

HOSPICE AND THE POINT OF NO RETURN: THE INTERSECTIONS OF LIFE,
INEVITABLE DEATH, AND BIOPOWER

by

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DEDICATION

This thesis is dedicated to Paige, Ray, Derrick, and Trevor, the participants interviewed for this research. You all made such an impact on my life in the short time we shared together. Through this thesis, your words and legacy will live on forever. Thank you for being a part of my life, and for sharing your life with me.

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ABSTRACT

This research focuses on the experiences of hospice patients in central Texas as a means to consider the complex (and somewhat hidden) relationships between dying individuals, a social institution developed to manage inevitable death, and modes of power over life and death in the United States. Through semi-structured interviews with hospice patients and hospice social workers, this research considers the ways in which a focus on life prevails in a social institution for inevitable death. After careful scrutiny, hospice reveals itself as a site for the exercise of Michel Foucault's concept of biopower, but in different and innovative ways.

The life-centric focus, relationship of expert discourses to individuals, and notions of control over life and death characteristic of biopower all persist in hospice. The life-centric focus of biopower manages and optimizes the remaining lives of patients. Expert discourses and specialized forms of knowledge dictate the care of the patient, guide and shape their experience with end-of-life, and contribute to the control of patients. Control over end-of-life on behalf of patients, which is at best an illusion, does not exist in the way hospice claims it does. In reality, hospice patients themselves are controlled. However, the life-affirming aspect of biopower, as well as the illusion of control, prove to be beneficial for hospice patients.

I. INTRODUCTION

End-of-life is one of the most significant aspects of human existence. On the one hand, it is absolutely fascinating. On the other, it is absolutely terrifying. Death, whether we want to admit it or not, shapes life and our journey through it. The experiences of loss and grief are transformative, causing a rupture and rebuilding of an individual's worldview. My own experiences with loss and grief have led to a profound interest in death, dying, and the end-of-life. This research has been an opportunity to give my interests academic expression.

Hospice care is an end-of-life option that, until the past decade, was relatively unheard of and unused. An approach to terminal illness that abandons curative treatment and opts for pain and symptom management, hospice provides individuals with comfort, love, and respect at end-of-life. Though a discourse on end-of-life generally has been growing over the past few decades, a widespread discourse on hospice as an end-of life option has yet to emerge. This thesis serves to contribute to that discussion.

Finally, this thesis serves to fill a gap in the anthropological literature concerning hospice and theory. Specifically, using the lens of biopower, it considers the ways in which a focus on life invades a social institution for inevitable death: hospice. In turn, this thesis considers the complex (and somewhat hidden) relationships between dying individuals, a social institution for immanent death, expert discourses, and modes of power over life and death in the United States. Though this thesis is primarily based in anthropology, I believe it will be of interest to researchers in public health, thanatology, palliative care, and other fields that are concerned with end-of-life in some way.

Instead of a traditional thesis format, this research is presented in an article format. I chose this format specifically because I want to publish this research in a professional (anthropological) journal, as well as receive feedback for future dissertation research. The following two chapters represent stand-alone aspects of the same research. Chapter two is the report of my research that I plan to submit for publication; chapter 3 is the applied aspect of this research that I plan to share with the hospice I worked with as part of this research.

II. HOSPICE AND THE POINT OF NO RETURN: THE INTERSECTIONS OF LIFE, INEVITABLE DEATH, AND BIOPOWER

We want to make sure that all of our patients and families are aware of what's going on, so they can have some sort of control and make their own choices about what this time looks like...It's really about choices...[hospice is] a choice you get to make about how you want to receive your healthcare. Patients generally think that they're coming here to die...and a lot of times, what we do, it does extend life....and my main piece of advice [for patients and families] would be to be open to the idea of hospice being something other than the end.

-Kate, a hospice social worker

That man [the doctor] kept me alive for the past five years, trying to get me to take meds when I wouldn't take meds...I was hard-headed and didn't want to swallow the damn pills, but he told me what I needed to do not to get sick...I used to hear what he was sayin'. I heard it, yeah, I heard, but I didn't do as he was sayin' - all I did was heard it. I wasn't puttin' no actions with what I heard, you know, I wanted to do it my way. Yeah, my way got me so sick. I thought I was dyin'.

-Derrick, a 54 year old hospice patient

I've got enough dope [laughs while pointing to multiple bottles of controlled substances], I could put myself out anytime I want...Hell, if I want to go out, I can go out anytime I want, you know? Until then, I'm gonna enjoy life. We're born to die, you know? So, might as well accept it and go on with it.

-Ray, a 59 year old hospice patient

This research is concerned with hospice patients in central Texas and what their experiences suggest about dying individuals' relation to the state, the gaze of biomedicine, and mechanisms of power and control over life and death in the United States. Participants were in-home and group home hospice patients receiving care under Hospice Austin, a nonprofit hospice organization. Hospice is an interdisciplinary approach to end-of-life care for individuals who have a life expectancy of one year or less, typically six months or less (HAA 2010). Unlike preventative biomedicine, it emphasizes comfort over cure, optimization of remaining life, and returning control to

patients and family members. Hospice abandons curative treatments and opts for pain management and symptom relief, also known as palliative care.

Semi-structured interviews with hospice patients provided insight into how Foucault's notion of biopower (1976) is relevant to a discussion about hospice, an institution that is primarily concerned with death. The interviews also suggested that the notion of control over end-of-life warrants further and more critical investigation. Interviews were conducted with four hospice patients, and two key informant interviews were conducted with hospice social workers. Though these patients were facing inevitable death, there was still an intense focus on life. Their remaining life was managed, optimized, and placed under the gaze of medical professionals. Biopower takes a new form in hospice, and begs the question: what kind of control do we truly have at the end-of-life?

Taken together, the quotes from Derrick, Ray, and Kate bring up issues relating to biopower: the control of individuals by hospice and its expert discourses, the perceived control over end-of-life on behalf of patients, and an intense focus on life in the face of inevitable death. Biopower is characterized by the development of different fields of knowledge and expertise concerned with life in general, resulting in control over life. "One would have to speak of bio-power to designate what brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of transformation of human life" (Foucault 1976:142-143). What is the hospice patient's relationship to knowledge and power? What control do hospice patients have over end-of-life? How are they controlled by hospice itself? Finally, what happens when a life-centric focus creeps into a social institution concerned exclusively with inevitable death?

The taken-for-granted assumptions that underlie hospice philosophy and care reveal the ways in which the gaze of biopower operates on the dying.

Interestingly, these aspects of biopower are beneficial for patients, instead of limiting. They can provide some kind of solace at end-of-life. For example, even if control is an illusion, this is still beneficial for patients psychologically, as end-of-life typically entails a loss of control over many aspects of life. Returning control over the most mundane of things can be magnified in significance at end-of-life. These features of biopower are manipulated by the context of hospice, and are expressed in different, more positive ways.

HOSPICE: A NEW APPROACH TO CARE FOR THE DYING

The term “hospice,” derived from the Latin word *hospes* meaning “host” or “guest,” was used during the Middle Ages to refer to a place of rest for pilgrims and also a haven for the poor (Olsen 1994 and West and West 1998). The modern hospice movement began in 1967 when Dame Cicely Saunders established St. Christopher’s Hospice in Sydenham, England. It began as a force to redress the impersonal and sometimes inhumane care of dying patients; for example, the lack of emotional support that was given to dying individuals. Thus, a major focus of hospice care was attending to the emotional needs of the dying patient and their family (Kane et al. 1985). Before hospice, the dying were treated as individuals with no right to an opinion and with no power in decision-making (Kübler-Ross 1969).

