicians were traveling from England. Trained and untrained women attended births as needed, and birth was viewed as a natural event for which special knowledge or skills were not required.

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<sup>51</sup> Rooks, *Midwifery*, 15.

<sup>52</sup> Rooks, *Midwifery*, 15.

<sup>53</sup> Rooks, *Midwifery*, 8.

Although midwifery grew in esteem throughout the early days of life in the colonial United States, the growth of modern medicine in the United States created problems for the practice. The first midwifery school in America was opened in 1848 and was harshly criticized, closing in 1874.<sup>54</sup> Laws governing midwifery were local and varied, and pertained only to a portion of women attending births. In most states, government control of midwifery was lacking until the 1920s. Childbirth during these times was often dangerous and a high rate of maternal mortality in the late nineteenth century led to a movement to abolish midwifery, especially where physicians were available.<sup>55</sup> Midwives, largely unorganized and uneducated, could not fight back against allegations that they were the cause of high mortality rates. And many midwives may have deliberately chosen not to seek formal training, especially from men, based on their belief that childbirth is normal and “inherently within the domain of female competence.”<sup>56</sup> The so-called “midwife debate” that took place following this movement, from 1910 to 1935, argued that midwives were untrained and incompetent to provide the necessary care, that pregnancy is dangerous and requires care provided only by highly trained specialists, and that midwives were undermining the progress of obstetrics.<sup>57</sup> In addition, obstetricians felt that as long as women who lacked formal medical training were allowed to deliver babies, their profession would not gain respect. Because it was thought that improving medicine would be easier than training midwives, the move to

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<sup>54</sup> Rooks, *Midwifery*, 19.

<sup>55</sup> N. Devitt in Rooks, *Midwifery*, 22.

<sup>56</sup> Wertz and Wertz in Rooks, *Midwifery*, 19.

<sup>57</sup> Rooks, *Midwifery*, 24.



abolish midwifery, particularly in large cities, continued. In 1900, midwives had attended almost half of all births, by 1935, this number was 12.5%<sup>58</sup>

The prominence of male physicians at births between 1770 and 1820 marked a change in attitudes toward childbirth. The presence of male physicians, historian Catherine Sholten contends, meant that childbirth was no longer viewed as a normal part of a woman's life, strictly in the female domain, but was now viewed as a medical problem.<sup>59</sup> This transition was true for upper-class women almost exclusively, as lower-class women, black women, and immigrants remained under the care of midwives during the nineteenth century. This wealth divide added to the respect given to physicians over midwives. By the 1960s, physician interventions such as anesthesia, episiotomies, and forceps-assisted delivery were common in American hospitals, the site of almost all births. In addition, women were generally removed from all support systems, infants were taken almost immediately from their mothers, and bottle-feeding became the norm for most babies.<sup>60</sup> No scientific evidence pointed to any of these interventions as superior for the health of mother or baby, and many of them proved harmful.<sup>61</sup>

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<sup>58</sup> Nancy Sullivan, "A Short History of Midwifery," *MidwifeInfo* (May 6, 2002), Accessed October 14, 2010, <http://midwifeinfo.com/articles/a-short-history-of-midwifery>.

<sup>59</sup> Catherine Scholten, *Childbearing in American Society, 1650-1850*, (New York : New York University Press, 1985), 32.

<sup>60</sup> Sullivan, *Short History*.

<sup>61</sup> See Marsden Wagner, "Fish Can't See Water: The Need to Humanize Birth," *International Journal of Gynecology & Obstetrics*, 75 (2001) S25-37 and Robbie Davis-Floyd, *Birth as an American Rite of Passage*, (Berkeley: University of California Press, 2003) for an in-depth discussion of harmful interventions. For example, Wagner cites that non-emergency cesarean sections have a rate of maternal mortality nearly three times higher than for vaginal births (S27). Other interventions, such as routine IV infusion, while simply unnecessary in a developed country, can prove harmful in developing countries as resources are limited. Additionally, Wagner claims, science has proved home safer than hospitals, family support safer than hospital staff, and midwives safer than doctors for low-risk birth.

Although the practice of midwifery was largely curtailed by the rise of modern obstetrics in America, many of the convictions of the midwives about the normal nature of childbirth continued to be studied, both in America and abroad.<sup>62</sup> In 1930, Grantly Dick-Read, an English obstetrician, asserted that “much of the pain of labor and delivery results from tension induced by fear—women confident in ability to birth could experience it without fear.”<sup>63</sup> Dick-Read’s theory was seen as radical and he was accused of abusing women. He faced much formal critique, but his book, published in 1944, stimulated the beginning of a small “natural childbirth movement” and led to the increased availability of childbirth education classes for pregnant women.

While the proportion of births occurring in hospitals rose from 37 percent in 1935 to 97 percent in 1960, and reached a peak of 99.4 percent in 1970, the percentage began to drop in the 1970s. The percentage of births taking place outside of hospitals more than doubled during the 1970s (from 0.6 percent in 1970 to 1.5 percent in 1977).<sup>64</sup> These births were not accidental or due to isolation or poverty, but, Rooks claims “resulted from the deliberate choices of middle-class American women.”<sup>65</sup> These women cited a variety of reasons for making this choice, including controlling the circumstances of their births, enjoying a supportive environment, seeking to avoid procedures and interventions, allowing families to be together and adhering to religious beliefs, as well as the simple nature of birth and the low cost of delivering at home.

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<sup>62</sup> In 1970, midwives were present at nearly all births in England, and were the responsible attendant at 70 percent of those births. (H. Arthure in Rooks, *Midwifery*, 17).

<sup>63</sup> Rooks, *Midwifery*, 33.

<sup>64</sup> Rooks, *Midwifery*, 60.

<sup>65</sup> Rooks, *Midwifery*, 60.

The desire to return to a natural birthing process that led to the natural childbirth movement persists today in the choices of women to seek care from midwives rather than (or in addition to) the hospital setting. Midwives who practice, legally or illegally, work to show that their practice is safe for low-risk births, and advocate for policy changes making midwifery legal in all states. In addition, they work to advocate for the midwifery model of care as the best model of care for mothers and babies. This model includes a belief that childbirth is normal and natural, a commitment to individualized physical, spiritual, and emotional care, and the involvement of social support networks in the birthing and mothering process. In addition, the modern midwifery movement discourages the use of technological intervention when not indicated for the individual woman, and thus critiques the biomedical model of care that makes routine technological interventions for every woman.

Midwifery slowly began to creep back into the American birth scene, although the extent of involvement varied widely across the country. Nurse-midwives, generally trained under the medical model, moved almost completely into hospital settings. Although this led to a loss of control and autonomy, it also provided legal protections, including the assurance of physician-aided intervention when necessary.<sup>66</sup> At the same time, a less formal midwifery model remained and began to grow. Formally untrained, these midwives came to the practice trained almost exclusively through apprenticeship. In some states, this practice was simply unregulated, and in others, it was illegal. These changes attracted the attention of the government, and regulations began to be written. In

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<sup>66</sup> Sullivan, *Short History*.

some cases, midwives were (and continue to be) arrested or prosecuted for practicing medicine without a license, and non-nurse midwives are prohibited from practicing in 11 states. Many other states do not prohibit the practice, but do not provide licensure avenues—effectively preventing the practice in those states as well.<sup>67</sup> In 1982, the Midwives' Alliance of North America was founded, and began to focus on the expansion of rights for direct-entry, home-birth midwives.<sup>68</sup> During the 1990s, midwives in many states were successful in establishing certification programs allowing them to practice autonomously.

### **Hospice Care, Midwifery, and the Biomedical Model**

Perhaps one of the best ways to understand both midwifery and hospice care is to examine to what each movement is responding. Each is a minority movement in mainstream culture. Less than two percent of American women give birth at home, so midwifery is seen as marginalized by, or deviating from, the values of wider society.<sup>69</sup> Although hospice care is more widespread and quickly gaining popularity, it developed as a minority movement, and continues to have limited influence until the final days for most patients. The National Hospice and Palliative Care Organization (NHPCO) estimates that approximately 41.6% of deaths in the United States are now “hospice

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<sup>67</sup> “Direct-Entry Midwifery State-by-State Legal Status,” last modified May 18, 2010, <http://mana.org/statechart.html>. Many other states have no regulations about midwifery. In some of these states, midwives are prosecuted, and in others generally left alone. Direct Entry Midwives are only considered to be practicing legally in 27 states.

<sup>68</sup> Sullivan, *Short History*.

<sup>69</sup> Robbie Davis-Floyd and Elizabeth Davis, “Intuition as Authoritative Knowledge in Midwifery and Homebirth,” in *Intuition the Inside Story: Interdisciplinary Perspectives*, ed. Robbie E. Davis-Floyd and Sven Arvidsen, (London: Routledge, 1997), 146.

deaths.” This figure fails to tell the whole story, however, as the median length of stay (a person is typically qualified for up to six months following a terminal diagnosis) is 21.4 days, and 34.4% of hospice patients die within seven days, far shorter than the time required to fully utilize hospice services.<sup>70</sup> At the same time, both midwifery and hospice care also mark a return to the historical way of caring during the vital life passages of birthing and dying. This tension, that each is a new movement with old roots, creates important parallels for hospice care and midwifery.

Hospice professionals (nurses in particular) and midwives also share the common background of practicing in a largely female-dominated field. Male midwives make up only approximately two percent of all midwives. While obstetrician/gynecologists are largely women, they represent a small portion of physicians, and much of their training is done within the male-dominated world of general medicine. Similarly, while hospital medical directors are more likely to be male (64%), hospice directors (85%) and hospice nurses (95%) are overwhelmingly female.<sup>71</sup> Participating in a female-dominated field may allow midwives and hospice nurses, through their training and experience, to engage more deeply in types of caring for patients that are traditionally identified with the female experience. Traditionally female ways of caring, nurturing, and building relationships are emphasized to a much larger degree in the fields of midwifery and hospice care than they

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<sup>70</sup> NHPCO “Facts and Figures: Hospice Care in America,” Alexandria, VA: National Hospice and Palliative Care Organization, September 2010, 4.

<sup>71</sup> [http://www.payscale.com/research/US/Certification=Certified\\_Hospice\\_and\\_Palliative\\_Nurse\\_%28CHPN%29/Hourly\\_Rate](http://www.payscale.com/research/US/Certification=Certified_Hospice_and_Palliative_Nurse_%28CHPN%29/Hourly_Rate). Nursing as a profession is also largely female, as only 9% of nurses in all fields are male.

are in the larger biomedical establishment. This may also, however, lead to an undervaluing of the work done by both midwives and hospice nurses (as well as nurses in general), as the traditional association of their work with “women’s work” causes it to lose the status that is associated with medicine in a broader sense.

One of the clearest parallels between the rise of the modern hospice movement and the emergence of the natural birth movement is the response to the medicalization of what each movement characterizes as a natural process. Both movements largely identify themselves in opposition to mainstream culture, and that often entails a criticism of the biomedical establishment and its way of approaching health care. It is important to notice that hospice professionals and midwives, as well as many critics of the biomedical model more generally, recognize that many of the negative aspects are not dependent on the individual practitioners, but rather on the kind of system that has been created, its reliance on technology, and its structure that emphasizes efficiency. Thus, criticisms of the biomedical establishment should be seen as resulting from these larger structures that have grown up around physicians, rather than the actions of individual practitioners, who generally wish to provide the best care possible for their patients. The power and authority that physicians wield, increased by knowledge of and availability of technologies, creates many of the problems experienced by patients, particularly those with long-term care concerns. Because the power of physicians that comes from their specialized knowledge and skill set is centralized in large institutions, the patient experience is often intimidating and immediately puts patients at a disadvantage when

advocating for their health care concerns, regardless of an individual practitioner's desire to listen to and address those concerns.

In order to fully understand the criticisms of the biomedical model of care, it is important to understand what comprises that model. Although a full treatment of the biomedical model is beyond the scope of this thesis, it is possible to lay out some of its predominant features. According to the biomedical model of care, health is defined as the absence of disease, injury, or pain.<sup>72</sup> While recent attempts have been made to expand the definition of health to include general well-being, the major model of medical care in the United States still takes the absence of disease to indicate the health of a patient. In addition, under the biomedical model of care, power is located in institutions and organizations, especially hospitals. This includes the right to decide which treatments ought to be not only used, but presented as options to patients, and the power to control resources, including technology. These centralized, powerful institutions are organized for efficient delivery of services. These institutions are, for the most part, alienating to the patient, often reducing them to the disease or illness, treating only physical symptoms. Under this model, care is provided by professionals who are strangers to the patient, so that the intimacy of caring becomes impersonal. In addition, caring is a goal that is secondary to curing.<sup>73</sup> Perhaps most importantly to the comparison of midwifery and hospice care, in the biomedical model technology has displaced natural processes as the

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<sup>72</sup> Gillian Einstein and Margrit Shildrick. "The Postconventional Body: Retheorizing Women's Health," *Social Science and Medicine* 69 (2009), 298.

<sup>73</sup> This is reflected in the secondary position of nurses, who primarily focus on "care," to physicians, who primarily focus on "cure."

dominant guide to the processes of birth and death. These technological interventions are also given over a long period of time, months in the case of pregnancy, where medical interventions are involved in monitoring the pregnancy from the start, and years in the case of chronic illnesses that lead to death.

The biomedical model of care now dominant in the United States and much of the world, Siebold argues, “applied reductionist principles to the care of the sick and the study of illness. From this perspective, disease was defined as a deviation from certain physical and biochemical norms.”<sup>74</sup> In this model, social factors apart from the physical body become irrelevant to treatment, which focuses instead on finding and fixing the defect.<sup>75</sup> When there is an actual disease to be cured, the biomedical model has been successful, and improved the health of many in measurable and important ways. However, critics argue that highly technological methods of treatment are not always necessary or helpful in all areas of care, particularly in the case of birthing and dying. When the biomedical model focused on cure through technology is applied to such processes, control is displaced from the patient to the professional. This loss of control can lead to disempowerment of the patient and alienation from important relationships, including that with one’s own body. While such a method may work for attending a broken arm, critics claim, the same model may not be appropriate for treating other illnesses, which include not only the biological disease, but the human experience of

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<sup>74</sup> Siebold, *Hospice Movement*, 19.

<sup>75</sup> Einstein and Shildrick, 294. Although the feminist critique of biomedicine is beyond the scope of my thesis, it is important to note that exclusively female processes are also treated as abnormal in biomedicine. Typical biomedical care is built on the model that a “normal” body is the white, male body. Female bodies differ from this norm just as “sick” bodies do, and so female processes, such as birth, are marked by difference and deviance at their very nature.



illness.<sup>76</sup> Critics—among them midwives and hospice nurses—argue that ignoring social and emotional factors that contribute to the human experience of illness limits the effectiveness of biomedical models of care.<sup>77</sup> As modern medicine developed and became the dominant model of care for the sick or injured, concern for the political and economic factors that shape our health was lessened or removed altogether. For our purposes, it is also important to note that the biomedical model of care, because it focuses on deviations from the norm to define what is not healthy, relies heavily on technology and medicine to remedy what it views as “abnormalities.” Because the power and authority in the biomedical model is located not with the patient, nor even the individual physician, decisions are made within the context of the institutional constraints of the hospital. It is important to recognize that it is the differential in power between the institution and the patient that many critics of biomedicine target, and should be the focus of much of its criticism. Hospice professionals and midwives would prefer to locate decision-making power with the individual patient (or client), and within the home, rather than with the institutional context of the hospital.

In contrast with this biomedical model of care, hospice professionals and midwives are devoted to the concept that dying and birthing, respectively, are natural processes that our bodies are prepared to—and “know how to”—do. They need not be combated, or “fixed” by biomedical treatments that seek to control the processes. While

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<sup>76</sup> Arthur Kleinman et. al., “Culture, Illness, and Care: Clinical Lessons From Anthropologic and Cross-Cultural Research,” *The Journal of Lifelong Learning in Psychiatry*, 4:2 (2006) 141.

<sup>77</sup> See Einstein and Shildrick, *Postconventional Body*, for a critique of the biomedical system, particularly from a feminist perspective.

people engaged in both processes often require physical, emotional, and spiritual support, the processes themselves can, for the most part, be free from most medical interventions. In contrast with the assumption that these processes are natural and innate, the biomedical model makes both processes pathological. Once these processes are considered pathology, and thus problematic, medical tools and technologies must be created to try to eliminate them (in the case of dying), speed them up and clean them up (in the case of birthing), or control them (for both).