The hospice movement was introduced to the United States a few years before the establishment of St. Christopher’s Hospice in England through a series of lectures by Saunders at Yale University (Abramson et al. 2007). Elisabeth Kübler-Ross spearheaded

the development of an American version of Saunders' movement, and her work represents the beginning of a dialogue concerning death and dying in the United States (Levine 1982). In her cornerstone work *On Death and Dying*, she provides firsthand cases from over 200 dying patients from which she identified and described five stages through which the dying supposedly move: denial and isolation, anger, bargaining, depression, and acceptance (Kübler-Ross 1969). Thanatology, the study of death and care for the dying, emerged as a specialty and led to a rediscovery of death within and outside medical professions. Kübler-Ross, despite the critiques against the validity of her stage approach, was a catalyst to increase public awareness of the inadequacies in the established institutional care of the dying (Fox 1981).

Two major sets of 20th century developments in American society also aided in the proliferation of discourses surrounding end-of-life, leading to the development of hospice. The first is the advancement of biomedical knowledge, skill, and technology, particularly since World War II. These technological advances have led to longer life spans, which in turn has created a larger population of older individuals. The second development, a result of the first, is a heightened awareness of death resulting from demographic changes. Declining fertility rates and declining mortality rates enhanced both the proportion and number of persons who are living longer. One could say that in American society, there is no place to hide from information about death and dying (Fox 1981). The social movements and developments described above led to an increase in public awareness and in discourses surrounding death and dying. Hospice represents one avenue of the proliferation of discourses concerning end-of-life in American culture.

The goal of hospice is to care for dying patients via symptom management in hopes of alleviating pain and maximizing comfort at the end-of-life (MedPAC 2012 and West and West 1998). Patients must have a life expectancy of six months or less to enroll in most hospice programs, sometimes one year or less. Hospices can function as free-standing institutions, home health agency-based hospices, hospital-based hospices, or skilled nursing facility-based hospices (HAA 2010 and MedPAC 2012). In-home care can occur in the patient's home or in group home settings. Medical equipment can be moved into the home, and hospice workers travel to the patient's residence for any evaluations or complications. The environment is thus less acute than that of free-standing hospice facilities or nursing home-based hospices, where everything is on-site.

Hospice emphasizes and supports self-determination by the patient and their family and attempts to optimize the remaining life of the patient. It is intended to provide a death of one's own: it strives to provide individuals with an opportunity to exercise control over death in terms of where, under what circumstances, with whom present, in what state of consciousness, and with what supports of life. That is, hospice endeavors to return control to patients and family members over end-of-life, attempting to provide individuals with "the opportunity to die as they choose" (Wallston et al. 1988:178).

Hospice services often include emotional support, guidance for spiritual conflicts, and aid in terms of coping with loss and grief in addition to medical aid (Lorenz et al. 2004). Medical services include biomedical approaches to palliative care, such as pharmaceutical pain management, but also eastern approaches to healing such as meditation, yoga, and reiki. Emotional support is provided for the patient throughout their care, for example, counseling by social workers. Emotional support is also provided

for the patient's family in the form of bereavement services after the patient dies. This type of emotional support typically begins before the patient dies, as families are involved throughout the course of the patient's hospice care. The emotional aspect of hospice influences almost all interactions with patients, as all hospice staff tend to the emotional needs of the patient. If desired, the patient can utilize the chaplain assigned to their case for spiritual guidance. A patient's interdisciplinary team also includes a "home maker" role, a person who may help with laundry and other domestic tasks around the home. The wide range of services provided suggests hospice is a pastiche (Rosenau 1992 and Strathern et al. 1987). It is a deliberate juxtaposition of seemingly contradictory contexts: the medical, social, psychological, and spiritual to help the dying through their final journey.

In the early 1980s, there were over 1,000 hospices in the United States, but many Americans were unprepared to choose hospice when thinking about the end-of-life due to the treatment-driven nature of our culture (Abramson et al. 2007). American ways of thinking about illness and disease, especially those at end-of-life, typically include a set of beliefs about an individual's ability to "beat" or "overcome" an illness, even when it is not possible. Accepting hospice could have been seen as a sign of giving up, or of not treating a disease in the appropriate manner (even though it might not be treatable at all).

The high value which hospice care places on comfort and relief of suffering conflicts with the dominant model of mainstream biomedicine with its emphasis on high-tech, treat-and-cure approaches. This has a direct effect on hospice enrollment numbers, which tend to be low (West and West 1998). The conflict between hospice and biomedicine may also explain the lack of contemporary discourse and widespread

discussion concerning hospice as an end-of-life option. Hospice is a type of care that is low technologically, and biomedicine's high technological approach conflicts with hospice in many ways. Hospice does not seek to cure patients, as this is not possible, and abandons invasive or hazardous medical procedures aimed at treatment or cure. Hospice, unlike biomedicine, does not plan their delivery of care in terms of a recovery process of medical interventions, but tends to be more flexible and is aimed at comfort. In this sense, accepting hospice might have been viewed as an inappropriate response to end-of-life in the past, leading to low enrollment numbers. However, this trend is changing, as hospice enrollment and the number of hospice providers has grown substantially in the last decade (HAA 2010, MedPAC 2012).

Hospice literature and training materials consistently refer to the remaining life of a patient, instead of their inevitable death (. In turn, hospice workers consistently focus on life rather than death. Palliative care has emerged as a specialized form of medical knowledge, practice, and discourse. The expert discourses of palliative care inform and shape the delivery of hospice care. The individual's relation to their experience is thus shaped and dictated by specialized hospice discourses. These aspects of biopower are manipulated by context to serve the episode. Hospice patients do not escape the gaze of biopower, it is merely expressed in different ways. Through hospice, one can consider the relationships between individuals, social institutions, discourses, and methods of power.

BIOPOWER: CONTROL OVER LIFE

Michel Foucault's concept of biopower (1976) provides a unique lens through which to view hospice care. Similar to other postmodernists, he rejects the

metanarratives of the Enlightenment tradition. Reason and progress, for example, are rejected as master narratives that explain the intersections of history, experience, power, and knowledge. Foucault subsequently posits that an interface between modern forms of power and knowledge has served to create new forms of domination. His conception of power concentrates on the domination of the individual via social institutions, discourses, and practices, and his work is concerned with how individuals are related to the state and mechanisms of power and control. Various human experiences, such as sexuality and health, become objects of intense analysis and scrutiny. They are discursively (re)constituted within rationalist and scientific frames of reference, within the discourses of modern knowledge, and thus made accessible for administration and control. Foucault subsequently develops new postmodern perspectives of power as dispersed, indeterminate, heteromorphous, subjectless, and productive, constituting individuals' bodies and identities (Best and Kellner 1991). Biopower is one such conception of power.

According to Foucault (1976), biopower is a form of power/political technology that arose in the 17th to 18th centuries in industrialized societies. Biopower differs significantly from previous modes of (sovereign) power, where the sovereign wielded indirect control over both the life and death of their subjects. Sovereign power, in this sense, was conditioned by the defense of the sovereign. For example, if threatened by external enemies, the sovereign could wage war, and thus indirectly control both the life and death of their subjects. Power was essentially “the right to take life or let live” (Foucault 1976:136). Industrialization, demographic changes (particularly unprecedented population growth), and the emergence of modern science during the 17th and 18th

centuries provided the space for a new form of power to develop. However, it did not emerge as the dominant political technology, as the Enlightenment-era discourses of sovereignty, natural law, and social contract were held on to and helped to mask the radical shifts that were taking place at the level of cultural practices. For Foucault, power's success is equal to its ability to hide within its own mechanisms (Dreyfus and Rabinow 1983). As biopower developed, the focus of power shifted from taking life and letting live to fostering life and ensuring the continuance of the species.