Moller, in the context of dying, argues that there are two major social forces that, in combination, have contributed to the “isolating and falsely hopeful experience of the dying.”<sup>78</sup> The first is technologizing—the increased use of technology at the end of life. The second is a cultural valuation of individualism that is “manifested in the human potential movement,” that is, our desire to believe that all it takes to accomplish something is to “pull oneself up by one’s bootstraps.” Thus, painful or fearful deaths are often made worse not only by life-prolonging but painful or futile technologies, but also by the idea that much of the dying process is in the dying person’s hands and one ought to simply take care of it alone. It is not that Moller does not think it is possible—and desirable—for the dying process to be one of growth. The problem is the emphasis in what he calls the “human potential movement” on an individual’s ability to do that growing all by oneself. The problem, then, lies not in the individual’s desire for growing self-awareness and understanding, but in “becoming increasingly detached from the

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<sup>78</sup> Moller, *Without Dignity*, xiv.

social bonds of shared concerns and community.”<sup>79</sup> These social forces “are merged in the managing, packaging, and containment of dying as an individual experience subject to unrealistically indefinite, technological postponement.”<sup>80</sup> If one not only must suffer a painful death made longer by technology, but must also do so alone, without the traditional social supports our society has now lost, the process of dying becomes even further isolating and fearful. A “meaningful death” must be achieved by an individual through his or her own effort, rather than through any shared cultural meanings. In addition, the technology and social belief in the ability to always do better for oneself often means that patients hold beliefs about their ability to beat an illness or live that are largely misguided. This false hope often means that people are unable to engage in a process of growth at the end of life—the process advocated for by the hospice movement.

In order to understand why death became feared and avoided, particularly in light of the ideas held at least in early America that accepted death as a natural part of life, it is important to understand how death became “dirty” and why it was important to clean it up. The twentieth century brought radical change to how humans perceive death and dying. Stripped of its religious and social significance, death began to be connected to the failure of a medical system committed to conquering disease and death, as if it were a war to be won, and not an inevitable part of human nature. “Dying,” Moller writes “has,

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<sup>79</sup> Moller, *Without Dignity*, 10.

<sup>80</sup> Jack Elinson in Moller, *Without Dignity*, xiv.

in the modern setting, been redefined into something dirty that takes place in social isolation and under the jurisdiction of medical and technological control.”<sup>81</sup>

As death became viewed as “dirty,” physicians and others sought ways to “clean it up,” most notably by transferring death from the home under the guidance of the family to the hospital, under the guidance of the medical profession, which largely took place between the 1930s and the 1950s. This relocation of death into the hospital conceals death and hides it from the public, sanitizing it by removing it from our sight and minds. Although moving death from the home to the hospital made it public in the sense that strangers became involved, it also isolated and sanitized death. In addition to a shift in the view of death itself, a shift in how we view ourselves and our culture also contributed to this attitude towards death. Munley contends that “Contemporary Americans are creators of a culture in which a communal orientation has been replaced by individualism and a sacred worldview has been displaced by science.”<sup>82</sup> Combined with a need to “sanitize” death, this commitment to individualism pervasive in contemporary America removes many of the social supports such as family members and close community members who surrounded the dying with care in earlier times. And with these shifts, historian Philippe Ariès argued, death became “a technical phenomenon obtained by a cessation of care, a

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<sup>81</sup> Moller, *Without Dignity*, 14. The historian Philippe Ariès provides a complete analysis of the transformation of death from the Middle Ages to the present day and the increasingly technologized processes associated with it. See Philippe Ariès, “The Reversal of Death: Changes in Attitudes Toward Death in Western Societies,” in *Death in America*, edited by David E. Stannard, (Pennsylvania: University of Pennsylvania Press, Inc., 1974).

<sup>82</sup> Munley, *Hospice Alternative*, 11.

cessation determined in a more or less avowed way by the decision of the doctor and the hospital team.”<sup>83</sup>

Similar ideas apply to the idea of technologized birth. The number of interventions, from heart rate monitors, to C-sections in non-emergency cases, to IVs, has turned birth into a scary and risky disease. Laboring women are treated as patients, and successful births are seen as the outcome of the successful interventions, not the strength and work of the mother. Individualism plays in here as well. As birth moved into the hospital, it moved out of the context of social support for the mother. No longer were family and friends around and supportive during the birthing process, and for the most part, not even the mother’s partner was in the delivery room. Now birth, once done in a social context and with few interventions, is fully immersed in biomedicine’s technology, and also largely isolating. While the experience often includes many people, their social ties to the woman are limited, and her traditional support people are not allowed in the delivery room. Although steps have been taken to reverse some of these isolating effects, the view of mother as patient makes the sense of isolation and of dependency on health care staff to the exclusion of family or friends, a key part of the birthing process.

Technology has a special place in American society and in Western society in general. It is so pervasive that it is essentially taken for granted as a part of everyday life. Moller argues that this glorification of technology means that often the dying rely on the technology until the last moment, when the technology then has failed them. Even when a

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<sup>83</sup> Philippe Ariès, *Western Attitudes Toward Death From the Middle Ages to the Present*, translated by Patricia M. Ranum (Baltimore and London: The Johns Hopkins University Press, 1974), 88.

treatment is probably medically futile, the sense that something is being done to continue to treat the patient keeps alive an often false sense of hope that dying can be stopped or reversed. While it is difficult to draw a direct parallel to the birthing process here, as the goal is certainly not to stop the process, a clear reliance on technology as the saving grace for women is certainly widespread. The common use of epidurals, induced labor, and other interventions speaks to a reliance on technology, often when it is not necessary. The natural birth and hospice movements both call into question this reliance on technology as the most important part of either process.

Although a heavy reliance on technology has played a large role in pathologizing both the birthing and dying processes, Moller's second force, the cultural value of individualism, is equally important. While we value individualism, what we lack are culturally shared meanings of death and dying. We lack a shared narrative about what it means to die, what is necessary or even helpful to the dying, and how survivors do or should live on after a death. This lack of a shared narrative fails to help us construct and extract meaning from the dying process. Similarly, although people do share their birthing stories, the meaning of birth has shifted in important ways as birth has moved from the home, where social support networks were interwoven into the process, to the hospital, where birthing is a challenge to be overcome.

## **Chapter 2: Professional Identity, Power, and Patient Care**

In order to understand the opposition of the midwifery and hospice care movements to the major biomedical model, it is important to understand the institutional constraints placed on those who practice in the setting of a hospital or other large bureaucratic structures-. Questions of professional autonomy, constraints from within and outside of the professions, and the ideologies associated with particular institutional settings all affect not only how a professional practices, but what kind of experience a patient has within that context. This chapter will examine the idea of professional identity, including the constraints on the profession of physicians within a hospital setting. I will contrast this with the increased autonomy that midwives and hospice professionals experience when these constraints do not inhibit their ability to treat patients in a way that is typically outside the bounds of the biomedical model.<sup>84</sup> The institutional constraints faced by physicians largely because of their institutional affiliations are tied to the biomedical ideology associated with mechanistic views of the human body, as well as a health care system based on the marketplace. This ideology can, among other things, lead to the depersonalization of the patient, which can result in the disempowerment of those patients. It is for this reason that both midwifery and hospice philosophy seek to remove some of these constraints by practicing in alternative

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<sup>84</sup> Although of course both hospice professionals and midwives face constraints in their practices, my goal here is to examine how the particular institutional setting of a hospital prevents physicians in that environment from practicing in the holistic manner advocated for by midwives and hospice professionals. This does not apply universally, as midwives in states without licensure programs face enormous constraints on their practice. This chapter is limited in its scope to places where direct-entry midwifery is practiced legally.

environments, and by practicing in ways they see as empowering for the people in their care.

### **Professional Identity**

Those in the medical field, particularly physicians and nurses, are generally seen as professionals, and thus separated from people with careers or jobs by the traditional marks of a profession, including specialized knowledge limited to a few, application of expert skills, the idea of service, and some control over admission and regulation or licensure of practitioners. While the traditional definition of a profession does not fit either midwives or hospice professionals (as such—though they may be considered professionals in another field), it is important to understand the idea of professional status, and how this status confers authority to the biomedical model present in modern hospitals. While many of these professional markers also apply to midwives (for example, specialized knowledge, licensure in some states, and working for the common good), the idea of midwives as professionals is by no means well-established. And while hospice professionals may be considered professionals in their original field, the hospice team approach brings members of various professions into a single unit that provides care to each patient. A brief examination of professionalism will allow me to pinpoint the different starting point from which midwives and hospice professionals begin to give care in contrast to the assumptions from which medical professionals in a hospital environment approach patient treatment. By examining how the philosophies of these



caregivers outside the major biomedical model approach care, similarities between the professions are illuminated. If these similarities are instructive, then the metaphor of hospice professionals as midwives to the dying may prove helpful in the practice of hospice nurses. It may also provide a vehicle for a better public understanding of hospice and its approach to end-of-life care.

Becoming a nurse or a doctor, like becoming a lawyer, an engineer, or a professor, is more than a career. These vocations are true professions, requiring a set of skills and certifications and intense, specialized training. Ethicist William May points out that “To ‘profess’ means to ‘testify on behalf of,’ to ‘stand for,’ or to ‘avow’ a high good that defines one’s fundamental commitment—a covenant, if you will, that shapes and constrains the practitioner, the professor.”<sup>85</sup> There are requirements of a professional—to his or her peers, the organization that he or she belongs to, and to the people he or she serves—that go beyond those required of a layperson. These requirements are created through a set of relationships, and they call upon professionals to act in certain ways. Whereas in a career, the employed pursues private goals—a livelihood, advancement, or other goods, professionals pursue goods external to their own private goals. Roscoe Pund said:

The term [profession] refers to a group . . . pursuing a learned art as a common calling in the spirit of public service--no less a public service because it may incidentally be a means of livelihood. Pursuit of the learned art in the spirit of public service is the primary purpose.<sup>86</sup>

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<sup>85</sup> William May, *Beleaguered Rulers: The Public Obligation of the Professional*, (Louisville: Westminster John Knox Press, 2001), 14.

<sup>86</sup> Pund in May, *Beleaguered Rulers*, 14.

Professionals are regulated by the state in ways that many careers are not. “Normally,” May argues, “the state licenses [professionals]. The society expects professionals to state publicly their own standards of excellence, to conform to those standards individually, and to enforce them upon colleagues within the guild.”<sup>87</sup>

Because professionals are set apart from others based on their profession and specialized knowledge, they hold a special kind of power. While the power they wield is not absolute, and often faces constraints from other professions or outside sources, it is certainly substantial. Because of the training and expertise required of professionals, we defer to their authority readily, particularly in the profession of medicine, because for the most part a patient is in a vulnerable situation where sickness and health are beyond their control. The power in the situation lies with the professional. This power grew in two stages, according to May. The first accompanied the rise of science and technology in the seventeenth century, and the second involved the transfer of the training of these professionals to the modern university in the twentieth century, which now holds exclusive claim to this body of knowledge. Instead of celebrating the human power *for* knowledge as the ancient Greeks did, May argues, we now celebrate the powers that can be acquired through knowledge. We acquire such power only through attendance at a university and transmit that knowledge to future generations of professionals in the same way.

May claims that the specific obligations of a professional (as opposed to a careerist or worker) come in three forms:

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<sup>87</sup> May, *Beleaguered Rulers*, 21.

The professional's covenant, in my judgment, opens out in three directions that help distinguish professionals from careerists: the professional professes something (a body of knowledge and experience); on behalf of someone (or some institution); and in the setting of colleagues. This summary definition highlights three distinguishing marks: *intellectual* (what one professes), *moral* (on behalf of whom one professes), and *organizational* (with whom one professes). These distinguishing marks call for three correlative virtues—practical wisdom, fidelity, and public spiritedness.<sup>88</sup>

The knowledge held by professionals requires practical wisdom to know when and how that knowledge ought to be applied. This moves professions beyond applied science.

Professions such as a physician “call for the skill of an artist, not simply the knowledge of an applied scientist. Thus professionals need the correlative virtue of practical wisdom as they bring their knowledge to bear in the service of an important human good.”<sup>89</sup> A physician needs not only specific knowledge about the disease of a patient, but also information about how treatment options affect lifestyle, how likely a patient is to follow one form or another of treatment, how to speak to a patient about a diagnosis or treatment, and a host of other factors that go beyond technical training.

Because the body of knowledge the professional professes is both complex and esoteric, May claims, it takes both time and money to acquire it and a gap is inevitably created between professionals and lay people.<sup>90</sup> Professionals do not acquire such knowledge in order to hold it over others, but rather to serve others. Thus, May points out, free clinics staffed by doctors on their own time or pro bono legal counsel by

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<sup>88</sup> May, *Beleaguered Rulers*, 7.

<sup>89</sup> May, *Beleaguered Rulers*, 9.

<sup>90</sup> In addition to creating a knowledge gap between professionals and lay people, the transition of professional training to the university effectively denied medical education to black people and women.

attorneys have become a common expectation of professionals. At the same time, he argues:

The ideal of service should control not simply the supererogatory works of the professional but the terms and constraints under which he or she daily practices...the disproportionate intellectual power of professionals plus the moral standard of altruism combines to demand of the professional the virtue of fidelity.<sup>91</sup>

The professions draw their substantial power from the community and thus owe fidelity and loyalty to that community.

While the two major shifts in the professions occurred in the seventeenth and twentieth centuries with the rise of modern technology and the modern university, respectively, the position of the professions has again changed in our current marketplace society. In the twentieth century university setting, “questions of ethics and values could not surface in the classroom. The professor could teach facts, not values, because values reflect only subjective, emotive, arbitrary preferences.”<sup>92</sup> Thus, the knowledge base for the professions became even more specialized, but also more limited. Modern professionals also face substantial institutional constraints on their practices, occasionally from the government, but more often—particularly in the United States—by the pressures of the marketplace. “The large-scale organizations for which professionals increasingly work in the United States,” says May, “substantially condition professional practice.”<sup>93</sup> The mega-corporations that now dominate in the modern market place limits and expectations on professionals to practice in certain ways. For physicians, this includes

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<sup>91</sup> May, *Beleaguered Rulers*, 10.

<sup>92</sup> May, *Beleaguered Rulers*, 19.

<sup>93</sup> May, *Beleaguered Rulers*, 3.

insurance companies, which have largely shaped how physicians practice medicine, often with negative results.

In addition, while the statements of the professions themselves “resonate with the language of a high calling in service to the common good...their daily worries and behaviors play out in the low-to-the-ground trajectory of a career.”<sup>94</sup> Professionals in a market system must not only practice their profession, but advocate for it, market it, protect it from lawsuits, and complete a variety of other tasks that are sometimes only loosely related to the set of skills that define the profession. In addition, as more and more people are trained in the professional sphere, colleagues have been redefined as competitors, where “the capacity for mutual nurture and renewal diminishes, and service to the common good yields to the necessities of survival.”<sup>95</sup>

### **Constraints on the Medical Profession**

The power within a profession as well as the constraints placed on professionals is nowhere more obvious than in the sphere of medicine. And because the medical profession (unintentionally) draws its power from fear about suffering and death, its fidelity to the common good becomes more important, even as it faces more outside constraints. The complaint of doctors that they are facing constraint, according to May “only reflects their discovery that still other professionals—lawyers, accountants,

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<sup>94</sup> May, *Beleaguered Rulers*, 7.