Biopower places emphasis on life, and is dispersed and productive rather than repressive (Best and Kellner 1991). Survival and the continuance of the species become of central concern. Biopower involves an increased observance over the life of individuals, as well as promoting the growth and care of populations. It is a power that works diffusely to “incite, reinforce, control, monitor, optimize, and organize” life (Foucault 1976:136). The social body becomes the focus of power, rather than the sovereign. “Wars are no longer waged in the name of a sovereign who must be defended; they are waged on behalf of the existence of everyone; entire populations are mobilized for the purpose of wholesale slaughter in the name of life necessity” (Foucault 1976:137). This new, dispersed form of power maintains productive relations, and it is worth noting that Foucault posits that biopower is an indispensable element in the development of capitalism (1976). Healthy, docile, and productive bodies are needed to fuel the capitalist machine. Individuals are considered as a resource, and are of interest in terms of their contribution to the state. Individuals subsequently become objects of political and scientific concern (Dreyfus and Rabinow 1983). In order to ensure the continuance of the

species and maintain productive relations, biopower focuses on two phenomena: the bodies of individuals and entire populations.

Biopower evolves around these two distinct, but related poles. The bodies of individuals become objects to be manipulated, as the goal is to produce docile bodies (Dreyfus and Rabinow 1983). Individual bodies are disciplined and optimized to ensure the maintenance of productive relations. Disciplinary power thus refers to the nature and aims at standardizing behavior that is structured by the human sciences, centering on the individual and the body (Abélès 2006). The body-as-machine is disciplined and inserted into systems of efficient, economic controls (Foucault 1976). The other pole, the species body, involves interventions and regulatory controls that were developed to supervise the continuance of populations. It is the regulation and control of the vitality of life (Dreyfus and Rabinow 1983). Problems of birthrate, longevity, and public health become central concerns of the State for the first time to ensure the continuance of the species. Statistics relating to these types of problems become means to concretize the value of human lives (Rock 2003). Biopower is what brought life and its mechanisms into the realm of explicit calculations, marking knowledge-power as an agent of the transformation of human life (Foucault 1976). The need to regulate and control life leads to the development of techniques of discipline and power that exist throughout the social fabric in institutions of discipline and fields of knowledge.

Biopower is thus anatomic and biological, directed toward the performance of individual bodies but with attention to the processes of life relating to the continuance of populations. As the mode of power developed, so did numerous and diverse techniques to achieve discipline of bodies and regulation of populations. Techniques of power

become utilized by diverse social institutions, present at every level of society. Institutions of discipline, such as universities and barracks, begin to emerge (Foucault 1976). The development of different fields of knowledge concerned with life in general, including the human sciences and modern medicine, occur simultaneously. For the first time, scientific categories such as species and population become the object of political attention (Dreyfus and Rabinow 1983). Methods of power and knowledge effectively assume responsibility for the life processes and begin to control and modify them (Foucault 1977). Embedded throughout society in numerous and diverse institutions, biopower creates a web of power that connects social institutions, discourses, and individuals. There is no source or center for biopower; it is exercised from many points throughout society. It is important to note that misinterpretations of Foucault tend to conflate power as omnipresent and power as omnipotent. While power is everywhere, it is not separable from contestation and struggle. Under biopower, the modern individual becomes both an object and subject of knowledge, and is shaped and formed within the matrices of scientifico-disciplinary mechanisms (Best and Kellner 1991).

Biopower consequently intervenes into all details of life in the form of scientific, economic, and regulatory techniques. It moves into the very interior of its subjects: it regulates through its subjects internalizing it (Youatt 2008). An example is the social norms regarding hygiene and cleanliness. We internalize these norms, which are backed by legitimizing scientific and medical discourses, and thus police ourselves in terms of health and hygiene, which in turn promotes healthy and productive individuals. Suicide is another example, which is viewed as inherently bad, regardless of whether it was a doctor-assisted suicide or something else that might be deemed “justified.” Rather than

commit suicide, individuals should be alive and healthy and thus able to be inserted into the capitalist machine. Subsequently, the ongoing administration and regulation of populations aimed at optimizing individual and collective life and health has led to self-monitoring of individual conduct (Johnson-Hanks 2008). Biopower moves beyond rule by fear, and becomes so ingrained in the way we think about ourselves and the population as a whole that it goes largely unnoticed. Through biopower, Foucault demonstrates the relationships between the individual, administration, state intervention, and biological processes (Dreyfus and Rabinow 1983).

The History of Sexuality, where Foucault introduces the idea of biopower, is a broad overview of a larger project (1976). The general interpretation Foucault presents should be considered to be an interpretive exaggeration, a way of setting out markers of terrain to be covered, issues to be confronted, commonplaces to be recast, and figures to be reevaluated (Dreyfus and Rabinow 1983). Hospice represents one of those markers of terrain to be covered, expressing biopower in different ways. It therefore allows a recasting of the terrain of biopower itself, and is a site where a focus on life meets inevitable death.

Hospice is a social institution where the effects of biopower would not seem to exist, as it is one of the only social and medical institutions concerned entirely with inevitable death. The individuals under hospice care are no longer part of the economic force nor are they reproducing to ensure the continuance of the species. For these reasons, it would seem that they are not relevant to a discussion of biopower. However, many aspects of biopower still exist in the societies in which hospices are situated. These aspects are expressed differently in hospice, and are beneficial for patients.

METHODS

Semi-structured interviews were conducted with four hospice patients: Paige, Derrick, Ray, and Trevor (pseudonyms have been assigned to all participants to ensure confidentiality). Derrick, Ray, and Trevor were receiving care in group home settings, and Paige received in-home care. Interviews with patients focused on perceptions of hospice care, as well as their emotional and day-to-day experiences. Each interview was unique, based on the participant, but major themes explored included engagement with hospice workers, family dynamics, and emotional experiences. The only inclusion criteria for patients were being U.S.-born citizens, at least 18 years of age, and that they were currently under hospice care. All interviews were recorded, transcribed verbatim, and coded to tease out themes.

Two key informant interviews were conducted with hospice workers. Kate and Alex were medical social workers affiliated with Hospice Austin. Alex worked with patients receiving hospice care in a hospital setting, and Kate was the lead medical social worker at Hospice Austin's in-patient facility. The key informant interviews focused on interactions with patients and the experiences of patients and their families. Alex' and Kate's interviews were useful in understanding hospice philosophy and delivery of care, but also served as corroborating data for the interviews with patients to capture a more detailed picture of hospice and the experiences of patients.

Hospice Austin, the organization which the patients interviewed for this research were affiliated with, was established in 1979 as the first hospice in Central Texas. It is now a nonprofit organization whose mission is to ease physical, emotional, and spiritual pain of any person facing the final months of a serious illness by providing care,

education, and bereavement support. In turn, Hospice Austin provides care to anyone who needs it, regardless of illness or financial situation, and all resources go back into Hospice Austin services. Each patient is assigned a team consisting of the patient's physician, a Hospice Austin physician (who is a specialist in pain and symptom relief), a nurse, a nurse's aide, a social worker, a chaplain, a home maker (who helps with cooking or other types of housekeeping), and a volunteer. This is referred to as the patient's personal care team: board-certified specialists that work with the patient and the patient's doctor to create a unique care plan. Hospice Austin is where the patient care teams meet to discuss each patient and the patient's plan of action.