<sup>95</sup> May, *Beleaguered Rulers*, 11.

professional managers—often control the large institutions with which medical practitioners must now contend.”<sup>96</sup>

The interests advanced by these large institutions—whether insurance companies or the hospitals themselves—can undercut fidelity to patients or to the common good, as physicians weigh their obligations to the patient against competing obligations to their colleagues, other patients, and organizations. One example of the constraints facing the medical profession can be seen in the payment system used by insurance companies. Two common payment options act upon physicians in ways that negatively affect the treatment received by patients. When physicians are paid on a fee-for-service system, they are often tempted by structural constraints to overtreat patients to increase profit not only for themselves, but for their institution. On the other hand, prepayment systems encourage doctors to undertreat patients. Although individual physicians wish the best for their patients, they also must work within systems that occasionally emphasize under- or overtreatment in the name of efficiency or profit for the institution at large. Many of these pressures or incentives are subtle and built into a system such that they may be unrecognizable to individual physicians. Both of these options negatively affect patient care and create higher costs in the health care system at large. In addition, managed care, a major constraint placed on doctors from corporations, is done in the name of efficiency and profit. At the same time, to fully practice the craft of healing, a physician also “requires practical wisdom in bringing science artfully to bear in order to restore

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<sup>96</sup> May, *Beleaguered Rulers*, 4.

harmony to the patient's universe. That healing is the end purpose of doctoring. Such doctoring takes time; whereas the name of the new art in managed care is saving time.”<sup>97</sup>

### **The Professions of Midwifery and Hospice Care as a Critique of the Biomedical Model**

While it is important to understand the constraints on the medical profession, some of which are addressed, at least partially, both by midwifery and hospice care, it is also important to recognize that the underlying foundational beliefs of the modern biomedical model place other constraints on the profession that limit the way physicians see and work within it. This ideology, which can be disempowering for patients within that model, focuses on technology to provide answers. When the rise of modern science transferred the responsibility for healing from religious institutions to secular science, it took as authoritative the mechanical model of the body. “This developing science,” according to childbirth researcher Robbie Davis-Floyd in her book Birth as an American Rite of Passage, “had taken the mechanical model as its philosophical foundation and so was much better equipped than religion to take on the challenging conceptual task of transforming the organic human body into a machine.”<sup>98</sup> What the body-as-machine model means for physicians is that it reduces their profession to what May would consider a “careerist.” Instead of professionals that are deeply engaged with patients,

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<sup>97</sup> May, *Beleaguered Rulers*, 47.

<sup>98</sup> Davis-Floyd, *Birth*, 45. Further, Davis-Floyd argues, the male body was seen as the prototype for this machine, and the idea of the female body as a “mutilated male” permeates the work of thinkers as early as Aristotle. The historical fidelity to the idea of male superiority left this idea of the female body as a defective male body in place and, combined with the idea of the body as machine, means that our medical model is built to “fix” and “repair” a broken body—particularly those of females.

physicians under this model become “technicians” or even “mechanics” for the body and its parts.

In order to understand how midwifery and hospice care redefine the approach to health care that is advanced by the medical profession of doctoring, it is important to examine the underlying beliefs about the human body, health, and healing that are held by both. Although there is variation within the traditional medical profession, we will take for a moment the biomedical model in its entirety. Moller, in describing the modern hospital as it relates to end-of-life care, writes:

A hospital is a bureaucratically organized social institution whose function is to treat and heal disease. The management of disease is approached through a technological and scientific orientation which emphasizes the priorities of rationality and efficiency. According to institutional justifications of the medical point of view, rationalization and standardization of care and depersonalization of patients are ‘worth the price’ when medical results benefit the patient. The underlying premise of the hospital’s organization of medical care is consistent with the central motivational values of the technological consciousness, namely, that the vital needs of human beings are reducible to technologically manageable components. Therefore, in the hospital scheme of things, the requirements of a patient’s humanity yield to medical means of technical analysis, carried out by specialists possessing certain impenetrable skills which translate patient needs into a series of management procedures and regiments.<sup>99</sup>

Both midwifery and hospice care work under a different model of illness and health and serve as an important counter-example to the culture of modern biomedicine. Moller points to a number of important constraints on the physician practicing in a hospital setting, including the bureaucracy within which they work, the pressures they face to treat the largest number of patients as quickly as possible, and the balancing act they must go

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<sup>99</sup> Moller, *Without Dignity*, 49.



through to assign priorities to patients. These constraints are tied to the ideology of technologized medicine, which Moller, among other critics, views as leading in part to the depersonalization of the patient. This reduces doctors, he argues, to managers of care rather than masters of the art of medicine. Although his critique does not allow for the individual work of physicians committed to providing care for their patients (he does not allow for the possibility that some physicians might fight back against the constraints they face), he provides a compelling story that links the constraints physicians face in an institutional setting with the ideology of biomedicine built at least in part on the model of the body as machine.

Biomedicine is inextricably linked with cultural assumptions about what we know, how we come to know it, and who has the authority to speak the “truth.” In a quote by cultural anthropologists Nancy Scheper-Hughes and Margaret Lock, this tension is brought to light and criticized:

Biomedicine is still caught in the clutches of the Cartesian dichotomy and its related oppositions of nature and culture, natural and supernatural, real and unreal. If and when we tend to think reductionistically about the mind-body, it is because it is ‘good for us to think’ in this way. To do otherwise, using a radically different metaphysics, would imply the ‘unmaking’ of our own assumptive world and its culture-bound definitions of reality. To admit the ‘as-ifness’ of our ethnoepistemology is to court a Cartesian anxiety – the fear that in the absence of a sure, objective foundation for knowledge we would fall into the void, into the chaos of absolute relativism and subjectivity.<sup>100</sup>

The Cartesian dichotomy referred to by the authors is the idea of 17<sup>th</sup> century philosopher René Descartes who, among others, established the idea of the separation of the mind and

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<sup>100</sup> As cited in Einstein and Shildrick, 293.

body in the 1600s. This separation allowed for the metaphor of the body as a machine to permeate Western thinking. It also established a series of dualisms—male and female, good and bad, light and dark, etc. Biomedicine is built on the distinctions of mind and body, nature and society, and the separation of the individual from society, as if once “broken down” into our components, we can be “figured out,” and “fixed.” These ideas are highly influenced by structuralist ideas that component parts explain the whole, that regardless of cultural diversity, all humans think through similar structures and are—and thus can be treated—essentially the same. Post-structuralists, such as Michel Foucault, provide a critique of this view, insisting that we look not only at an individual (through technology or other means), but include the ideas of social context which influence and are influenced by the embodied experiences of individuals, both healthy and sick. Midwifery and hospice care both stress the complexity of an individual rather than his or her “technical” body. It is one of the ways in which both traditions work to provide agency to those to whom they provide care.

These biomedical dichotomies are built on Cartesian ways of knowing, and are clearly seen in Foucault’s use of the term “medical gaze,” the idea that medicine dehumanizes people by separating a patient’s body from their identity.<sup>101</sup> Biomedicine often separates a person’s body from his identity, such that when I am ill, I am somehow not “myself,” set apart from some standard or norm by an outside intrusion that must be repaired before I am myself again. In medical science, we constantly compare that which

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<sup>101</sup> Deborah Lupton, “The Social Construction of Medicine and the Body,” *Book of Social Studies in Health and Medicine*, edited by Gary Albrecht et. al., (London: Sage Publications, 2000), 56.

we see with what ought to be considered as “normal,” and deviations from this norm are defined as disease or disability. When we deviate from this norm—when we are ill, dying, in pain, or disabled—everything must be done to return us to the norm, and if that is not possible, biomedicine has little to offer. Gillian Einstien and Margrit Shildrick state that we have created, among other binary divisions, one of “healthy” and “sick.” Biomedicine’s goal is to make a person “better” by bringing him or her closer to a universalized notion of “normal” which defies cultural differences in awareness and reality.<sup>102</sup>

Deborah Lupton claims that the language of biomedicine appears “non-cultural or pre-cultural” and that this perpetuates the idea of biomedicine as separate from culture.<sup>103</sup> The appearance that biomedicine, unlike other knowledge, is not culture-bound creates a power dynamic that limits the usefulness and validity of other ways of knowing. This limitation of the validity of other ways of knowing and biomedicine’s monopoly of the “truth” are detrimental to the health care system as a whole and to patient experiences and health outcomes. Medical anthropologist Arthur Kleinman and colleagues argued that the biomedical model (which they refer to as “medicocentric,”) excludes other explanatory models (those of the patients) when physicians work to treat patients. Physicians unwilling to take into account their patient’s explanations for why he or she is ill or what might cure the illness both possibly miss important things about it and also

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<sup>102</sup> Einstien and Shildrick, *Postconventional Body*, 294.

<sup>103</sup> Lupton, *Social Construction*, 52.

potentially disempower patients from taking an active role in their own healthcare.<sup>104</sup> It is against this framework that both midwifery and hospice care must fight in order to emphasize ways of caring for patients beyond the medical model, though both also incorporate aspects of biomedicine into their care.

While biomedical “truth” appears to resist the limitations of cultural knowledge, according to Lupton, it is just as subject to change or variation as other ways of knowing.<sup>105</sup> Many historically revered treatments, such as bloodletting or harmful medicines, have since been deemed not only unhelpful but detrimental to health. Indeed, medicine seems to recognize both its limitations and variability and wishes to claim the authoritative knowledge for the present. While we may not know everything about a disease, biomedicine seems to claim, we have the “best” understanding of it and biomedical research will find the “solution” in time. Looking elsewhere for explanations or treatments will be futile at best and harmful at worst.

Perhaps most importantly, biomedicine both results from and contributes to power structures that define those with knowledge as providers for those “without” knowledge. We trust that if a doctor tells us something, we ought to believe him or her unless presented with compelling arguments to the contrary. In fact, we are taught that it is at least slightly rude to question the authoritative knowledge provided by the doctor. Strikingly doctors are not the only players in the power structure—patients also expect this sort of authoritative advice. People go to the doctor hoping for a “cure” or

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<sup>104</sup> Arthur Kleinman, Leon Eisenberg, and Byron Good, “Culture, Illness, and Care: Clinical Lessons From Anthropologic and Cross-Cultural research,” *The Journal of Lifelong Learning in Psychiatry*, 4:2 (2006).

<sup>105</sup> Lupton, *Social Construction*, 54.

“treatment” and are often unhappy if a quick fix is not presented. Both provider and patient play into a power structure that assumes that one will provide knowledge and the other experience it, and both are often powerless to change such a dynamic. Medical knowledge is often steeped in technical terms not easily understood by the general public, and linguistic and structural frameworks create dominant discourses which often preclude other ways of knowing or possible solutions. When we create discourses that incorporate the difference between our body and our mind, ourselves and others, or “normal” and “abnormal,” we are constructing realities that are then perpetuated in the ways patients and physicians interact. Biomedicine, then, defines what counts as truth.

In contrast with the biomedical model and its power structures, midwifery and hospice care both strive to empower individual patients, work from within their worldviews, and treat the patient, rather than the disease. To do so, they also require more from the person in their care, physically and emotionally. With this elevated responsibility comes elevated agency, and mothers and patients become an integral part of their own care. Biomedicine has handed us two assumptions, that the world is constructed of binary divisions, and that our bodies are autonomous, independent of outside influence.<sup>106</sup> What midwifery and hospice philosophy assume is that we are all individual, social, and political, and that these characteristics are inseparable; they form connections and interactions that are always dynamic and flexible. Biomedicine has come to understand such interconnectedness in some ways, such as through the interactions among different bodily systems, but has not applied that concept to people and society.

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<sup>106</sup> Einstein and Shildrick, *Postconventional Body*, 294.

### **Obstetrics and Midwifery: A Professional Comparison**

While midwifery does not hold the status of a profession in the same way that doctoring does in public opinion, it is still possible to draw a comparison between midwifery and obstetrics. The conscious conviction that midwives hold to provide different care from that offered in a hospital entails not only different practices, but also different fundamental beliefs about pregnancy, women's bodies, and human experience. Davis-Floyd claims in her work on the anthropology of reproduction that through a series of hospital-based ritual procedures, the biomedical model (which she refers to as the technocratic model) and specifically modern obstetrics "deconstructs birth, then invents and reconstructs it as a technocratic process."<sup>107</sup> Numerous metaphors have been used to describe the work of obstetricians, from mechanics to supervisors, and they are commonly seen as facilitating the "active management" of labor and birth.<sup>108</sup> This assumption, that birth is something that must be actively managed, is countered by the midwife assumption that women's bodies know how to labor and give birth, and that, while they benefit from social support and coaching, the extent to which they are "managed" in the hospital is not only unnecessary, but potentially harmful to the woman and her baby.

Davis-Floyd argues that through a series of purposefully designed rituals that are now passed down as the only way to effectively monitor birth, modern obstetrics transmits core values of American society, including patriarchal views about the

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<sup>107</sup> Davis-Floyd, *Birth*, 153.

<sup>108</sup> Davis-Floyd, *Birth*, 49.

weakness and physical inferiority of women and the need for modern medical care in order to produce a baby. In Birth as an American Rite of Passage, Davis-Floyd argues that far from being an objective, scientifically based set of procedures, the routines that surround modern hospital birth resemble in important ways rituals from around the world. She uses Arnold van Gennep's three stages of life passage ritual to contend that this modern ritual transmits ideas and beliefs about modern society. These three stages include: first, a separation of the individuals involved from their preceding social state, second, a period of transition in which they are neither one identity nor the other, and third, the reintegration phase in which they become part of their new social state. In this very simple form, we see a pregnant woman—no longer a wife, but now in a transitional state, then a woman who is giving birth—not a person with or without children, and finally, a reintegration into motherhood—a new social state. Anthropologist Sheila Kitzinger observed birth in a number of countries, and noted that ‘in any society, the way a woman gives birth and the kind of care given to her point as sharply as an arrowhead to the key values in the culture.’<sup>109</sup> Davis-Floyd argues that because in modern society, we have no universal spiritual or humanistic rite of passage in the birth process, some of those functions have been integrated into a ritual of modern hospital birth. There is, she argues, “a surprising standardization of medical procedures for childbirth across this country—a standardization most reminiscent of the standardized rituals that make up rites of passage in traditional societies.”<sup>110</sup> This standard set of procedures serves not only to

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<sup>109</sup> Kitzinger in Davis-Floyd, *Birth*, 38.

<sup>110</sup> Davis-Floyd, *Birth*, 1.

deliver the baby, but also to socialize the new mother—and by extension, the baby—into beliefs about herself and her body that Davis-Floyd and others believe are often harmful.

Davis-Floyd claims that because the biomedical model is built on mechanistic beliefs about the body, obstetrics as a science (though not necessarily obstetricians as individuals), has responded by developing procedures that transform the natural childbirth process in such a way that it works within the technocratic model. Thus, modern obstetrics developed “a set of ritual procedures that could be uniformly applied to the natural process of human reproduction in order to transform it conceptually into a cultural process of human production.”<sup>111</sup> Unlike most rituals, however, birth does not require the ritual to be performed in order to occur—a baby will be born with or without these procedures. Because of the extremely vulnerable position of women who are giving birth, however, especially in a society that transmits ideas about birth as scary and dangerous, these rituals performed around her easily transmit ideas about society, including the continued need for biomedicine in the woman’s future as a mother—she needed biomedicine to birth the baby, and will continue to need it to mother her baby. These ideas are not, of course, purposefully designed to transmit these sorts of messages—rather, the history of obstetrics practice requires that certain things are done because that is the way they have been done, with little evidence showing they provide a benefit to mother or baby.<sup>112</sup> It is not the ritual itself that is the problem, but rather its setting, its administrators, and its consequences for the mother.

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<sup>111</sup> Davis-Floyd, *Birth*, 56.

<sup>112</sup> See M. Wagner, *Fish Can’t See Water*.



Unfortunately, Davis-Floyd argues, certain ritual procedures are not helpful to birthing women, and many prove harmful. Davis-Floyd claims that the “scientific” procedures that have grown up around institutionalized childbirth in a hospital setting “more than meet the anthropological criteria for ritual behavior, and their primary functions have at least as much, if not more, to do with the culturally appropriate socialization of the birthing woman as with her ‘rational-technical’ medical care.”<sup>113</sup> She draws on characteristics of ritual such as the symbolic nature of its messages, its emergence from a belief system, its repetition and redundancy, its association with performance, and its importance in preserving the status quo, demonstrating that many aspects of hospital birth are better explained through the realm of ritual than evidence-based medicine. She contends that rituals in the context of rites of passage (which occur in the context of natural processes including birth and death), serve many purposes, one of which is to give humans a sense of control over natural processes. Davis-Floyd argues that ritualized procedures such as the use of IVs, wheel chairs, and fetal monitors for all women, their separation from partners and family, the use of hospital gowns, and other ritual procedures referred to as “standard procedures for normal births” are largely used, then, to transmit ideas about the woman, her body, her ability to mother, and her place in society.<sup>114</sup> For example, Pitocin (a synthetic form of the natural hormone oxytocin that controls labor) is often given to speed up labor when a team arrives ready to deliver a baby and the woman’s labor suddenly slows. While there is no medical need for this

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<sup>113</sup> Davis-Floyd, *Birth*, 7.

<sup>114</sup> Davis-Floyd, *Birth*, 75.

intervention in most cases, giving pitocin relays messages about the importance of the institution as a “more significant social unit” than the mother.<sup>115</sup> In addition, the incredible amount of modern machinery now deemed necessary to deliver a baby communicates messages about the inability of a woman to birth a baby unaided by such interventions. Indeed, such ideas have been internalized by the medical establishment itself. In an interview with Davis-Floyd, an obstetrician noted his dependence on fetal monitors in his practice: “I couldn’t practice modern obstetrics without them. I couldn’t sit over there with a woman in labor with my hand on her belly, and be in here seeing twenty to thirty patients a day.”<sup>116</sup> The same obstetrician noted that after twenty years of practice, what obstetricians do today “is 90 percent different than what we did.”<sup>117</sup> The contrast between these two statements, the utter reliance on technology by the obstetrician while acknowledging that he successfully completed his job 20 years ago with few of the modern interventions he uses today, points to an internalized message about what is necessary to deliver healthy babies. Another obstetrician noted “I could never attend a home birth. I wouldn’t know what to do.”<sup>118</sup>

Modern obstetrics has responded to birth by working out “a strong and consistent philosophical rationale for the management of birth which interprets birth specifically and exclusively in terms of the technocratic model.”<sup>119</sup> Thus, those immersed in the technocratic model are inevitably going to share beliefs about the need for such

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<sup>115</sup> Davis-Floyd, *Birth*, 56.

<sup>116</sup> Davis-Floyd, *Birth*, 55.

<sup>117</sup> Davis-Floyd, *Birth*, 55.

<sup>118</sup> Davis-Floyd, *Birth*, 64.

<sup>119</sup> Davis-Floyd, *Birth*, 62.

interventions for a pregnant woman, regardless of her medical need or desire for them. Davis-Floyd points to numerous examples of times when women in labor or after birthing expressed wishes but were ultimately denied those wishes in the name of the health of the baby (though rarely explained in any extensive fashion) or as a typical procedure. While some women were able to compartmentalize this experience, others remained angry about the denial of their ability to control the circumstances of their own birth, particularly when the interventions clearly had no bearing on the outcome of the birth.<sup>120</sup> Often decisions made for the sake of the hospital (the more important social unit) negatively impacted the mother's birth experience and her memory of that birth experience, a central focus of midwifery.<sup>121</sup>

It is not only the actions of midwives and obstetricians as groups that vary, but their underlying beliefs about women, their bodies, and the birth process. Throughout the early history of male-attended births, the male experience with birthing was limited to deliveries in which medical interventions were needed. These complicated births were a far cry from those experienced by midwives, who might attend hundreds of normal births in their lifetime. In addition to the difference in exposure, male attendants were trained in pathology. While obstetricians, like other physicians, consider part of their role to include health education and preventative screening, Rooks asserts that these things are not the source of the authority of physicians:

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<sup>120</sup> One interesting example is the refusal to allow the mothers' male partners to be present during the "prep" for a labor, even when such presence was requested or promised. See Davis-Floyd, *Birth*, 79.

<sup>121</sup> Some of these procedures can be attributed to the new constraints on the profession of medicine, including the threat of malpractice, while others are difficult to root in any particular explanation.

The physician's unique and awesome role lies in his or her ability to diagnose and treat disease, especially the use of medications and surgery...In contrast to medicine, the midwife's education, training, knowledge, skills, and role focus on protecting, supporting, and enhancing normal childbearing and family formation. Midwives are expected to detect abnormal conditions and work with physicians in such a way that medical expertise is brought into situations involving a medical problem.<sup>122</sup>

While physicians focus on pathology and what could go wrong in a pregnancy, midwives strive to protect the normalcy of childbirth as free from technological intervention. Of course, midwives also prepare, monitor, and assess for potentially dangerous situations, but their approach attempts to avoid technological interventions by providing information and help to women throughout the pregnancy and birth to prevent these situations from happening. Midwives thus are critical of physicians who attempt to control labor and delivery, particularly when this requires restricting how women behave during childbirth.<sup>123</sup> Midwives object to these procedures when they "limit freedom of movement and interfere with the social, emotional, and spiritual experience of giving birth."<sup>124</sup> It is, however, important to note that, even in states where midwifery is legal, midwives attend only "low-risk" births. And midwives do believe that there are situations in which births ought to take place in a hospital, and when birthing mothers experience complications that require modern biomedical techniques, midwives will transfer care to a hospital. Pregnancies and births with more risk are often referred to obstetricians because they do require some of the interventions of modern medicine.

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<sup>122</sup> Rooks, *Midwifery*, 126.

<sup>123</sup> Rooks, *Midwifery*, 5. This includes reclined childbirth, lack of social support, control over what food and water are available to women, and other non-technological interventions as well.

<sup>124</sup> Rooks, *Midwifery*, 15.

Because obstetricians focus on pathology, they frame their prenatal care and labor experiences in terms of their potential for pathology. According to Rooks, this leads physicians to certain perceptions, including the imperfection of women's bodies at giving birth and the belief that "medicine can and should improve on nature."<sup>125</sup> Pre-natal care is focused on screening for abnormality and assessing the likelihood of complications, while acknowledging that every woman and her baby are at risk. In addition, Rooks claims, obstetricians have a set of expectations around childbirth that limit what it ought to look like. Obstetricians believe, Rooks argues, that "Childbirth must be closely monitored and controlled; it should start on or near the predetermined day, and each phase of labor should not take more than a specified amount of time."<sup>126</sup> Midwives, on the other hand, come to the field of childbirth "predisposed to respect the natural birth-giving ability of women's bodies."<sup>127</sup> While acknowledging that childbirth can be dangerous, occasionally, midwives focus instead on pregnancy and birth as fundamentally healthy, with a wide array of normal variations. In addition, a midwife's acceptance of a larger amount of variation in the range of normal may shape the outcome of potentially dangerous childbirth. As Rooks notes, "Treating more labors as normal may help them to remain normal; some of the interventions applied because a woman is high risk can actually cause complications."<sup>128</sup>

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<sup>125</sup> Rooks, *Midwifery*, 127.

<sup>126</sup> Rooks, *Midwifery*, 127.

<sup>127</sup> Rooks, *Midwifery*, 128.

<sup>128</sup> Rooks, *Midwifery*, 131.

In addition to holding different beliefs about what normal pregnancy and delivery look like, physicians and midwives have different interests in what is experienced and gained through the delivery process. For obstetricians, the most important goal is a healthy baby and mother. Under a technocratic model with market-based undertones, an obstetrician's number one priority—a healthy mother and baby—often means other aspects of the birth process are of limited importance. In contrast, midwives are highly interested in the woman's experience of her pregnancy and delivery. As Rooks reveals, midwives are interested in all facets of a pregnancy, including the mothers' mental state:

perceptions and beliefs; her knowledge, opinions, questions, and worries; her feelings, satisfactions and dissatisfactions, comforts and discomforts; her desires, decisions, and actions, and the effect of all of these on her pregnancy; the development of her fetus; her labor, delivery, breast-feeding, and postpartum recovery; and how she mothers her infant.<sup>129</sup>

The scope of care for a midwife goes far beyond the typical concerns of an obstetrician, in large part because a midwife cares for far fewer patients at one time than an obstetrician. The practical constraints on the time of the physician make giving such attention to each patient impossible if an obstetrician is to care for the number of patients required of them. While obstetricians focus on anatomy, physiology, biology, and pathology, midwives focus on the limitations of these sciences to fully understand pregnancy and childbirth. Midwives believe that a deep respect for the process of childbirth and the profound meaning it has for many people means that “treating it as a medical procedure has a detrimental impact on both the biological and social processes of

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<sup>129</sup> Rooks, *Midwifery*, 127.

reproduction.”<sup>130</sup> In fact, medical interventions may end up disrupting the birth process, in large part because even “harmless” hospital routines or interventions, fear, and discouragement “can rob labor of its power.”<sup>131</sup> This power has been described as a force that “invades” women and takes over the process, but can easily be undercut by interventions and disturbances. Dr. Michel Odent, a French surgeon who led a maternity unit for twenty years beginning in 1962 described the power of what he called “The Undisturbed Birth.”<sup>132</sup> Most of the births in the maternity clinic were overseen by midwives. Odent discovered that when mothers were coached to relax and “let themselves go,” that their C-section rates were lower and women had a lower rate of problems. When the women in the clinic gave birth “undisturbed” (free from the presence of strangers and with few technological interventions), they were able to have more successful births.

Neither Davis-Floyd nor many midwives would suggest that it is impossible to have a healthy and empowering hospital birth, but rather, that it is difficult to do so. Davis-Floyd described the women in her study who experienced positive birth experiences in the hospital as those who were able to “compartmentalize” their birthing experience. These women often were anesthetized and able to put the birth experience outside everyday life, and they ascribed little meaning to the birthing process (though this did not prevent them from assigning the birth itself meaning). Others who were able to successfully control parts of the birthing process that were important to them, while

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<sup>130</sup> Rooks, *Midwifery*, 128.

<sup>131</sup> Rooks, *Midwifery*, 128.

<sup>132</sup> Rooks, *Midwifery*, 128.

seeing the hospital interventions as only slightly cumbersome, but not as an interference, also were able to have positive birth experiences. Yet the general trend in her interviews was that women who gave childbirth “naturally” (that is, more-or-less according to the midwifery model), felt that the process of giving birth was transformative in itself—that they felt empowered *because of* their birthing experience.

Midwives recognize the potential for the detrimental long-term effects of a labor process that robs a woman of her power and ability to trust her body, and strive to work with women to create empowering labor experiences. In contrast to the power that a physician holds—by virtue of his or her training, degree, and knowledge—the goal of a midwife is to place that power back in the hands of the mother. The history of birth movements—first into the hospital, and now out of it—were both built on the idea of women gaining more power. The move into the hospital was heralded by early feminists, hoping that it would serve to equalize the sexes by removing the place of birth from the home, the cultural place of the woman. Many of the reforms that the natural birth movement now works against (bottle feeding, anesthetized birth, etc.) were once held as potential freedom-creating advances for women. Instead, these changes, supporters of natural birth movements say, have played into the technocratic ideas of bodies as machines and been reincorporated into the patriarchal hospital structure.

While these larger-scale changes are important to midwives, it is also important to note that midwives are concerned about the power that individual women feel in their birthing experience. Because midwives believe that everything a woman thinks or believes affects not only her birthing process, but also her parenting, her relationship with



the baby, and her relationships with others, none of it is beyond the midwife's concern. In addition to sharing a physician's goal of a healthy baby and mother, a midwife's goals include a positive subjective experience of birth from the mother, enhancing her self-expression and satisfaction, and other more subjective criteria. In addition, midwives strive to communicate messages to women about their strength and ability to birth their baby by themselves. The mother is the active participant in the birth, with a midwife supporting. This serves as a contrast, midwives assert, to the idea that it is the physician who births the baby, with or without the assistance of the mother.

By emphasizing a wide array of emotional, social, and environmental factors, midwives aim to empower women to be in control of their own birth process. While they offer education, midwives define their role as a support figure, which is evidenced by the term they use for delivery. Rather than using the term "deliver" to describe their role in the birthing process, midwives often say that they "catch" a baby. The switch from an active to a passive role puts the process of birthing firmly in the purview of the mother. The birth experience belongs to her and she has the obligation and opportunity to take part in it. In contrast, physicians are more likely to see themselves as being in charge of the process. They are likely to prescribe birthing positions, medications, or interventions. While they are sometimes presented as true options for a woman, a physician is likely to step in at some point and require the use of one intervention or another, in order to deliver

a healthy baby – a baby who would have in all likelihood arrived healthy with or without the participation of the physician.<sup>133</sup>

## **Hospice Care and Hospital Death**

Hospice nurses are initially trained in the same way that other nurses are, although they often receive additional training upon entering the hospice field. While differences in training play a large role in the differences in practice between a midwife and an obstetrician, the same is not necessarily true for a hospice nurse or other professional. Instead, it is more helpful to contrast the view of death and dying in a hospital with the view of death and dying in a hospice. In doing so, important ideological differences and practical concerns between those who work in these settings are revealed.

Many differences in how care is provided to patients in a hospital and in a hospice stem from one fundamental difference in how death is viewed. For physicians in a hospital, the prevention of death is the primary aim, and the authority the profession holds is largely based on their ability to stave off death. Death of one's patient marks failure for a physician, even if that death was inevitable. Particularly in the context of the popular metaphor of medicine as war, and disease as an "enemy invader" that must be "fought," death is often viewed and experienced as a failure. Thus, dying patients are

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<sup>133</sup> While it is generally beyond the scope of this thesis to address the cost to the healthcare system of unnecessary hospitalized births (of course, some births would need to continue to be monitored there, as midwives specialize in low-risk births), it is important to note that the high health-care costs of medicalizing low-risk pregnancies takes funds away from other places where the money might be better spent. Using physician-attended births as a matter of routine—rather than necessity—requires the use of funds that, in a country as wealthy as ours is simply wasteful, but in a developing country to which we export our healthcare model could be detrimental. (Wagner, *Fish Can't See Water*, S28).

kept from death by available technology, even when that technology is painful or futile. Additionally, some physicians struggle with dying patients and their own role as healer. “Those physicians who define their role exclusively in terms of curing (as opposed to caring),” Moller claims, “will naturally tend to spend their time and energy in the treatment of those patients, seriously ill or otherwise, who have a reasonable chance of responding to the doctor’s curative therapies.”<sup>134</sup> This tendency to provide treatment to those who will benefit from it often led to the virtual abandonment of dying patients in hospitals, or the overuse of technology when its use is deemed futile. Both of these were the target of research in the 1960’s and 70’s about treatment for the dying, and eventually formed the basis of the hospice movement.

While working with dying patients is difficult and non-intuitive, a physician’s training in this area is generally limited. The root of this training for most physicians comes in the form of work with cadavers in medical school; such work, Moller argues, as well as autopsies on the recently dead, form a “seed of detachment” that is fostered further in continued medical studies. This detachment from patients plays a role in self-preservation for physicians, and is often done in the name of self-care for the physician.

As Schoenberg and Senescu contend:

Care of the dying patient usually induces so much anxiety in health personnel that in many hospitals emphasis is placed on the routine technical aspects of physical care rather than on the development of close interpersonal relationships with patients... Terminal patients are frequently avoided by hospital personnel, thereby increasing their sense of loneliness and isolation. Physicians and nurses may avoid conversation or otherwise distract a patient when he begins to discuss death. When the patient feels

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<sup>134</sup> Moller, *Death Without Dignity*, 33.

the hospital personnel are uncomfortable in allowing him to discuss the taboo topic, he will gradually erect his own communication barrier. It is the conspiracy of silence that is most destructive since it tends to separate the dying from the living and offers the patient no opportunity to verbalize his feelings and thoughts, or allow his positive feelings for others to emerge.<sup>135</sup>

The fault for this “conspiracy of silence” does not lie solely, or even largely, with the physicians or nurses, but rather emerges from the societal rejection of death discussed in chapter one. However, doctors and nurses often perpetuate the codes of silence that we have created to surround death to the detriment of the dying patient. Robert Kastenbaum, in his book On Our Way: The Final Passage Through Life and Death, lays out what a panel of caregivers and researchers in the mid-1970s believed to be the hidden or implicit standards of care for a good death. These included: a successful death is quiet and uneventful, no one is disturbed, few people (including staff and family members) are around, no emotional or awkward goodbyes, physicians are generally not involved, the staff makes few technical errors, attention is focused on the body rather than the individual, the person dies “at the right time, that is, after the full range of medical interventions has been tried out and before the onset of a long period of lingering,” the staff believes they did everything possible for the patient, and that money was not wasted.<sup>136</sup> This set of standards emphasizes that a good death is marked by the experience of the medical establishment, not that of the patient.

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<sup>135</sup> Schoenberg and Senescu in Dubois, *Hospice Way of Death*, 49.

<sup>136</sup> Robert Kastenbaum, *On Our Way: The Final Passage Through Life and Death*, (Berkeley: University of California Press, 2004), 111.