I spent six months as volunteer at Hospice Austin in the Bereavement Department. I had the opportunity to take part in a family support group, make bereavement calls to family members after someone had died, co-facilitate a support group for family members of the deceased, and be a counselor at a summer camp for children who had experienced a recent family death. These experiences gave me a glimpse into everything that would happen after the deaths of the patients I would interview, and insight into how death affects family dynamics. Volunteering at Hospice Austin not only allowed insight into hospice organization and delivery, but also was an opportunity to give back to the population under study.

CASE STUDIES

Paige

Paige was a 58 year old white woman living in Austin, Texas, who was receiving in-home hospice care for brain cancer. Paige woke up one day to a dull headache that would last for two weeks before she went to a doctor. According to her, it was "unusual"

and “not right.” An MRI showed the presence of a glioblastoma (the most common and most aggressive type of malignant brain tumor) in her right temporal lobe. She immediately had a craniotomy and a resection of the right temporal lobe, followed by radiation and chemotherapy. Despite these efforts, Paige was given a prognosis of about fifteen months and entered hospice soon after. At the time of our interview, it had been a year since her headaches began, and she had been under hospice care for about six months. She had not noticed any drastic changes in brain functioning, only “subtle defects, nothing real dramatic,” such as difficulty creating new memories. The glioblastoma qualified her for hospice care, and besides mentioning feeling “suicidal” after receiving her diagnosis, the transition did not seem to give her much trouble. “I didn’t really have any huge feelings about hospice going into it...other than, this is the end of life- we don’t know what tomorrow brings.” A typical day for Paige was spent in her home. Her symptoms and the side effects from her medications kept her from driving, she had not “found any miraculous desire to do any hobbies,” and often found herself nauseated and out of energy.

Paige was married and had two children in their late twenties. Her family was close, but it was not always easy. Her diagnosis and entrance into hospice brought up “hurdles” they had to mediate, such as Paige starting to smoke cigarettes and drink alcohol again after quitting both years before. One hurdle that she spoke at length about was the difficulty her daughters had with her being prescribed Marinol (the only legal form of Cannabis in Texas) and Xanax, both “mind-altering medications,” according to Paige. “The girls thought I got a little too goofy...and they’re probably right,” she explained. The medications “take the edge off,” but her behavior upset her daughters.

They decided Paige would lower her dose, and she thought this act had successfully mediated the hurdle. Paige was vocal about the role of family in the hospice patient's experience, and had a strong support network. She thought it was important "to get your family on board," saying, "that's probably the biggest challenge. We're not always totally aligned, but we're not at odds, you know?"

Paige was a critical care nurse for twenty years before becoming a nurse paralegal, and she was highly educated and well-versed in the intricacies of intensive medical care. Paige's father died under hospice care, and thus had some previous knowledge of hospice in terms of personal experience. As she described it, "I [know] how to be a patient." She understood everything that was being told to her, "right down to the medications." While her family was a salient theme in our interview, much of her experience was grounded in a medical perspective. "Don't let there be more distance [speaking of advice for future hospice patients]," she explained, and then jokingly said, "the idea is to come together...so at the end, if you wanna give me 10 milligrams of morphine, nobody is gonna freak out." Paige's past involvement with the expert discourses of medical care seemed to shape her entire experience with hospice. She described events and her overall experience in terms of these discourses. She viewed her experience as going from one medical event to another, besides the brief discussion about family dynamics (which was concerned with issues relating to pharmaceuticals).

Paige only utilized the medical aspects of hospice care, as the only interactions with hospice workers that she recounted were those with her nursing assistant and her RN. She met with her social worker during her first week, but had not utilized this service since and had never met with the chaplain. Most of her experience was grounded

in medical settings and events, such as medical procedures and visits with doctors. She seemed to think these were the necessary components of hospice, explaining that she could access the other aspects of hospice care if she wanted to (while implying that she did not). Her lifetime of exposure to expert medical discourses may have affected the way she perceived her experience with hospice, particularly emphasizing the medical aspects over all others.

Paige's quote about knowing how to be a patient speaks to this and reflects the influence of biopower. She viewed dying as one of the various human experiences Foucault posited to be constituted within scientific frames of reference, which in turn created the possibility for administration and control (1976). She knew how to be controlled, in a sense, as a patient. Its disciplinary power had been ingrained in Paige for over two decades, structured by medical science. She knew how to follow the orders of professionals and how to accept expert discourses at face value. She found the medical aspects of hospice to be more important than the other, more emotional aspects. Biopower regulated the remaining life of Paige by moving into the very interior of its subject.

The life-centric focus of biopower was evident in Paige's experiences with hospice. While she mentioned death indirectly a few times ("we don't know what tomorrow brings" and "at the end," for example), Paige's experience seemed to revolve around aspects of life. She did not talk about feelings about death, final arrangements, and when talking about her family, she did not mention how her death might affect them. Instead, when talking about her family, she spoke of their futures and how her experience

with end-of-life had changed their relationships. Thus, Paige found herself increasingly observing the life of not only herself, but also of her children and family.

Derrick

Derrick was a 54 year old black man living in a group home for terminal patients with HIV/AIDS operated by Hospice Austin. He was receiving in-home care in a group home setting, and was diagnosed with HIV/AIDS and Hepatitis C, along with other medical issues. At the time of our interview, Derrick had been at the group home for four months. Derrick struggled with drug addiction, had been homeless, and was in and out of jail for most of his adult life. “I got some horror stories about myself that I’m ashamed to even talk about, you feel what I’m saying?” Derrick was very religious and seemed to ground much of his experience in his beliefs, as he read bible verses and sang church hymns throughout the interview. Derrick’s religious beliefs and his relationship to his doctors led him to think he had “more time” than his prognosis of six months. He explained, “...the spirit of god spoke to my spirit, and said ‘Derrick, you ain’t goin’ nowhere till I call you home...You gotta finish what I started.’ And I don’t believe I got no six months or less. I feel like I’ve got a lifetime.” Derrick only focused on aspects of life, even in the face of inevitable death. His perception of having more than six months speaks to the influence of biopower in his life.

Derrick’s initial diagnosis and prognosis made him feel “angry, depressed, and frustrated,” as he explained that “I almost had an ‘I don’t give a damn’ attitude.” After finding religion while incarcerated and moving into the group home, his attitude changed drastically. “It gave me a different outlook about life, about myself, and how I felt, because at one time I used to think suicide.” Derrick happily recounted the day he got to

the group home: “when that man said infirmary, I couldn’t help but throw my hands up cause I knew I was gettin’ out [of jail]...so Thanksgiving eve, like I said, I got [to the group home].” When he was admitted to the group home, he quit smoking crack and quit drinking. “I say, just for today, I’m not drinkin’ no alcohol, I’m not smokin’ no crack, and I’m gonna leave it at that.” Derrick did not have any family ties, but did mention a few friends, suggesting the existence of at least a small support network. He had no previous experience with hospice and did not know what hospice was until he showed up at the group home, but had some experience with intensive medical care while he was kept in an HIV/AIDS unit while in jail.