For hospice, death is not an enemy to be prevented, but rather a given reality of nature within which all other work is done. The focus is not on what is efficient or practical for the medical establishment, but rather on the needs and desires of the patient and his or her family, the “unit of care” in hospice philosophy. While the primary aim of the hospital for care of the terminally ill focuses on medical expediency, prolonging life, and pain relief, hospice care broadens the definition of terminal care to three primary aims: medical management, comfort, and spiritual care. According to Cicely Saunders, the founder of modern hospice, hospice care aims:

...to recognize the interest and importance of the individual who must be helped to live until he dies and who, as he does so in his own way, will find his ‘own’ death with quietness and acceptance. A staff who recognize this as their criterion of success will not find this work negative or discouraging and will know that it is important, both in its own right and also in all the implications it holds for the rest of medicine and, indeed, the rest of life.<sup>137</sup>

In order for a patient to qualify for hospice care, a physician must certify the patient has approximately six months or less to live, and the patient must agree to forgo curative treatment. While this prospect can be scary for a patient, hospitals often struggle to follow the wishes of a patient, either because they believe treatment could prolong their life, because of difficulty with other family members (who do not wish to let go or who have false hopes about the probability of recovery), or even fear of lawsuits. In his article “Letting Go,” physician Atul Gawande chronicles the story of a number of patients who

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<sup>137</sup> Cicely Saunders, “Terminal Patient Care” in *Geriatrics* 21:12 (1966), 74. This language of finding one’s own death resonates with hospice professionals who emphasize that patients ought to be allowed to die as they have lived. Saunders’ statement that a patients must find “his own death” resonates with a hospice philosophy that emphasizes patient control in the circumstances surrounding death.

knew that their condition was terminal, often for a long time, but remained unprepared for the final stages of illness and death. His friend, a critical care physician in charge of ten patients, only two of whom had any chance of leaving the hospital for any time, and many of whom had expressed wishes not to be kept alive in such circumstances but who had been convinced otherwise by physicians or family members, noted that conversations about end-of-life care between physicians and their patients are happening more often. Unfortunately, though, “it’s way too late.”<sup>138</sup> By the time these patients are having conversations with their physicians about end-of-life care, they have often already limited the number of possible choices they have.

Like midwives, hospice professionals start from different beliefs about health and death, the human body, and the individual. While the hospital model of care is built upon assumptions of the Cartesian mind-body split, treating the physical body almost exclusively, hospice integrates the care of the mind and the body. Hospice professionals hesitate to separate the care of the body from the care of the mind or spirit, and their care reflects a deep belief that spiritual suffering can be just as debilitating as physical suffering. While they treat both kinds of pain, hospice professionals do so with an integrated approach. This approach focuses on the individual’s beliefs and experiences of their own life and body, as well as those of their family. Individual desires and beliefs are accounted for in the management plan, even when those beliefs conflict with what a nurse or other member of the hospice team believes would benefit the patient. Finally, in

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<sup>138</sup> Atul Gawande, “Letting Go: What should medicine do when it can’t save your life,” *New Yorker*, August 2, 2010.

contrast to the silence about life-ending conditions that pervades hospital rooms, hospice concentrates on open communication with patients about the reality of their condition, and their wishes in the face of that reality. Above all, the patient in hospice care is allowed to make choices based on their beliefs about themselves and their family.

Part of what has changed about our perception of death is a shift in the common causes of death. No matter the cause, before modern medicine, the time period between realizing that one had a life-threatening ailment and one's dying was limited to days or maybe weeks. Now, dying often lingers for months or years, not quite there but never gone. In addition, the loss of a common narrative that serves as an explanatory guide for our lives, generally rooted in religious belief, also leaves us with few guides or rituals surrounding dying. These rituals and guides "provided families with prayers and questions for the dying in order to put them in the right frame of mind during their final hours."<sup>139</sup> Now final hours stretch into final weeks and months and patients are rarely lucid during their final moments. Catastrophic illness has been replaced by long medical struggles where "death is certain, but the timing isn't," Gawande notes. "So everyone struggles with this uncertainty—with how, and when, to accept that the battle is lost."<sup>140</sup>

In the article, Gawande guides us through his discovery of—and eventually his advocacy for—hospice care. As he visits patients with his friend, a hospice nurse, she explains to him how the hospice philosophy differs from "ordinary medicine:"

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<sup>139</sup> Gawande, *Letting Go*.

<sup>140</sup> While Gawande is sympathetic to—and supportive of—hospice's goals, his language here clearly places him outside the hospice philosophy of care. Hospice discourse rarely uses military metaphors such as "the battle is lost" to characterize death or the dying process.

The difference between standard medical care and hospice is not the difference between treating and doing nothing, she explained. The difference was in your priorities. In ordinary medicine, the goal is to extend life. We'll sacrifice the quality of your existence now—by performing surgery, providing chemotherapy, putting you in intensive care—for the chance of gaining time later. Hospice deploys nurses, doctors, and social workers to help people with a fatal illness have the fullest possible lives right now. That means focusing on objectives like freedom from pain and discomfort, or maintaining mental awareness for as long as possible, or getting out with family once in a while. Hospice and palliative-care specialists aren't much concerned about whether that makes people's lives longer or shorter.<sup>141</sup>

What hospice provides, then, is an opportunity to prepare for the inevitable. Instead of pouring time and money into futile “curative” medicine, hospice can provide what dying patients need—support, pain relief, spiritual care, and help to realize the potential benefits that can come from embracing the end-of-life time. Like midwifery, hospice care values the experience of an important life process, not simply the “success” of that process.

Like midwives, hospice professionals are wary of the interventions used in a “normal” life process. Gawande argues that we are taught to hope that the cure is right around the corner, and that when there is no hope, the doctor will tell us that there is nothing more they can do. “But rarely,” he says, “is there nothing more that doctors can do. They can give toxic drugs of unknown efficacy, operate to try to remove part of the tumor, put in a feeding tube if a person can't eat: there's always something.”<sup>142</sup> And while we want these choices, we also struggle to make them. Physicians generally are willing to limit at least some kinds of treatment, but require patients and families

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<sup>141</sup> Gawande, *Letting Go*.

<sup>142</sup> Gawande, *Letting Go*.



themselves to make such decisions. Sometimes, Gawande suggests, that is asking too much. So often we fall back on our default, “do something.” These “somethings” done by physicians often not only fail to prolong life, they lead to diminished quality of life or even hasten death.

So hospice, in contrast with hospital deaths, focuses on quality conversations about how the patient and his or her family would like death to look and feel. People who have substantive conversations with their physicians about their end-of-life wishes are “far more likely to die at peace and in control of their situation, and to spare their family anguish” according to a study of terminal cancer patients.<sup>143</sup> By allowing a patient to control the experiences around death, monitoring and preventing pain, and providing the opportunity to have important conversations with health care workers and family, hospice strives to provide a less painful death with opportunities for growth and empowerment, whatever that might look like for an individual patient.

The fundamental opposition of the view of death as an enemy and death as a natural process within which one works echoes the contrast of the views of childbirth as natural and childbirth as needing to be controlled. Both midwifery and hospice care share the view that natural processes need few medical interventions, and that often these medical interventions are harmful. Both struggle with the view that we ought to control—to fight—these natural processes, to make them fit a “normal” pattern, and to make them

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<sup>143</sup> Gawande, *Letting Go*. The study, conducted by Wright AA, et al. included 332 patients and caregivers. It was published in the *Journal of the American Medical Association*, 2008; 300(14): 1665-73.

as “sterile” as possible. These parallels will be discussed further through interviews with both midwives and hospice professionals in chapter three.

### Chapter 3: Fitting the Metaphor to the Reality

*"The art of medicine is to entertain the patient while nature cures the disease." ~ Voltaire*

#### Interviews

The historical and ideological similarities between midwives and hospice nurses seem to provide evidence that the metaphor of hospice professionals as “midwives to the dying” holds at least some relevance to the practice of caring for the dying. In order to explore whether this metaphor holds meaning beyond these realms, I chose to conduct interviews with both midwives and hospice nurses. By interviewing these professionals, I hoped to uncover similarities about their practices, their relationships with one another and their clients, and their convictions about their work. I wanted to test whether the scholarship from the last two chapters would have any relevance to the work of midwives and hospice professionals, whether it held true for their own sense of professional identity. My study included five interviews, two with hospice nurses and three with midwives.<sup>144</sup> Although hospice is built on a team model of care, and many patients work with teams of five or six individuals, I chose hospice nurses as the most direct parallel to the dual role of holistic care and medical knowledge in midwifery. In semi-structured interviews, I elicited narratives from the women about their views of working with patients (or “clients” in midwifery), the role of their practice in mainstream society, and their views about birth and death.

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<sup>144</sup> See Appendices A and B for a record of IRB approval and the list of questions asked in the interviews.

The interviews, conducted in the spring of 2010, are not meant to be conclusive, but rather serve as a guide to how we ought to think about the metaphor and whether it holds any kind of relevance for the people to whom it is applied. The questions covered a broad range of topics, from the care my interviewees provide to people in their care to the sources of knowledge they find instructive to the views about the body they believe are communicated through the care provided in a midwife-driven or hospice-based experience. This chapter will discuss some of the interesting similarities that arose through the interviews.

The first important similarity is the metaphor of birthing or dying as a journey, and the importance of the experience of the mother (or patient) through that experience, as well as the idea of the potential for the experience of birthing or dying to be empowering for the patient. Second, and this point is deeply connected to the first, is the centrality of the individual (mother or patient) to the process of birthing or dying, particularly in contrast to their perceived role in the larger biomedical establishment. Third, some of the very physical similarities between birthing and dying were seen as instructive for both midwives and hospice nurses, and many drew parallels between the labor of birthing and the labor of dying. In addition, the midwives and hospice nurses had similar ideas about the importance of the physical body as a part of the integrated whole of the person in their care. Fourth, the hospice professionals and midwives drew many direct parallels from their work to that of the other profession, and many of these provided insight into their beliefs about their role in the birthing (or dying) process. Finally, one of the similarities that the midwives and nurses both discussed was their

profession's response to the medicalization (generally they referred to this as the hospitalization) of birthing or dying. The metaphor communicates a sense of trust in natural processes, a value placed on choice and relationships, and a belief that technology has its limitations and there is value in embracing life and death without technology as a driving force. Midwives to the dying provide skilled spiritual, emotional, and physical care to their patients, just as midwives do for the mothers in their care. Further exploring the metaphor may help the dying, their families, and hospice professionals themselves to shape the experience of dying in a positive way.

There are, of course, many important differences between the professions of midwifery and hospice care. Most obviously, their anticipated outcomes appear opposites to us—birth and death are both important life processes, yes, but they are marked in very different ways by society, and generally accompanied by very different emotions. And while midwives do occasionally fear for—and experience—the death of an infant while providing care, these cases are rare and tragic, certainly not a part of what midwives aim to achieve in their practice. As discussed in chapter two, another important difference is the professional climate in which hospice professionals and midwives operate. Midwives struggle to gain legal status in many states, while hospice professionals face no such struggles in their own. In addition, hospice professionals do not see themselves in the kind of antagonistic relationship with the larger biomedical establishment that midwives do, although they do discuss problems with the medicalization of death. Midwives also generally practice with one or two other midwives, but are considered the primary care

provider. In contrast, a hospice nurse is one part of a team of individuals from many disciplines providing care to a dying patient.

One other difference to note is that hospice care is built on the idea that a team of people works with each patient to help them through the process, so that some of the midwifery parallels are more easily drawn to other members of the team, rather than hospice nurses. For example, a bereavement coordinator continues to work with a patient's family after a death, where a nurse ends their relationship. This parallels a midwife's commitment to continue care after the delivery. Despite these differences, however, the similarities between the two professions provide important ideas about the kind of care provided in life's critical moments. The interviews with both midwives and hospice nurses make it possible to examine whether the metaphor of hospice nurses as "midwives to the dying" can provide guidance in understanding the role of a hospice nurse.

### **Birth and Dying as a Journey**

The language and metaphors of death as a challenge, as life's last great act, or a transition to another world that used to surround death, according to sociologist Albert Banerjee, "have given way to the materialist metaphors of modern science."<sup>145</sup> He contends that instead of talking about the meaning and impact of death, we talk about its causes. "Distance from death can be 'gauged' through T-Cell counts, cholesterol levels,

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<sup>145</sup> Albert Banerjee, "Speaking of Death: Representations of Death in Hospice Care" Florida State University, accessed May 5, 2010, [iph.fsu.edu/interculture/pdfs/banerjee%20speaking%20of%20death.pdf](http://iph.fsu.edu/interculture/pdfs/banerjee%20speaking%20of%20death.pdf), 1.

blood pressure measurements, and, undoubtedly sooner than we think, through genetic tests of various kinds,” he argues. And this has become the way in which the average person relates to death. While medical language currently centers on quantitative measurements, both midwives and hospice nurses use a number of metaphors to illuminate their practices. Both midwives and hospice nurses talk about birthing and dying, respectively, as a journey.<sup>146</sup> Although a more common term in talking about dying, two of the midwives also talked about childbirth as a journey. One midwife reflected “I use the journey [metaphor] a lot...I talk to them about how every journey has its peaks and valleys and I try to walk them through each of those.” Speaking about dying as a journey, rather than a scientific process, suggests a different approach to dying than that reflected in the medicalized culture. “It also,” Banerjee suggests “reflects a different understanding of who, ultimately, ought to be in control of the dying process—the ‘adventurer’ rather than the ‘therapist,’ for instance.”<sup>147</sup> The metaphor of journey was used by both hospice nurses and midwives to emphasize the active role of the dying person or pregnant woman in their own life process (rather than their role in caregiving), and the importance of the experience over the end result.

The journey for a pregnant woman and her midwife is relatively fixed in time, at least leading up to the birth. Although there is plenty of uncertainty in the process regarding the timing of the birth itself, for the most part, women and their midwives have

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<sup>146</sup> The “journey” is discussed alternatively by midwives as including the entire pregnancy and extending into parenting. At the same time, many midwives talk about the more fixed time frame of labor and birth as a journey as well. I believe it is fair to include the entire process within the journey framework, while including the important time of labor and birth as the critical point in that journey.

<sup>147</sup> Banerjee, *Speaking of Death*, 1.

a relationship starting 7-9 months before the birth of a baby, and then continuing after the birth for a variable but pre-determined amount of time between a month and a year. The hospice nurses, on the other hand, emphasized the variability in time frame of their work with individual patients leading up to the death. In order to qualify for hospice care, a doctor must give a patient a prognosis of six months or less to live. Although some patients do live beyond that time frame, and some even get better enough to “graduate” from hospice, the average length of time in hospice care is only 14-20 days.<sup>148</sup> This reflects, in part, a misunderstanding of the hospice care movement by the general public and terminally ill patients as well as a desire by physicians not to forego curative measures prematurely. One nurse reflected

The journey can be as short as less than a few hours or sometimes we have them longer than the six months, because the doctors don't always know exactly. So time-wise, there's a huge difference, but the longer you have to get to know a person, the stronger the bond is between you and the working relationship between you and the family.

Hospice nurses face tremendous variability in the time they spend with each patient, but the overarching goal of hospice, that the patient gets to make his or her own end-of-life decisions, remains a guide.

The midwives emphasized the importance of the time around birth in a number of ways. The first was to recognize that in pregnancy and birth a woman is, as one midwife put it, “psychically open” and that this experience will likely be in her memory forever. “Their experience of pregnancy is that profound, and the same thing is true of the birth. I

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<sup>148</sup> Angela Morrow, "Hospice Myths - Common Myths about Hospice," *About Palliative Care - Hospice and Palliative Care*, October 12, 2008, accessed May 20, 2010.



have a strong sense that birth is transformative for women; it's certainly something they will never forget," the midwife continued. Midwives also emphasized that the midwife understanding of the birth *experience* as important is in contrast with the belief that the only thing that is important is that the mother have a healthy baby and be healthy herself (something that the midwives I spoke with ascribed to those who work in a hospital setting). "How they get the baby is just as important as the fact that they get the baby and we can't be traumatizing women in the process," one midwife commented. The emphasis on the importance of the mother's experience in the process of birthing relates directly to the metaphor of birthing as a journey, and shifts the focus onto the one taking the journey, rather than the guide.

For midwives, protecting the birthing experience is extremely important. In her interviews with 100 pregnant women and mothers, Robbie Davis-Floyd noted many negative birth experiences that resulted from a hospital birth experience where the mother felt her experience had been taken from her or that she was not allowed to make choices or her choices were ignored. One mother remarked, forty years after her birthing experience, which ended with a cesarean section:

I've never gotten over it. I still remember that mask coming down over my face, and I still feel as angry as I did then, when I woke up. Those people took my birth away from me. I don't know why and I don't know how, but I've never felt the same about myself since.<sup>149</sup>

This mother's lack of input into—or even understanding of—her birthing process left her hurt and angry. While hers was a “successful” birth in the sense that she and the baby

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<sup>149</sup> Davis-Floyd, *Birth*, 40.

were both physically healthy, midwives would see this kind of birth as detrimental to the mother's beliefs and feelings about herself and her baby, as well as the bonding process of mother and child.

While the ideal image of childbirth has shifted over the years, the idea of a “natural child birth” that emerged between the 1960s and the 1980s was not exclusively framed to be opposed to the number of procedures applied to the mother in the hospital, but rather the experience of the mother in her birthing process. Davis-Floyd argues that this model focuses on the conscious participation of the woman, with “(1) her being “awake and aware” as she labors and gives birth; (2) her feeling the sensations of labor and birth; and (3) her active efforts to push the baby out.”<sup>150</sup> In the classic biomedical model (what Davis-Floyd calls the “technocratic viewpoint), the mother's active participation is not a necessary part of the birthing experience, beyond her actual presence. Because the uterine contractions are involuntary, her participation is welcomed, but not necessary, and therefore useful only when she complies with the interventions and procedures recommended by the physician.

A second way midwives felt the birthing experience was important was that they saw a possibility for the experience to be empowering for the new mother. One midwife reflected, “If the experience is validating, you know you felt empowered or made choices or were strong and supported, then you're entering this new phase of life from this empowered position.” Not only is it empowering to the woman that her body was able to give birth alone, without medication, but also, she was able to make choices, listen to her

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<sup>150</sup> Davis-Floyd, *Birth*, 162.

body, and trust the process. This empowerment comes from the knowledge that a woman's body works on its own. Davis-Floyd ties this empowerment to the recognition that:

The mother's body knows how to grow a baby and how to give birth; she can trust the 'knowing,' for it belongs to her. The uterus, much more than an involuntary muscle, is a responsive part of the whole; the mother's mental and emotional attitudes affect its performance during labor.<sup>151</sup>

In addition, she has to learn to relinquish control and let go, as one midwife commented "so they have that work of surrendering and waiting for something that's largely outside of your control, which is very hard in this society where we control everything." Both of these factors, the empowerment and the relinquishment of some control, set the stage for the mother in the postpartum period and as a parent.

For hospice nurses, the idea that dying and death can be both an important memory and empowering take on different meanings. The nurses reflected that it was important to think about hospice deaths in contrast with negative death experiences. One nurse described the contrast: "There can be a traumatic, complicated death with guilt, all sorts of horrible feelings. So having a well-supported death can really influence...through the generations, their attitudes and their fears, their hopes and dreams, all those things." Here the idea of empowerment is transferred from the dying person, who is empowered initially to make choices about the situation around their death, such as what level of medication they desire or where they would like to die, to the family as they experience

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<sup>151</sup> Davis-Floyd, *Birth* 157.

the death of a loved one.<sup>152</sup> This death can set the stage for how the family members look at their own mortality. Hospice nurses Miriam Schneider and Jan Bernard argue that not only does the actual event of dying serve as a powerful moment for a family, but that just like birth, the retelling of that event is also important. They claim that “The process of retelling how birth or death looked, felt, and sounded is important. It is an event that influences us for a lifetime. Memories of this experience will drift in and out of our conscious thought for the rest of our lives.”<sup>153</sup>

A good, well-supported dying experience can be empowering for the family. In addition, it was important for the hospice nurses to make sure the death reflected the reality of who that person was. This memory was important not only to help the patient make sense of their own life, but to help the patient’s family reconcile the death of their loved one with the life they lived. While birth is an important and transformative experience for the mother, her last act as a childless woman, death is “a culmination of your life, it’s the last thing you do, it’s your last chance to make an imprint with your life,” one nurse said. In their book *Midwives to the Dying*, Schneider and Bernard make the connection between birth and death explicit: “Retelling how birth or death looked and felt and what it sounded like is important. This event influences us for a lifetime.”<sup>154</sup>

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<sup>152</sup> The sense of being a companion to the dying person specifically is strongest for hospice nurses, particularly because their time with patient families terminates shortly after the death of their patient. At the same time, hospice care still extends through the work of other team members, who continue to work with the patient’s family after death. In that sense, these other hospice personnel, including bereavement specialists, social workers, or chaplains, continue the companionship for the patient families.

<sup>153</sup> Miriam Schneider and Jan Selliken Bernard, *The True Work of Dying*, (New York NY: Avon Books, 1996), 79.

<sup>154</sup> Miriam Schneider and Jan Selliken Bernard, *Midwives to the Dying*, (Sherwood, OR: Angel's Work, 1992), 4.

Where death is feared and avoided systematically, “hospice culture offers a promising way of thinking: providing inspiring interpretations that encourage individuals to confront death and move through the dying process.”<sup>155</sup>

The “ideal birth” and “ideal death” discussed by both hospice nurses and midwives raised a number of common themes. Both midwives and hospice nurses spoke about the birthing and dying processes as “natural.” They did so both in the context of pushing against the medicalization of these processes, and in their role of supporting those individuals immersed in those processes. By emphasizing to a pregnant mother or a dying patient that the processes are natural, messages about their connection to nature, their importance in the process, and its closeness to us, even as it presents something new. The term “natural” does not, of course, have a single meaning, but its use by both midwives and hospice nurses to describe a goal of the process links them together. Other terms were used by both midwives and hospice nurses. Both midwives and nurses also felt that the processes should be “well-supported,” emphasizing the social nature of the processes over their medical nature.

Another related theme recognized by both hospice nurses and midwives is the idea that they work with an alternate view of time. The specialness and distinctive nature of the time around birth makes the experience of birthing even more vital. Thus, David-Floyd contends, the messages given to women during this time are incredibly important. Midwives, by acknowledging the importance and challenge of this time, hope to allow women to grow through this experience and carry it with them into the postpartum period

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<sup>155</sup> Banerjee, *Speaking of Death*, 9.

and into motherhood. Similarly, hospice professionals try to assist the family in creating growth and opportunity during this time, allowing this different sense of time to be meaningful for the dying patient and his or her family. This special time is referred to by anthropologists as “liminal space,” where one is caught between two things, belonging not to one or the other, but somehow to both and neither. Thus, a birthing mother is neither not a mother nor fully a mother, and a dying person is neither fully alive nor fully dead. This sense of difference relates to the ritual aspects of both birth and death as major life events, and points to the specialness of that time.

One midwife recalled the way that time and space appears different around birthing and dying, the things that become important and the transition back to “regular life:”

I think about the liminal space you're in as you're dying where people are bringing food, there's this outpouring of social support, people are sharing sentiments that they don't share on an everyday basis. People are processing some of the bigger life questions that we don't think about in our everyday life... So you're existing in this strange space where time has a different meaning, it's just a different place to be. And midwives have to dwell in that time all the time, so we go to the birth and we're at the birth and then we leave the birth and if I go to the grocery store or a restaurant right afterward, I'm always struck by the fact that everybody's going on with their regular life... And I have a close friend who died from breast cancer, her family was living within this liminal space where they could look out the window and see life occurring around them as if the death had not occurred. It's an interesting time to be the person who's asked to walk through and dwell for a long period of time in that liminal space. And so midwives and hospice workers have to be pretty comfortable being in that space and then leaving it and coming back to it periodically.

The midwives also drew strong parallels to a different kind of time surrounding death in their practice. Although all viewed birth as safe (“or I wouldn't do it at home,” one said),

they all spoke of the constant reminder that they live and work on the edge of life and death. One midwife commented:

There are rare moments in your life, especially where you can see it coming, where you are going to get that close to death...We want women to trust it to not have fear and at the same time we want to acknowledge that these are huge forces and the body is going through really drastic and dynamic changes.

Midwives and hospice professionals must work in a place where time is not within their control, and be okay with being in that place.

Even when all does go well, there is still a sense of not being in control and not knowing when something is going to happen. In hospice care, Schneider and Bernard comment that “There is no predictability of when either labor [of birth or death] will begin. So many times we are asked how much longer it will be before the death happens. The answer lies deep within the dying one.”<sup>156</sup> One midwife commented she was learning to trust “that real not sort of in control feeling, for just being in a place where we’re watching something unfold...and we’re ready to step in and we’re also not wanting to be overeager to step in and mess up something that’s actually finding its own balance.” Hospice professionals also contend with where and when to intervene with a patient. By definition, hospice does not provide curative measures, but hospice professionals do have to think about the level of comfort care they will provide in order to meet the patient’s wishes, and explain to the family what kinds of interventions they will perform in order to provide comfort, as well as the things that are “normal” and with which they will not intervene.

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<sup>156</sup> Schneider and Bernard, *Midwives to the Dying*, 4.

### **Centrality of the Individual**

One of the clearest ties between midwives and hospice nurses is their emphasis on the individual as central to the process. While this is evidenced in the journey metaphor described above, the interviews made it clear that every step of the process in both midwifery and hospice care is driven by the individual being cared for. In addition to providing physical care for their client, midwives engage in holistic treatment of the mother, believing that they need both a healthy mind and a healthy body in order for the birthing experience to be empowering. Midwives see their role as including a commitment to encouraging the mother, telling her she is beautiful or that she is doing a good job. One midwife explained, “A lot of women need someone else to see what they’re going through... And that I think gets overlooked so much [in] the medical model of care.” Midwives want their clients to feel like “their whole life is supported, or at least a really big portion of it, and like they can talk to their midwife about anything,” another midwife explained. Not only is this important so the mother feels she is emotionally ready for the birth experience, it is also important, the midwife explained, because “any of these things are going to translate into her blood pressure or her immune response. They all have very direct physical manifestations as well.” What midwifery provides, then, is one-on-one support. One midwife commented:

I tailor my care specifically to what I know she needs and what she communicates to me that she needs so I deal with all sorts of belief systems and I’ve been asked to do all kinds of things at birth that make that birth more meaningful for that family. And I feel comfortable doing that, I’m happy to do that.



This willingness to adjust care to include the individual desires of the mother sets midwifery apart from giving birth in a hospital. This individualized care might be reflected in the choices the mother makes about where she wants to birth and what kind of care she wants to have. Although some of the individualized care is possible in the hospital, this type of care is generally unavailable in a hospital not only because of beliefs about proper care, but largely because of the bureaucratic nature of a hospital that orients it to the most medically efficient type of care, and the very real constraints on the time of medical professionals in that setting. One midwife reflected, “there’s simply not as much flexibility in the protocols and the way they do things. And there are so many people to manage and the shift changes so those individualized requests are not feasible.” She continued by placing blame on the system rather than individual practitioners, “I don’t hold the medical establishment responsible for that; it’s just not possible in that system.”

The individualized care present in midwifery is also central to the hospice philosophy of care. One nurse commented:

I try to kind of meet them wherever they’re at. I don’t have an agenda for where they need to be or where they need to get to... At the same time, I try to open doors along the way that they can choose a different path or help them move along toward a more peaceful ending, but if they don’t want to choose that, then that’s okay, too.

Like midwives, hospice nurses are often willing to do things that are not available in a traditional hospital setting. “They can really indulge their own idiosyncrasies and little comfort habits” said one nurse. “There are things you can’t do in the hospital, which people have done their whole life, whether it’s smoke in their bed and leave the TV on as

high as it goes.” These choices were important, the nurse continued, because these “comfort patterns” marked a continuation of the ways patients had lived. Things should be done, the nurse reflected, to meet the individual’s needs “because it’s all about them, and I want it to be all about them.” Both nurses described the family as vital to the process. Information available from a patient’s chart, though important, does not hold the kind of information that one can get from the family. One nurse described the process of gathering important information. After receiving a chart from the doctor, “...honestly I might glance at that and then I just go to the family. I don’t care about your knee replacement in 1972, because it just doesn’t matter, you know.” What is important to the hospice professional is getting to know the individual, and then honoring their choices in the dying process, even when those choices may not be what the nurse thinks is best. “There are many, many times,” one nurse noted, “where I think I would not choose this, I would not choose to die like this or live like this but it’s not about me. So that’s okay, so then I can take myself out of that experience and just support them.” This strongly parallels the midwifery model of care; midwives often commented about something a patient asked them to do that caused them to step outside their comfort zone or worldview, but that in order to support their patient, that is what was required of them.

### **Physical Similarities**

One of the parallels between the birthing and dying processes that is most compelling is the idea of laboring. Both birth and death require a certain amount of labor,

and hospice professionals do draw on labor analogies to help their patients and their families to understand the process. Schneider and Bernard explain, “Each labor of birth and death is as unique as the person entering this world or leaving it. Some labors are long and hard, while others are short and sweet.”<sup>157</sup> In addition, they describe three parts of the labor of dying; pre-active labor, active labor, and death. This structure parallels the stages of the labor of birth, pre-active labor, active labor, and transition and birth. Although birth is followed by the expulsion of the placenta, the earlier stages of birth help the dying and their families to think about what happens to them physically during this time. One nurse commented on the physical labor of death

Often at the very end of life there’s physical labor that takes place. People are shocked by that. They are very distressed, the family, that it looks like the patient is working so hard. And this is like the last two days usually of dying where they’re really actively dying, and I do liken that to the labor of birth.

In their book The True Work of Dying, hospice nurses Miriam Schneider and Jan Bernard draw upon these important physical similarities between birthing and dying to describe how they help dying patients.<sup>158</sup> The authors, who refer to the hospice movement as “home deathing,” argue that the labor of death strongly parallels the labor of birth:

In the labor of birth, the uterus contracts in response to a force deep inside the woman. There is uncertainty and pain but also a deep knowledge within the body about what it needs...The labor of the dying is no less all consuming and demanding; it is marked by the same uncertainty and pain.

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<sup>157</sup> Schneider and Bernard, *Midwives to the Dying*, 4.

<sup>158</sup> Before becoming a hospice nurse, Bernard served as an obstetrics nurse, and for many years, attended births and deaths in close proximity, even on the same day.

Yet this process also holds within it the possibility of realizing and achieving the core needs of the dying.<sup>159</sup>

Schneider and Bernard maintain that it is the midwife (both in the context of birth and hospice care) who can best guide a person through the birthing or dying process, not because of their medical skills, but because of their willingness to be present for the hardest moments in another's life. They write that these times are marked by difficulty and require support. "During these labors, our bodies and souls are pushed to their limits and beyond. In the midst of the struggles of labor, either in birth or death, it is often only the midwife's voice that breaks through and comforts or strengthens."<sup>160</sup>

The nurses also draw other parallels between life and death, including the mark of the first (or last) breath. While the infant does not control, but simply trusts, the process of breathing as it leaves the comfort of the amniotic fluid in which it has lived, similarly the work of the dying person is to trust the release of that breathing as his or her lungs fill with liquid. Being there when a patient takes his last breath can be as moving and powerful as when a baby takes her first.

For both hospice professionals and midwives, one of the important things during this stage of either process is to emphasize the importance of the physical body. One of the things midwives try to communicate to a woman is that her body works, that she can and should trust it and listen to it. This sense of trust and letting go is important. As one midwife noted, "We trust birth and the birth process, we trust that it usually almost

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<sup>159</sup> Schneider and Bernard, *The True Work*, 64.

<sup>160</sup> Schneider and Bernard, *The True Work*, 83.

always works itself out, we trust a woman's body to do what it needs to do." Hospice nurses sometimes cite a similar attitude toward the body, "One senses a profound trust in the body's capacity to die and to die peacefully in the majority of cases."<sup>161</sup> In both birthing and dying, hormones are emitted that help the process. In Banerjee's interview of hospice professionals, one noted that:

Your body is so wonderful, for anyone who is going through a gentle dying process. The body chemistry changes, just as it does at birth...As the body becomes dehydrated the endorphins—like you get in a runner's high—start to be released in the body so it creates a calming effect, a sort of euphoria.<sup>162</sup>

This profound trust in the ability of the body to work puts both midwifery and hospice in contrast to the medicalization of birth and death, where the assumption is that a body breaks and must be fixed by modern medicine. Trust in the body is not a central concept in our contemporary medical model. In addition, both midwives and hospice professionals attempt to honor the body of the person. One nurse noted "I'm still pretty protective of the shell [after death] so when I go out on a death, I try to pay attention to the body; you know a bath, cleaning, fresh clothes." This honoring of the body also stands in contrast to biomedical models, which generally removes a dead body from sight as soon as possible, covering it up and whisking it away.

In large part, the transformation of the body (particularly the dead body) from something to be revered and cared for to something dirty and unclean, had to do with a change in the view of the human body from a natural organism to the metaphor of the

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<sup>161</sup> Banerjee, *Speaking of Death*, 4.