Derrick is a great example of what nonprofit hospices can provide for the disenfranchised and the marginalized. “I’m livin’ a life of luxury- naw, bro- I’m livin’ like a king. I ain’t always had it this easy, man. I mean, I know for a fact there’s no other place in Austin, Texas- or anywhere in Texas, period- if it’s not with hospice, you’re not livin’ like this.” Not surprisingly, Derrick spoke very highly of the care he received. He delighted in the amenities that he never had access to before, including a TV, a telephone, a ceiling fan with lights, and medical supplies like his oxygen tanks. “If I had to pay for the stuff I got, man, you know what kind of bills I would have?” He also was very appreciative of the way he was treated by hospice staff. “These people treat me like a person, they not lookin’ at my situation.” As a black man with AIDS, who struggled with crack addiction, and was in and out of jail for most of his adult life, this aspect was very important to Derrick.

Derrick thought his condition had gotten better because of the medical care he received, particularly because he had “followed [the doctor’s] orders.” “They take care

of me better than I take care of myself, you feel what I'm saying? That man [his doctor] kept me alive for the past five years," he said while talking about the doctor that was overseeing him in prison and the anguish he felt when he had to change doctors. "He told me what I needed to do to not get sick." Though he did not follow "the doctor's orders" initially, he found that once he did, his situation became much easier. "I just recently started taking the meds, and it works."

Derrick spoke of his doctors as the reason he was still alive. Their expert knowledge and orders, once he followed them, caused him to perceive his situation as improving, despite an increasing frequency of hospital visits. He scolded himself for not listening to their orders, talking about the complications that arose because of it. Derrick seemed to have put complete faith in his doctors, saying that they knew exactly what he needed "to be doing to get better." The professionalization of palliative care, an effect of biopower, is manifested in the way Derrick perceived his doctors and his medical care. He followed his doctor's orders without question, accepting expert discourses as absolute truth. These discourses shaped his experience, but also monitored and controlled his remaining life. Biopower's influence moved into the interior of its subject. That is, Derrick's behavior was modified by scientific regulatory techniques that he internalized. The expert discourses of palliative care and hospice were methods of control in Derrick's case. The doctor's orders led to Derrick willingly monitoring his own conduct.

Derrick also grounded much of his experience in his interactions with his doctors. Derrick felt like he had "a lifetime" left to follow their advice, and much of our interview revolved around aspects of life: his faith, what he would do if he was discharged from hospice, and day-to-day life. Biopower's focus on life affected Derrick in such a way

that he did not truly think he was dying. This is an extreme expression of a life-centric focus. Though facing an increasing frequency of hospital visits, he was convinced he had a lifetime to live. Derrick spoke about the multiple ways in which his body was “breaking down,” yet still felt he was not dying. Derrick’s experience also speaks to the issue of control under biopower.

Derrick talked at length about the *control* he had over his life while at the group home. “They don’t give a damn what I do out there in the streets.” He mentioned multiple “hang outs” that he would attend while living at the group home, appreciating that the staff wanted him “to just call and let [them] know what’s going on.” Derrick was very appreciative of the control he perceived himself to have over daily life. For example, he spoke of having control over when and what he ate, what he wanted to do during the day, and being able to go out and see friends. “That’s always their question- what do *you* want?” While he might have had control over aspects of day-to-day life, he did not have control over his care, and certainly not over end-of-life. Contrary to hospice philosophy, Derrick was controlled in terms of his care, and in reality exercised very little control during his experience with hospice. Though Derrick claimed the hospice workers “don’t give a damn” about what he did during the day, they still asked him to call and check-in. Derrick had an extreme focus on life and perceived to have control while being controlled. The expert discourses of hospice shaped and affected his entire experience with end-of-life.

Ray

Ray was a 59 year old white male living in a group home in Austin, TX, receiving in-home care for his diagnosis of Chronic Obstructive Pulmonary Disease (COPD).

COPD is a type of obstructive lung disease characterized by chronically poor airflow (Abramson et al. 2014). Ray also suffered from anxiety, which further complicated his COPD. “It makes it worse...when you can’t breathe, and you start panicking, then you really can’t breathe, and it sets everything back.” He smoked cigarettes for most of his life, which he claimed led to his diagnosis, as he said it did for both his mother and grandfather (who both also died from COPD). He was homeless most of his adult life, and spent many years battling crack addiction and alcoholism. Ray talked about the emotional dimension of his diagnosis and prognosis, and while he was initially sad, he was realistic about his situation. “I was kinda sad, man, back at that time. I was 59...but I was sayin’, man, I’m only 60 years old.” He continued, “The more I thought about it, the more I thought, you know, I don’t have anything to regret...I’ve had a good life. We’re born to die, you know? So might as well accept it and go on with it.” This quote exemplifies the focus on life characteristic of biopower.

Ray had been hospitalized four times within two months for pneumonia before receiving his prognosis of one year of life and a recommendation to enter hospice care. “The last time I was in [the hospital], three doctors just come up and tell me there ain’t nothin’ else we can do for you...there’s nothin’ more we can do for you, so we’re gonna go ahead and turn you over to hospice. At that time, I didn’t even know what hospice was, and I still learn a little bit each time.” Ray had experience with intensive medical care, but no experience or knowledge of hospice. One experience with intensive medical care that Ray saw as very significant was his episode of respiratory arrest for three minutes. “One thing that scared the hell out of me was that I died. I went into respiratory arrest, and I died for about three minutes, and I didn’t see no light. That tells me I got

more to do before I go.” Ray wanted to make the most of the life he “had left”: to deal with his “unfinished business.” Again, the life-centric focus of biopower has crept into the experiences of individuals facing inevitable death.

Similar to Derrick, Ray’s experience also highlights what nonprofit hospice programs can provide for the disenfranchised. Ray was very grateful to have the help he did, and mentioned several times that he would not know what to do if he was “doing this on [his] own.” He boasted about his TV and his bed, while also explaining how hospice had him “set up” with medications, breathing treatments, oxygen tanks, and air concentrators that he did not have access to before. “They take good care of me...without hospice, I don’t know...it wouldn’t be as easy on me.”

“I do what they say,” he explained, telling me that their instructions had helped his situation greatly. Similar to Derrick, the effect of professionalized discourses is evident in Ray’s perception of his experience. He follows their orders, viewing them as beneficial. They shaped his experience and understanding of hospice. Ray was very appreciative of hospice workers and services. “I got my own personal nurse...she knows what’s going on with me at all times. They take really good care of me...I call it special treatment.”

Ray recounted a typical day in terms of the choices he had about what the day would look like. While his C.O.P.D. kept him from doing any strenuous activities, he talked about his options for the day: taking a walk, going out with a friend, going to the store, or watching movies in his room. Note that these options have nothing to do with his care, but represent control over mundane, day-to-day activities.

Ray had a somewhat abnormal experience with his diagnosis and prognosis, being under hospice care for a little over a year, and moving around from different nursing homes and group homes. He talked at length about getting his own place and his plans for the future, such as visiting California. “I think there’s still things I need to do or something,” he explained. “Maybe that’s the reason why I’m living longer than maybe I should be.” Ray had a plan for the day he would (read: might) be discharged from the group home he was in. “I try to buy stuff that I know I’m gonna need when I get my own place, ‘cause I gotta look for my own place.” The possibility of future life took precedence over his foreseeable death. He spent a considerable amount of time discussing the future, and our interview mostly revolved around aspects of his current life (not relating to his experience with hospice) and what would happen after hospice, a contradictory idea. Hospice is a point of no return: one does not overcome terminal illness.