<sup>162</sup> Banerjee, *Speaking of Death*, 4.

body as a machine. This mechanical model pervasive in the biomedical establishment allowed the body to become an object of research, a central part of biomedicine. In addition, as machine became the metaphor for body, Davis-Floyd argues, the male body was held as its prototype, and the female body was seen as an inherently defective machine.<sup>163</sup> Thus, obstetrics from its roots was devoted to finding tools and techniques to manipulate and improve the defective machine and the processes connected to it. One of the women interviewed by Davis-Floyd saw the interventions applied to her as removing her as a person from the picture of her own birth, and the mother found them disempowering and alien: “As soon as I got hooked up to the monitor, all everyone did was stare at it. The nurses didn’t even look at me anymore when they came into the room—they went straight to the monitor. I got the weirdest feeling that it was having the baby, not me.”<sup>164</sup> A similar feeling is often expressed by the dying (or more often, their families) that the tubes and charts and other interventions take center stage while the person experiencing these things is pushed aside. In contrast, midwives and hospice professionals generally view the body holistically. Under this model, Davis-Floyd claims, “the human body is a living organism with its own innate wisdom, an energy field constantly responding to all other energy fields.”<sup>165</sup> Women, because it is their body and their birth, midwives believe, know how to give birth. While that very natural process must be aided, it must ultimately belong to the mother, and so the subjective experience of the mother is of vital importance. Similarly, hospice professionals view the body as

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<sup>163</sup> Davis-Floyd, *Birth*, 5.

<sup>164</sup> Davis-Floyd, *Birth*, 107.

<sup>165</sup> Davis-Floyd, *Birth*, 156.

one small, integrated part of a whole person, and hesitate to separate its care from the care of the whole person, recognizing that spiritual pain or psychological pain can have physical manifestations.

### **The Role of the Midwife or Hospice Nurse**

All of the participants noted similarities between their field and the other. Many of these had to do with the role they played in providing care. Both midwives and hospice care workers have biomedical training that allows them to provide physical care. All of the participants, however, saw their emotional or supportive role as equally or more important than the physical care they provide. All of them commented that one of their roles is to provide comfort measures for the people in their care, including human touch, medicine in hospice care, or other things they feel would benefit the person or the person's requests. In addition to the physical comfort care, midwives also saw themselves as safeguarding the birth process and making sure things progressed safely, a sentiment less important to hospice professionals, as the outcome of the process is death. Beyond this, each commented that their role was largely one of support. One nurse commented that "My role is really a support person... I don't have an agenda for where they need to be or where they need to get to... It's so much more emotional than any physical care. That's so secondary to the practice I think." Another noted that the role of support extends to caring for the patient's family, "really working with the family, each one, to help ease them through this whole transition." Schneider and Bernard contend that the role of midwives (in both processes) is "to teach people how to function independently of

us, to be there for support and guidance, but to teach them to trust their bodies and their instincts about what they or their loved one needs.”<sup>166</sup>

Both midwives and hospice nurses also commented that they felt honored to be part of such an important part of the lives of the people they care for. One midwife commented,

It’s a big responsibility for a midwife to choose to put herself in the situation that it is about life and death, not as a real threat, but just as a possibility...and to choose to be with a woman and her family at that moment, because really there are few moments in life, hopefully, that we’re that close to death.

Midwives often talked about being the “guardians” or the “safeguards” of the birthing process, to prevent it from going wrong. While hospice nurses know that they are in a situation that will lead to death, and are not trying to prevent death, they similarly are with a family at a most intimate and vulnerable time. “I really feel it’s an honor to work with these patients and if they let me into their personal space, I really try to treat that with honor and I try to be very conscious of not putting my own agenda on it,” one nurse commented.

One midwife noted the similarities she felt there were between what is required of a midwife and what is required of a hospice nurse by saying:

There seem to be a lot of similarities I could imagine in terms of waiting. In that way that it can’t be scheduled, sort of choosing to enter that unknowing as to when it’s going to happen and how long it’s going to take and what it’s going to be like, is it going to be really hard and intense or is it going to be easier than you thought and is there going to be a lot of fear at the end or along the way.

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<sup>166</sup> Schneider and Bernard, *The True Work*, 85.



There is a skill in that waiting, she said, and both midwives and hospice nurses must have it and be able to identify a wide range of ways that a normal or healthy pregnancy or death can look and when intervention might be necessary.

The description of birthing and dying as a journey has implications for the role of those who use it. If birthing, or dying, is a journey, and the person birthing or dying is the adventurer on that journey, then the role of the midwife or hospice professional is not immediately clear. Many of the women I interviewed stated that they saw their main role as one of support, but this is not the only role needed by someone on either of these difficult and powerful journeys. Other metaphors that were used by midwives in particular may be more accurate descriptions of the kinds of work they perform, and may be the key to using the metaphor of hospice nurses as midwives to the dying. One metaphor used by two of the midwives described their role as being a “guardian” of the birthing process. If we take seriously the description of birthing and dying as journeys, then the idea of a guardian or guide may be more helpful. One midwife described at least part of her role as one of being a guide: “A midwife cannot take charge but sort of take the steps ahead of the woman.” By taking steps before the woman, a midwife can serve as the necessary guide and provide support through the journey in an active way. In a similar way, a hospice nurse describes the kinds of changes a dying patient and his or her family is likely to see, assure them that those things are okay, and help guide them through those stages.

### Caregiving as a Response to Medicalization

Perhaps one of the best ways to understand both midwifery and hospice care is to understand the context of the medical care typically given in a hospital that both professions work to improve upon. Western obstetrics, according to Barbara Katz Rothman “is the history of technologies of separation. We’ve separated milk from breasts, mothers from babies, fetuses from pregnancies, sexuality from procreation, pregnancy from motherhood.”<sup>167</sup> Midwifery attempts to combat these ideas of separation by providing holistic care that does not rely heavily on modern technology, but uses low-tech solutions to provide care. Hospital births, one of the midwives says, is “disempowering to women and gives them the impression that their bodies don’t work on their own.”

Although the hospice nurses did not see themselves as having the same kind of antagonistic relationship with the biomedical establishment as midwifery does, and generally work with the patient’s former physicians, they echoed the sentiments of the midwives in viewing the hospitalization of death as harmful to the dying process:

It’s very hard to die now. People need to make it a lot more clear what their desires are because if you don’t, they’re going to do absolutely, one hundred percent everything...So you can still be alive and have your days extended and prolonged, but whether they’re necessarily truly living [is difficult to say].

Banerjee claims that the medical framework that we have placed on death removed it from its setting within the home and the family and replaced it with “a professional

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<sup>167</sup> Rothman in Davis-Floyd and Davis, *Intuition*, 146.

performance at the hospital bedside that depended on equanimity, rationality, and a detached commitment to saving the life of the dying patient.”<sup>168</sup>

These sentiments parallel the ideas in midwifery that intuitive, embodied knowledge was replaced by technology in the name of rationality, and the devaluing of these kinds of knowledge have proven harmful to the childbirth process. These transformations have not only caused damage to the emotional processes of maternal-child bonding, but have led to practices that run counter to the physical realities of childbirth. These changes include the reclining position for childbirth, a sterile environment that minimizes the importance of social support, and the increasing reliance on technology.<sup>169</sup> Hospice similarly works with low-tech comfort measures in lieu of endless curative technology. One hospice nurse saw her work as a rejection of the medicalization of death, affirming instead that “it is a normal process, it doesn’t need to be so compartmentalized to a sterile hospital environment separate from your real life.”

Davis-Floyd argues that the medicalization of these natural processes does not mean that they are completely controlled. “When obstetricians and nurses see babies being born and dying in spite of their predictions and technologies,” she writes, “they know that ultimate control over birth is beyond them, and they recognize their powerlessness in the face of birth’s mysteries.”<sup>170</sup> In the face of uncertainties such as these, or those faced by physicians when they encounter a patient who lives far beyond

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<sup>168</sup> Banerjee, *Speaking of Death*, 4.

<sup>169</sup> Robbie Davis-Floyd and Melissa Cheyney, “Birth and the Big Bad Wolf: An Evolutionary Perspective,” in *Childbirth Across Cultures: Ideas and Practices of Pregnancy, Childbirth and the Postpartum*, edited by Helaine Selin and Pamela K. Stone, (Dordrecht: Springer, 2009).

<sup>170</sup> Davis-Floyd, *Birth*, 14.

their expected lifespan (or dies far sooner than expected), biomedicine fights to maintain control. In contrast, midwives and hospice nurses try to embrace the uncertainty.

While both hospice care and midwifery reject the medicalization of normal human processes, neither rejects biomedical knowledge. Instead, they have different norms as to what ought to guide the use of technology. Banerjee writes, “flowing from a respect for the organic body, and nature more generally, good health care practice within hospice means *working* with, rather than attempting to correct, nature’s will.”<sup>171</sup> This was echoed in the birth process by a midwife who said, “I use biomedicine all the time. I don’t always use it for the intervention that it recommends, but I use it for diagnostics.”

For both midwifery and hospice care, the work is seen as combating the negative stereotypes of birth and death in mainstream society that have partly been caused by the medicalization of these natural processes. Both aim to remove some of the fear from something that has moved from familiar to the realm of the medical. Lisa Carlson, the president of Funeral and Memorial Societies of America, in an interview with NPR stated, “You know, years ago, grandma was laid out in the front parlor. But in a matter of two or three generations, we’ve lost that experience, we’ve lost the common lore of what to do at the time of death.”<sup>172</sup> This transformation of both birth and death away from the home and the familiar and into the medical realm has proven harmful to the birthing and dying processes. For hospice nurses, the common experience of clinging to the hope of intervention is a disservice to the experience of dying because if they are offered

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<sup>171</sup> Banerjee, *Speaking of Death*, 5, emphasis in the original.

<sup>172</sup> Lisa Carlson, “Do It Yourself Funerals,” interview by Bob Edwards and Jacki Lyden, *Morning Edition*, National Public Radio, December 8, 1997.

interventions up until the last week of their life, “and then they’ve just had it and they go home to die, they really have such a short amount of time to live that experience.” The emphasis here is again on the process of dying, rather than the act of death itself. In addition, the attitude of “fight until there is nothing left to do” often heightens the sense of abandonment for dying patients. When a doctor has exhausted all available options and then says “there is nothing more to be done,” the patient often receives the message that the doctor abandons the patient when he abandons hope for their recovery, especially if this is a sudden transition from active treatment to no treatment.

## Chapter 4: Conclusion

None of us wants to die, and in this culture, most of us deny that it will happen to us—death is what happens to everyone else. If we must die, however, then we wish to die in the best way possible. Although there is no shared vision of the perfect way to die, it seems clear that there are ways in which very few, if any, people would like to die. One of these ways is alone and in pain, suffering for long periods of time. Hospices have addressed the needs of the dying with that thought in mind. The honorable work hospice professionals perform is often met with exclamations about how hard it must be or how it must take a special kind of person to do the work. That is most certainly true, but we miss the point when we fail to look deeply and critically at the work of hospice professionals, find out what guides them and directs their actions, and evaluate whether that way is empowering to patients.

Metaphors have the power to shape and direct our attitudes, conversations, and practices. The shift in the use of the metaphor from nurses as loyal assistants to nurses as patient advocates, for example, not only reflected, but also created change within the nursing field. One aspect of measuring a metaphor's usefulness in the healthcare field is examining its impact on the empowerment of patients. As James Childress maintains, "Metaphors... are central to both discourse and practice, for framing our problems as well as shaping our responses to them. They...must be evaluated specifically according to how well they function to describe and/or direct actions, relationships, and the like."<sup>173</sup> So then the central question to ask about the metaphor of hospice nurses as midwives to

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<sup>173</sup> Childress, *Practical Reasoning*, 24.

the dying must be whether the metaphor accurately reflects the work of hospice nurses, whether it guides hospice nurses in particular ways that are helpful for themselves and/or their patients, whether it best reflects (or better reflects) the hospice nurses' relationships with patients, and whether it highlights more than it hides about the moral considerations involved. The historical similarities of the modern midwifery and modern hospice movements, the contrast of each with the major biomedical model, and the actual experience of midwives and hospice nurses lead me to conclude that, although not perfect, the metaphor of hospice nurses as midwives to the dying is a good one. The metaphor provides important guidance to hospice nurses, information to the general public, and perhaps most importantly, solace and assistance to the dying.

The critical review I have undertaken is reflective of the value for philosophical inquiry of analysis and reflection on metaphor. The study and analysis of metaphors in philosophy has the potential to touch on all four conventional areas of philosophy. The examination of the history of ideas correlates with the exploration in chapter one of the modern midwifery and hospice movements and their corresponding earlier movements, including their attitudes and beliefs as they were set in time. In addition, issues of "knowledge" that have arisen multiple times in the thesis through the avenue of ways of knowing touch on epistemology and metaphysics. Any examination of metaphors that may cause health care providers to act in a particular way toward patients is subject to the ethical inquiry I have undertaken here, the third major area of philosophical inquiry. And finally, while philosophers emphasize logical and deductive reasoning, the examination of imaginative reasoning that metaphors allow us to undertake corresponds with the

philosophical task of the examination of reasoning. What I hope to have demonstrated in this thesis is that the examination of this metaphor is consistent with the foundational understandings of philosophical inquiry. In addition, it also expands beyond them in important ways, engaging philosophy with the actual experiences of everyday professionals, patients, and their families.

### **Critical Assessment**

The metaphor of hospice nurses as midwives to the dying illuminates a number of things about the hospice nursing profession. First, using this metaphor in conjunction with the common metaphor of dying as a journey places the individual in the middle of all decisions about care. This is a central tenet of the hospice philosophy, and one that plays out through both metaphors. If dying is a journey, then the adventurer is the one who is dying. She must make the decisions—which way to go, how fast, how much is too much to handle. If death is the destination, it is not simply getting to the destination that is important, but how one gets there. If we must get there in extreme pain or limited consciousness, then the journey is unlikely to be a positive one. However, if the journey can be relatively comfortable, provide opportunities for growth and relationship-building, then the guide must work to make it so.

If dying is inevitable, then we ought to die in the best way we know how, and hospice strives to provide that. Your path and mine, however, will necessarily look different, and that is where hospice, with its individualized approach and willingness to place the patient at the center, even if that means making decisions that might shorten a



patient's expected life, provides an opportunity that is not often found in the bureaucratically organized hospital. The role of the guide, then, is what must be defined. To define hospice professionals—and nurses in particular—as midwives to the dying highlights certain of their roles and duties over others. A midwife provides information, checks on the health of the mother, recommends interventions that do not rely upon technology, listens to the mother, and tries to make the mother's birthing experience a positive one. Similarly, a midwife to the dying provides information to the dying patient and his family about how the dying journey will be experienced, what to expect, and what comfort measures are available. A midwife to the dying also monitors the health of the patient, providing comfort and personal care to the dying one. He or she uses medicine to provide that comfort, but only with the understanding of all involved that highly technologized curative measures will be foregone. Perhaps most importantly, a hospice worker listens to the patient, cares for them emotionally as well as physically, and tries to make the dying process one that has the potential to be transformative for the patient and her family.

Other similarities are less likely to be instructive for hospice nurses (they see these things as essential parts of their care already), but may provide the general public and the dying patient with more familiar terms that illuminate aspects of hospice work. Both midwives and hospice nurses provide care in the home of their client, an important factor both to mothers wishing for a more intimate birth experience, and to dying patients who often wish to die at home surrounded by loved ones rather than in hospitals. In addition, the care provided focuses on a more holistic model of patient care, such that the

midwife and hospice nurse provide for the physical, emotional, spiritual, and psychological aspects of the patient's care. Further, they see the aspects of patient care beyond physical not only as an important secondary consideration (because many nurses and physicians also see emotional care as important), but as intrinsically linked patterns of care. For many hospice nurses, the recognition that suffering can often be worse when linked to emotional rather than physical characteristics guides care. In addition, hospice's commitment to prevent, rather than treat, pain correlates with the midwife's commitment to prevent the need for technological interventions in the birth process. And the midwife's commitment to including others in the birth process (as requested by the mother), or even stepping back to allow the patient's family a more central role (while maintaining a careful watch and continuing to safeguard the process) parallels hospice's commitment to include the family in treatment of the dying, and to providing bereavement care at the conclusion of physical care for the dying.

If the metaphor of hospice nurses as midwives to the dying can be a guiding one for hospice nurses and an informational one for the general public, can it provide anything for the one who is dying? I think the metaphor provides the dying patient with a way to connect to the hospice nurse on a different level. The idea of a midwife for the dying provides the dying patient with a way of envisioning the role of their hospice nurse that emphasizes those functions that set him apart from the kind of care provided in a hospital setting. The metaphor emphasizes the journey of dying, the holistic care provided, and the story of dying. It emphasizes the role of nurses as one of listening, of compassion, and of active guidance. A hospice nurse will not simply provide physical

care, but will deeply engage with the patient, merging her world with the patient's and advocating for an end-of-life experience that places the patient in the center and that makes sense in the context of the life lived by that patient.

While the metaphor could play an important role in defining the work of hospice nurses, it is not a perfect metaphor. There are strong parallels between birth and death, and birthing and dying, but they are very different processes with very different outcomes. For the client in midwifery, birthing does not end with birth, for the mother herself takes her experience into her mothering. Birth is the culmination of one journey, and the initiation of another. In hospice, dying does end with death. So what is it that we are left with after death? Bereavement, a separate process, begins for others, but there is a finality that marks death for the individual that distinguishes it from birthing. If a midwife to the dying must usher the dying person into another journey, then this commits the midwife, and to some extent the patient themselves, to a metaphysical view about survival beyond death. I do not believe, however, that the metaphor of hospice nurses as midwives to the dying necessitates such a view of survival beyond death. It can instead be a metaphor for practical caregiving, one that guides the kind of journey a dying person and those around them go through, without necessitating that another journey is believed to begin. The emotions around the processes are complex and very different—for ultimately the expected outcome of one is new life and celebration, the other is the sad absence of a loved one. In addition, while we can ask a woman who has given birth about her experience with her midwife in the most critical moments of the birthing process, we can never ask that question of one who has died. We can only conjecture about what they

would say, and draw conclusions from the experience of third parties. One of the hospice nurses commented that she thought if patients could tell the story of their experience, they would see it as empowering and as a time of growth, and family members have commented that a hospice experience was positive for themselves or their dying family member, but this is the best we can do. While we can hear from women who have given birth whether their experience was empowering or disempowering, humanizing or dehumanizing, we can never ask for a retrospective evaluation from a patient who has died. We can, however, get cues from the patient and his or her family throughout the dying process. Many family members speak positively of their experience with a dying family member in hospice care, if they feel that person was cared for well and able to die in a dignified manner consistent with their life story.

One other important consideration which I have not explicitly addressed is that hospice nurses, unlike midwives, do not work independently or exclusively with other hospice nurses. They are part of a team of care, and there are certain functions provided by midwives that more closely parallel the care provided by other hospice professionals. For instance, hospice nurses end their relationships with patients and their families after death. At that point, other members of the team—the social worker, chaplain, or bereavement counselor—step in to provide care. While a midwife continues to provide postpartum care to a mother, the nurse has relatively little contact with the family after a death. In that way, the midwife metaphor transfers to these other team members. Because of this role-differentiation, the metaphor is incomplete.

Even if definitive proof were provided that the metaphor of hospice nurses as midwives to the dying was accurate and helpful in guiding the work of nurses, there still might remain problems for its implementation as a moral or practical guide. First, while midwifery might provide a good parallel to hospice work, it is not without controversy. In the many states that still outlaw midwifery, the stigma against midwives in the face of scientific evidence of their efficacy means drawing the parallel might prove problematic. It may be that using the metaphor will elicit the stigmas of the danger of the process or the lack of medical knowledge often associated with midwifery. Far from clarifying their roles, hospice nurses could then face further difficulty in sharing their work with others. Biomedicine's generally antagonistic relationship with midwifery is not true of hospice care, and if using the metaphor creates any of that stigma around hospice work, perhaps its costs outweigh its benefits. At the same time, however, it is possible that both midwifery and hospice would improve in the public estimation when tied together in the public consciousness. That is, if one regards hospice highly but not midwifery, then tying midwifery to hospice may lead to a change of attitude, and vice versa.

A second potentially problematic concern with using the metaphor is that its casual use does little to help guide or direct nursing actions. When the metaphor is used lightly or without thought, it provides little, and may serve as a gloss to avoid talking about the realities of dying. The same is true if the thing to which we compare something else (the midwife model of care, in this instance) is lesser-known than the thing requiring explanation. The argument brought against the use of metaphors in bioethics is that it clouds important issues with emotions. If the elicitation of birth memories is done

without appropriate care in the dying process, it could prove confusing to the dying one and her family or friends. The meaning of midwifery needs to be clarified and widely known in order for the metaphor to prove useful. Perhaps this is why it seems to ring most true for those who have given or received care during birth that was similar to midwifery care. For these individuals, whether they are providing or receiving the care, the parallels become more obvious and real, and may provide true guidance during the dying process, to patient and nurse alike.

Although these practical considerations require real attention, we must assess the metaphor on its own terms. Does it provide guidance to the nurse, information to the public, and comfort to the patient? Childress argued that “When [metaphors] are offered to guide relationships and actions, they are subject to criticism if they highlight only one moral consideration...while hiding or obscuring other relevant moral considerations.”<sup>174</sup>

It is my conclusion that the metaphor of hospice nurses as midwives to the dying highlights more than it hides with regard to patient care. It highlights the function of listening to stories. Stories are central to both birthing and dying, as they are to most major life events. Kathy Kalina, a hospice nurse provides this advice to her fellow nurses in her book Midwives for Souls: Spiritual Care for the Dying, “There is a need to tell the history of the terminal illness in the same way that any traumatic event must be told time

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<sup>174</sup> Childress, *Practical Reasoning*, 13.

and time again.”<sup>175</sup> In a similar way, Robbie Davis-Floyd points to the need to tell birth narratives as a central reason that midwifery provides important care to mothers.<sup>176</sup>

The metaphor also highlights the centrality of the mother or dying patient, and the inclusion of his or her family in the model of care. Kalina argues for the centrality of the role of the family:

The goal of midwifery in childbirth is a healthy mother, a safe birth for mother and child, and a healthy baby. In midwifery for souls, the goal is a comfortable body, a peaceful passage, and a triumphant soul. The family’s active involvement and loving presence greatly assist in the achievement of these goals.<sup>177</sup>

The active engagement and involvement of the family, rather than a burden, is an asset to the care the patient receives, and their own birthing or dying experience. If the model of midwifery elicits the idea of the family as important to the birthing process, then it would do the same for the dying process as well.

The holistic care of the individual, which is common to midwifery and hospice care, is also highlighted by the metaphor. What sets midwifery apart from hospital birth experiences, even more than the lack of technological intervention or its place in the home, is its commitment to the physical, emotional, and spiritual care of the mother. This same commitment, though already present in hospice care, is perhaps more easily seen through the metaphor of midwifery. Finally, what this metaphor highlights is the role of hospice nurses as guides on a journey where the experience of the journey is as

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<sup>175</sup> Kathy Kalina, *Midwives for Souls: Spiritual Care for the Dying; A Guide for Hospice Care Workers and All Who Live with the Terminally Ill*, (Boston: St. Paul Books and Media, 1993), XX. 36.

<sup>176</sup> Davis-Floyd, *Birth*, 245.

<sup>177</sup> Kalina, *Midwives for Souls*, 23.

important—even more important—than its destination. Midwives strive not just to deliver healthy babies, but to provide care to mothers that allows for a positive birth experience on their own terms. Similarly, midwives to the dying provide care on the patient's terms that hopefully allows for growth and empowerment of the dying (as well as his or her family). At the same time, hospice professionals must also respect the right of the dying patient to have the dying process not be one of growth and empowerment. Hospice nurses must be willing to live with deaths that are not the way they would choose to die just as midwives might attend a birth they would not choose for themselves. It is the centrality of the patient, rather than of the medical establishment and its efficiency, that most closely links the two caregiving circumstances.

### **Limits of the Analysis and Further Directions for Research**

There are obvious limits to any philosophical inquiry into the reality of a profession. Rarely do midwives or hospice professionals, or any other medical professionals, have the opportunity to spend time contemplating the philosophical ramifications of their own work. The day-to-day expectations and realities are far more real to them than philosophical ideals, even though they do form the basis for their work. The disparity between philosophical inquiry and practical experience is the true test for the use of any metaphor. While the interviews with midwives and hospice professionals are a start, the analysis of the metaphor and, if it proves useful, its integration into the training and philosophy of hospice nursing is necessary if the metaphor is going to make any difference for the reality of hospice care. Its use by hospice professionals must also



be useful to them and common enough that it makes a difference. Although the metaphor resonated with the hospice nurses I spoke to, they were speaking within the context of a project where I provided the metaphor for them. While both had heard it before, it did not seem to be a commonly used metaphor in their daily work. If it remains useful only to outsiders, then its usefulness is severely limited. In addition, the number of interviews completed in the interest of philosophical inquiry is no replacement for serious ethnographic data collection.

Further research would also include a deeper explanation of the various roles played by other hospice team members. While the hospice nurse provides the most direct parallel to the midwife, other team members fulfill functions that closely parallel that of midwives. Exploring these functions might enrich the metaphor, carrying it into the bereavement process as well. The journey for the family certainly does not end at the deathbed, and this understanding is clearly present in midwifery as well. Exploring the various roles in hospice care was beyond the scope of this thesis, but could provide further evidence for the illustrative or instructional functions of the metaphor.

In addition, while hospice care and midwifery are set up as models of care that contrast with the biomedical model, there is also room for improvement of the care of both birthing women and dying people. Kalina asserts that:

Hospitals are wonderful, necessary resources for the treatment of disease. But they are not the best places to die. Even if there are no painful interventions, the routine alone robs patients of control and peace. The focus is not directed to the comfort of the patient; it's directed to the convenience of the staff and the overall efficiency of the operation. Vital signs are taken every four hours, baths are given every morning, meals are

served at predetermined times—and the patient has no control over this routine. Staff members come in the room throughout the day and night, carrying out the variety of tasks at their convenience. There is often some limit on visitors. And patients usually hurt, because doctors and nurses have been taught that pain cannot be eradicated, just made a little easier to bear.<sup>178</sup>

Kalina contrasts this with hospice care, where pain is prevented before it happens and where “pain medication is given in pain-free ways.”<sup>179</sup> While these aspects of hospital care are barriers to effective care for dying patients, they are not met only through hospice care. These issues can be addressed in the hospital setting as well, and changes in hospitals are beginning to address them. Similarly, hospitals are beginning to make impressive strides in changes that make the birthing process more mother-friendly, including allowing different birthing positions or creating birthing centers attached to hospitals with more family-friendly atmospheres. Giving women more choices within a traditional hospital setting is a step toward providing more positive birth experiences for mothers, and perhaps better health outcomes as well. In similar ways, it might be possible for hospices to make changes that can better accommodate patients who want to continue curative treatment but are nearing the end of their own lives. Research into this sphere could also improve patient care.

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<sup>178</sup> Kalina, *Midwives for Souls*, 19.

<sup>179</sup> Kalina, *Midwives for Souls*, 19.

### **The Metaphor—Conclusions**

I have argued that the metaphor of hospice nurses as midwives to the dying for nurses, patients, and the general public is instructive and informative. It can guide actions of nurses and may provide them with ways to think about their work that will be transformative or insightful. It may also provide patients with a clearer way of perceiving their dying process, and bring it into a sphere that illuminates concrete connections between an experience they have had (or witnessed) and one that is foreign to them. It might also provide guidance and comfort to the family members of dying patients, who are often unprepared for the emotional challenges they face after the death of a loved one. If the preparation for the death is “guided” for a patient’s family, the metaphor may help them to prepare for and experience the death in ways that allow for personal growth and reflection. This is particularly true given the stigmatized nature of grief in our society. And finally, it might prove helpful to the general public as they try to conceptualize a profession that surrounds the very thing that we try to deny most in our culture. Despite its limitations, the metaphor fits Childress’ standard of whether its use “generates insights about what is or about what ought to be” and whether it empowers or improves the health (in all its forms) of the patient.

The metaphor of midwives to the dying generates insight about the kinds of care provided, the purpose of that care, and the kind of actions that accompany it. In this way, it is certainly a descriptive metaphor that rings true for midwives and hospice nurses alike. Its normative functions also seem evident, as the functions of listening, of supportive presence, and of individually relevant care are highlighted by the metaphor.

Following this model of care seems also to provide important kinds of support to patients that have been proven useful over an extended period of time in both hospice care and in midwifery. The metaphor thus highlights fairly the moral considerations necessary in care of the dying, and I would advocate for its use where practical.

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## APPENDICES



## **Appendix A: Interview Questions**

1. Describe the journey that the mothers (patients) in your care go through during birth (death).
2. What do you see as your role in the birthing (dying) process? What do you provide to the mother (patient) in your care?
3. Are there metaphors that help you to understand the work that you do? These could be metaphors for birth (death), the process of birth (dying), the people you care for, or yourself or your work.
4. What makes birth (death) an important time for a person? How does your work reflect the importance of this time?
5. What does the midwife (hospice) movement reflect about our views of birth (death) in mainstream culture? Within the movement?
6. Do you see the trend in the medicalization of birth (or death) as harmful to the birthing (dying) process?
7. What is a “natural” birth (death)? How does midwifery (hospice) hope to achieve a natural birth (death)?
8. What views about the body are communicated through midwifery (hospice care)?
9. Hospice workers have been referred to as “midwives to the dying.” As a midwife, what similarities do you see between the work you do and the work that hospice care workers do? (As a hospice worker, what similarities do you see between your work and midwifery?) What important differences do you see?

10. What sources of knowledge are important in your work? What sources of knowledge do you find yourself in competition with?
11. What does midwifery (hospice care) value? What forms its core commitments?
12. Given enough time (perhaps only in transit to caring for a patient who is close to birth (death)) are there particular ways you prepare to care for the mother (patient) in labor (at their death)?
13. What have you personally gained from being present at the births (deaths) you have attended?
14. What do you see as the important things that midwifery (hospice care) provide that are different from what a mother (patient) would experience in a hospital?

## Appendix B: IRB Approval



**Institutional Review Board • Office of Research Integrity**  
 8308 Kerr Administration Building, Corvallis, Oregon 97331-2140  
 Tel 541-737-8008 | Fax 541-737-3093 | [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu)  
<http://oregonstate.edu/research/ori/humansubjects.htm>

### NOTIFICATION OF EXEMPTION

March 22, 2011

Principal Investigator:	Courtney Campbell	Department:	Philosophy
Study Team Members:	N/A		
Student Researcher:	Jessica Cox		
Study Number:	4860		
Study Title:	Hospice Workers as "Midwives to the Dying"		
Funding Source:	None		
Funding Proposal #:	N/A		
PI on Grant/Contract:	N/A		
Submission Type:	Initial Application received 12/16/10		
Review Category:	Exempt	Category Number:	4

The above referenced study was reviewed by the OSU Institutional Review Board (IRB) and determined to be exempt from full board review.

**Expiration Date: 01/18/16**

*The exemption is valid for 5 years from the date of approval.*

Annual renewals will not be required. If the research extends beyond the expiration date, the Investigator must request a new exemption. Investigators should submit a final report to the IRB if the project is completed prior to the 5 year term.

Documents included in this review:

- |  |  |  |
|--|--|--|
| <input checked="" type="checkbox"/> Protocol | <input type="checkbox"/> Recruiting tools        | <input type="checkbox"/> External IRB approvals        |
| <input type="checkbox"/> Consent forms       | <input type="checkbox"/> Test instruments        | <input type="checkbox"/> Translated documents          |
| <input type="checkbox"/> Assent forms        | <input type="checkbox"/> Attachment A: Radiation | <input type="checkbox"/> Attachment B: Human materials |
| <input type="checkbox"/> Grant/contract      | <input type="checkbox"/> Letters of support      | <input type="checkbox"/> Project revision(s)           |
| <input type="checkbox"/> Other:              |  |  |

Comments:

Principal Investigator responsibilities:

- Amendments to this study must be submitted to the IRB for review prior to initiating the change. Amendments may include, but are not limited to, changes in funding, personnel, target enrollment, study population, study instruments, consent documents, recruitment material, sites of research, etc.
- All study team members should be kept informed of the status of the research.
- Reports of unanticipated problems involving risks to participants or others must be submitted to the IRB within three calendar days.
- The Principal Investigator is required to securely store all study related documents on the OSU campus for a minimum of three years post study termination.

If you have any questions, please contact the IRB Office at [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu) or by phone at (541) 737-8008.