Ray’s experience speaks to the effects of the professionalization of hospice care and its expert discourses, the role of control in hospice, and an intense focus on life. Ray, similar to Derrick, followed the doctor’s orders and saw this as beneficial. “I do what they say.” The discourses surrounding hospice care shaped Ray’s experience with hospice. Ray felt in control, that he made decisions for what the day will look like, though he was actually choosing from options that were given to him by hospice staff. He had plans for the future, already planning trips and finding his own apartment, in an effort “to enjoy life...I mean, about dyin’, I don’t really get upset or sad or anything about that at all. I don’t know if I’ve accepted it, or given up- well, I don’t think I’ve given up-

I take my medications and do what I'm supposed to. Until then, I'm gonna enjoy life.”
Again, a focus on life took precedence over inevitable death.

Trevor

Trevor was a 41 year old white male who lived in a Hospice Austin group home. He had diagnoses of AIDS and lung cancer. Trevor had been HIV positive since 2004, and was diagnosed with lung cancer in 2011. Trevor did not mention any kind of support network in our interview, scoffing and laughing to himself before saying, “My family don't support me on anything since I was HIV positive...so I'm on my own on this one.” The way he contracted HIV came up in our interview, and the pain was still evident in the story he recounted. “I thought I was healthy, I thought had been practicing safe sex, but apparently I wasn't...After I had been diagnosed, that's when my partner told me ‘Oh, by the way, I have AIDS’...you son of a...you should have told me from the start. Now that person is sitting in jail, in prison- [he] got a fifteen year sentence for that.” Seven years later, Trevor was diagnosed with lung cancer: “I was kinda like, really, god, what else are you gonna throw at me?”

Because of his diagnoses, Trevor already had experience with intensive medical care. He also had previous knowledge of hospice, as his adopted mother was also in hospice care at the time of the interview. Prior to being placed in hospice himself, Trevor had been on respice care until it was found out he also had lung cancer: “I had never told anybody, even the hospital, about the lung cancer until one day it slipped out here [at the group home]. And then that's when they got my medical records and found out I had lung cancer...and bam, there's hospice.” His experiences with HIV/AIDS and lung cancer seemed to prepare him for hospice. “In a way, it was easy for me because...I've

had these diagnoses for a while, so I pretty much knew that eventually I would either be in hospice or dead, one of the two. It was kind of an easy transition for me.”

“It was scary. I deal with depression all the time, I can tell you that,” he explained. “I think anybody’s health is due to the attitude they have about it.” Trevor did find some comfort in hospice: “They don’t make it feel like you’re dying,” he explained when talking about the personal aspect of the care he received. Again, biopower’s focus on life is visible in an institution for inevitable death in the way patients perceive hospice and in the ways they interact with hospice workers. Hospice workers focus on the patient’s life, treating the patients not just as terminal patients, but as individuals. In turn, this has an effect on the way patients navigate end-of-life, focusing on their remaining life.

Trevor had lost the use of his legs and was in a wheelchair, and also had started to have blackout spells. Trevor seemed to feel more controlled than any of the other participants, partially due to being in a wheelchair and having the blackout spells. “I used to leave a lot, but now that I’m having these blackout spells, they [the staff at the group home] don’t want me to even leave unless I have somebody with me. As far as that goes, that’s frustrating and, in a way, pisses me off....but I know it’s not their fault, they’re just looking out for me.” Thus, a typical day at the group home for Trevor was spent watching TV and getting on the computer. He would not leave unless he had doctors’ appointments. Trevor did not feel that he had control over these things the way that Ray and Derrick did.

Trevor did perceive to find control in terms of medical power of attorney. He thought it was important for all hospice patients to have their medical attorney of power

in order to “have some kind of decision-making in what happens to you.” He explained, “If you’re unconscious or something, then hospice or anybody can do what they want and make decisions for you.” Medical power of attorney (as well as DNR orders) may represent one way that patients actually have control over their situation, but it applies to only a small part of hospice care: what happens when a patient is nonresponsive or unconscious. It is also a form of control they do not actually exercise themselves, but one that is enacted via legal paperwork by other people. “If you get up to a point where you can’t make changes on your own, then the person that you name on your medical power of attorney can, that’s why that is so important.”

Trevor also thought it was important for patients to be in control of their care. “If you’re not getting that kind of respect from your hospice or from your caregiver, then you need to look into changing caregivers. If they’re not meeting your expectations, and there’s nothing wrong with asking for another nurse, you have that right. I mean, that’s the best advice I can give. If you’re not happy with what’s going on, then change it. Do something about it.” While changing nurses may represent some kind of control on behalf of patients, it is not control over their care and does not represent true choice or control. A patient can choose from predetermined choices, as was the case with control over a typical day. The control that hospice claims to relinquish to patients may not be control at all, but the ability to choose from predetermined options.

Arguably due to the diagnoses of AIDS and lung cancer, and the time he spent dealing with these diagnoses, Trevor was also realistic about his experience. He told me, “coming into hospice doesn’t have to be a scary thing unless you’re scared of your illness, you know what I mean?” He then said, “being scared of your illness is...gonna

cause more illness...that's why I get back to you have to have a good attitude about it- if you don't have a good attitude, then you might as well just lay down and forget it." Even with diagnoses of AIDS and lung cancer, it was still important for Trevor to not "just lay down." It was important for him to live out the remainder of his life, without worrying about the shadow of death creeping over his shoulder. Again, the life-centric focus of biopower is present in hospice.

BIOPOWER REIMAGINED: CONTROL OVER DEATH

After careful scrutiny, hospice reveals itself as a site for the exercise of biopower. Hospice is one of the diverse social institutions embedded within biopower's webs, exercising power and control through techniques of discipline and specialized forms of knowledge. Though the manifestations might be different, the proliferation and influence of expert discourses on individual experience, an intense focus on life, and the control of individuals all exist within the hospice framework. The last two prove to be beneficial for patients, instead of limiting. The intersection of life and inevitable death provides the space within which to recast biopower, explore its malleability, and consider how pervasive its effects are.

The proliferation of knowledge and expert discourses surrounding end-of-life care and palliative care is evident and representative of the effects of biopower. Specialists in pain and symptom management emerged as the hospice movement took shape, and are now a part of every patient's interdisciplinary team at Hospice Austin (as well as most hospice agencies around the country). In some ways, they dictate the care of the patients. They determine what types of pharmaceuticals will be used, for example. They also help create each patient's plan of care, determining what pain management methods will be

used at any given stage of the patient's dying process. In turn, these expert discourses shape and dictate the patient's experience with hospice, at times representing control over the patient's experience. Derrick is an example of how expert discourses can result in control. "I do what they say," he explained. He was not taking the medications his doctor had prescribed, and he said "I thought I *was* dyin'" as a result. When he began to take the medications, he felt that he had more than his prognosis of six months to live.

Additionally, all workers at Hospice Austin go through a training program that teaches them about hospice, including education concerning death and grief. They themselves become specialists in hospice care, dying, grief, and bereavement. During my volunteership at Hospice Austin, I participated in the training seminars that all employees must complete before working with patients and family members. I received an entire binder full of handouts from published books with titles such as "Navigating Children's Grief," "Myths of Bereavement and Mourning," and "Mental Responses to Grief." These training materials are presented as expert knowledge, and are taken from popular works in the fields of social work, psychology, and thanatology. Hospice workers then "educate" patients and family members with the discourses concerning these topics, which are determined by experts. The discourses of biomedicine in general also affect the experience of the patient. "I knew how to be a patient," as Paige explained. Expert discourses and specialized forms of knowledge exist, and shape the experience for the individual. For example, Ray and Derrick both spoke to the fact that they did not have previous knowledge of hospice, and relied on hospice workers for that knowledge. "I still learn a little bit each time," as Ray explained. While recounting her only interaction with a hospice social worker, Paige spoke about the effect it had on her daughters.

According to Paige, her daughters felt more comfortable with everything going on in their home after they spoke with the social worker, who educated them about the dying process, grief, and bereavement.

As they proliferate, experts teach these discourses to others. Professionals who manage death instruct the dying and their families in how to enact their roles at end-of-life with “optimum competence” (Kortaba and Hunt 1995:423). Specialists in palliative care instruct the patient on how to enact their role of the dying patient. Experts in bereavement instruct the families of the dying on how to engage with the dying individual, and how to process grief and loss. Kate and Alex both spoke on having to “educate” and “reeducate” patients and family members on “what this time looks like.” Both spoke to the fact that most of their job revolves around education. “There’s always going to be that piece of education,” Alex explained. “They [hospice patients] generally think they’re coming here to die...They’re like ‘I don’t understand what’s going on,’ so we have to go back and reestablish their understanding of what this time is going to look like for them”, Kate explained. It is clear from Kate’s quote that hospice involves a type of “training” of the hospice patient, as well as their family members, through expert discourses and specialized forms of knowledge.

The focus on life characteristic of biopower is visible in hospice philosophy, manifesting itself in the ways in which patients and particularly hospice workers think and talk about hospice. For example, Ray, Derrick, and Trevor were all vocal about not being treated as dying patients, but as living individuals. They appreciated that hospice workers focused on their lives, rather than their inevitable deaths. Ray and Derrick had future plans, and Derrick said he had “a lifetime” left to live. Derrick’s comments

included no mention of death but focused on his current and remaining life. Kate and Alex both spoke to the misconception that hospice is somewhere individuals go at the very end of their lives. Kate was adamant that hospice was not “giving up,” and that it was “making a proactive choice to receive a specific type of...aggressive, comfort care.” Alex expressed that “hospice doesn’t mean now you’re going to die,” and that hospice is able to “come in and alleviate pain and discomfort with aggressive means.” The language here is interesting, specifically the use of the word “aggressive” and of the concept of “giving up.” “Aggressive” seems to imply treatment, for example, when people speak of treating something with “aggressive means.” It also appears to contradict one of the unique aspects of hospice: abandoning curative treatments, which typically are aggressive, for more passive, therapeutic approaches to caring for the dying. Pain and symptom management do not seem to be “aggressive.” “Giving up” is interesting because, though the word carries somewhat of a negative connotation, hospice does involve abandoning treatment. It is not giving up on life by any means, but it is giving up on a biomedical, treat-and-cure approach that simply will not be effective. It is also giving up control, even in the face of the ultimate uncontrollable event: death.

While hospice may not be giving up, it certainly is a place where individuals go at the end of life, when recovery is not possible and death is imminent. The entrance criteria of prognoses of six months to one year (HAA 2010) speak to this. Hospice very much is a social institution for the dying. Aggressive, curative treatments are not possible and are not used. Hospice services may be aggressive in the sense that workers are constantly in contact with patients, and use a wide range of services and medical approaches to ease physical pain. Hospice is a certain type of healthcare, but not a

treatment, as treatment is not possible. The language that the social workers used when describing the goals of hospice also reflect the influence of biopower. Kate spoke about “enhancing” and “maximizing” the “quality of life,” while Alex spoke about the “management” of symptoms to “live with best quality of life possible.”

The issue of control is another topic worthy of theoretical investigation that relates to biopower. As previously mentioned, returning control to patients over end-of-life is a major tenet of hospice philosophy (Wallston et al. 1988), so “they can have some sort of control and they can make their own choices about what this time looks like,” as Kate said. By entering hospice care, patients have essentially abandoned curative treatments and opted for pain and symptom management. For example, a cancer patient may choose to stop receiving chemotherapy and opt for hospice when their illness is very aggressive and does not show any signs of remission. The patient then exercises control over end-of-life in this sense, determining what type of treatment they want (or do not want) to receive. However, this becomes more complicated, as hospice patients do not have control over *all* aspects of their care. It is hard to believe that anyone is able to die as *they* choose. Nonetheless, this idea was salient in all interviews. All participants felt that they made choices about their care, though the only control actually exercised seemed to be choosing from predetermined options about activities for the day. Both social workers spoke to the topic of control, but it was not a “real” control over the dying process or hospice care itself: it was control over mundane, day-to-day aspects of living and dying in hospice. Kate told me, “We’re wanting to give them choices for what the day is going to look like,” continuing to talk about whether they want to eat breakfast when they get up, if they want to venture outside at some point, and other choices about

daily activities. Even when Derrick expressed that the hospice staff “don’t give a damn what I do out there in the streets,” he then said he had to call and let them know what was going on. Trevor was only able to leave the group home for doctor’s appointments.

Hospice patients are given prescribed choices as the illusion of control, and most of the choices they make are over mundane aspects of daily life such as what they want to eat, or whether they want to take a walk outside. Patients do not have control in terms of their care, besides the possibility of deciding to take one pain medication instead of another. Still, the two medications have been suggested by experts in palliative care, not the patient. Though hospice works with patients to create a unique care plan, these are developed from templates, essentially. Specialists in palliative care and hospice guidelines dictate care, not the patient’s wishes. They do not have genuine control over most aspects of their care, and certainly do not have control over end-of-life. Arguably, end-of-life is one of the least controllable aspects of human existence.

Regarding death itself, hospice claims to provide individuals with an opportunity to “die as they choose” (Wallston et al. 1988:178). Though patients may have a voice in terms of which pharmaceuticals they want or do not want, and possibly which doctors or nurses they would like on their team, they are not a part of the decision-making process in most aspects of their care. They can choose to die at home if they can afford in-home care. Otherwise, hospice places them in a setting that fits their needs, according to their experts. There is little control to be had in end-of-life care, and even less in death. For many, being able to make choices about death is not feasible. Choice concerning end-of-life is at best an illusion for most people, who have “little control over when, how, or from what they will die (or live, or work, or give birth)” (Kaufman 2005:330).

The areas outlined above where the notion of control over life is evident beg the question of, why? The very diagnosis and prognosis of any individual points to death in a very near future. Though diagnosis and prognosis can be difficult and sometimes inaccurate, there is still something to be said for their relation to death in this context. While hospice workers do not shy away from the topic of death by any means, there is still a focus on life. Dual planning, simultaneously planning for final arrangements after death and for discharge in case of improvement, reflects how the focus on life has invaded a social institution concerned entirely with death.

While logistically, dual planning makes sense (the in-patient facility only has fourteen beds), it still reflects a focus on life. According to Kate's numbers, seventy percent of patients will die at the in-patient facility. Why would an agency plan for both options if one tends to occur much more than the other? Kate went as far to suggest that "a lot of times, what we do- it does extend life." While patients may live beyond initial prognoses, which are not always accurate, it does not seem that life is extended in the way they think. Pain relief does not contribute to the character and trajectory of terminal disease and illness. Kate even mentioned the problems with prognosis: "End-of-life can be so unpredictable, and prognosis can be so unpredictable." One of the training materials I received during my volunteership at Hospice Austin, "50 Pointers for a New Hospice Social Worker," even states: "Even hospice staff are not always right when it comes to estimating a patient's prognosis" (Lee 2010:174). Terminal illness results in one thing: death. Again, hospice workers realize this. They deal with it every day, and arguably it is more beneficial psychologically for patients to focus on their remaining life

rather than their inevitable death. Trevor was appreciative of not being treated like a dying patient, but as a person. Ray called it “special treatment.”

While volunteering in the Bereavement Department, I experienced first-hand the philosophy of hospice being acted out. As Alex told me: “I see so many individuals...people kind of maybe cast away by society, and we actually get to come in and help.” Kate had similar feelings about her work: “I think it’s just awesome in the sense that it’s free...and you’re having all of these people that genuinely care about you, that want to see you through this time that can be really tough, and it can be really meaningful.” Derrick’s and Ray’s experiences speak to what nonprofit hospices can do for the disenfranchised and the marginalized at the end-of-life. However, their experiences also speak to the ways in which the dying are controlled by the mechanisms of biopower.

While some aspects of hospice do reflect a type of indirect control exercised by patients, such as DNRs (Do-Not-Resuscitate orders) and medical power of attorney, there is little the patient or even the hospice workers can do about the timing and manner of death. Under the gaze of biomedicine, hospice patients are themselves controlled, but in different ways than the rest of the population. Biopower adapts itself to the local context, creating new social institutions and expert discourses to exercise its power, while its life-centric focuses moves into the interior of its subjects. Hospice is an opportunity to recast biopower and cover new terrain with it, to explore the malleability of diffuse power, and to consider just how pervasive the focus on life is.

It is important to note here, however, that these aspects of biopower end up being beneficial for patients. A focus on life for those facing inevitable death is beneficial for

patients so they can find some solace at end-of-life. Returning control to patients allows them to have a sense of control in a time characterized by a rapid loss of it. Though, up to this point, it may seem that I am criticizing hospice, in reality these aspects of biopower are extremely beneficial for patients and their families.

Hospice patients (and for that matter, any category of dying individuals) present an academic endeavor that comes with a different, more personal endeavor. It was an opportunity to blur the lines between work and life, to engage with a meaningful subject, and view a relatively silent population through an anthropological lens.

BLURRING THE LINES: ETHNOGRAPHY AND PERSONAL ENGAGEMENT IN THE ANTHROPOLOGY OF THE ENDINGS OF LIFE

The anthropology of the beginnings and endings of life has become a major subset of anthropological inquiry since the 1990s. The anthropology of the endings of life typically revolve around how death is attributed, contested, and enacted. This literature involves the sociopolitics of dead, dying, and decaying bodies (Kaufman 2005). It also involves a Foucauldian approach to understanding the ways in which biosciences and state practices govern different forms of dying. Theoretical approaches include the concepts of liminality and subjectification. The latter involves linking notions of life and its management to the production of knowledge and political forms of regulation (Kaufman 2005). This research examines the intersections of life and death, with attention to the ways in which the production of knowledge and political forms of regulation affect the lives of those facing inevitable death. It serves to fill a gap in this literature concerning hospice care.

Hospice has found a small niche in the anthropology of the beginnings and endings of life. This research serves to contribute to anthropological discussions of death and dying, but particularly of anthropological discussions concerning hospice. It is a type of end-of-life care that is relatively unknown, and rarely spoken about. Anthropological analyses of hospice include attention to topics such as the organization of hospice care (Kortaba and Hunt 1995), enrollment issues (Vig et al. 2010), hospice as the site of ultimate individualism (Seale 1998), and the bureaucratization of hospice (James and Field 1992).

However, little attention has been given to how anthropological research in the realm of hospice can enhance discussions concerning cultural theories of power, particularly those that link power and knowledge. Hospice is not a major topic in the anthropology of the endings of life. This research, in part, serves to fill the gap in the anthropological literature concerning thinking theoretically about the experiences of hospice patients, death and dying, and control at the end-of-life. It also serves to blur the lines between work and life, research and personal experience, researcher and subject, and to explore how blurring the lines in these areas is beneficial in the pursuit of anthropological knowledge.

Anthropological investigations of death and dying are representative of a tri-part movement occurring in ethnographic research of this nature. The tri-part movement highlights three important issues that need to be considered and grappled with: the ways in which personal loss contributes to the making of ethnography; how ethnographic fieldwork and writing shape personal engagement with death, grief, and mourning; and how writing culture, when death is the subject, alters one's relationship to informant's

lives, one's own experience, and the entire ethnographic endeavor. The boundary between native and stranger is erased, the boundary between work and life is blurred (Kaufman 2005).

While writing my master's thesis, I came across the notion of the tri-part movement and realized it explained much about the experiences I had, and the way I felt about my topic. Death and the dying have been important aspects of life since I was 18. More than an obscure interest, this topic was meaningful. Episodes of catharsis and subsequent self-discovery allowed me to truly connect with the individuals I talked to, causing them to trust me and open up to me. It aided in engaging with and writing about the dying.

I came into this research endeavor with some previous experience and knowledge of death generally, specifically the death of my best friend during our final semester of high school. These experiences had profound effects on the research endeavor, but also affected the way I engaged with participants and with the topic itself. The blurring of the boundary between life and work was beneficial instead of limiting. How could I entirely separate myself from the research endeavor, something that was so deeply meaningful and influential in my own life? The boundary must be blurred in order to grasp the true weight and significance of the experiences at hand.

My experiences with death have shaped my understanding of the world. They have put me in a position to study the dying. To witness what it is they are going through, without shying away from the inevitable or the emotions that accompany the journey. As prepared as I thought I was, nothing would prepare me for the experiences that lay ahead. It proved to be one of the most meaningful and cathartic academic

endeavors I had ever engaged in. It ended up being three distinct, yet related, spheres of experience: a research topic, a chance to give a relatively silent population a voice, and an opportunity for growth and self-discovery.

This thesis serves in part as a testament to the lives of Paige, Derrick, Ray, and Trevor. This research also serves to answer Renato Rosaldo's call to avoid eliminating emotions in anthropological studies of death by assuming the position of "the most detached observer" (1989:15). The tri-part movement mentioned above (Kaufman 2005) echoes Rosaldo's call, and both authors discuss how personal experience with death shapes research, writing, and engagement with the individuals under study. I will never forget you, Derrick. I will never forget you, Ray. I will never forget you, Trevor. I will never forget you, Paige. Your words and your stories will forever live on, and have changed my life and made me grow in ways I did not expect. By blurring the lines between native and stranger, life and death, and researcher and participant, research concerning death and the dying is necessary, important, and meaningful. "Death, for the dying and those attending the dying, becomes a test, an opportunity for growth" (Simon et al. 1993:424).

III. APPLIED COMPONENT

This research also has an applied component, and the following findings will be presented to Hospice Austin and the different groups of staff (nurses, chaplains, social workers, etc.) at this organization. These findings revolve around aspects of control, focusing on life, staff transitions, and what nonprofit hospices can provide for the disenfranchised at end-of-life. The presentation slides are included in the appendix section.

First, control matters, even if it's perceived. In a time characterized by a drastic loss of control, even giving some control back to patients is beneficial. It makes individuals feel that they have some power in decision-making at end-of-life, a time where they have lost control over most aspects of their life. All participants in this research were very appreciative of the control they had over certain aspects of living and dying under hospice. Even if they are prescribed choices presented as the illusion of control, and revolve around mundane aspects of daily life, they still are beneficial and appreciated.

Next, the life-centric focus of hospice philosophy is also beneficial for patients. Hospice patients are surrounded by the immanency of death, and focusing on life allows patients to find some solace at the end of life. By focusing on their remaining lives, patients can make the most of the time they have left. All participants spoke to feeling appreciative of the way they were treated by hospice workers, specifically being treated as living individuals instead of anonymous terminal patients.

One issue that came up during one of the interviews had to do with staff transitions. Ray recounted when his nurse was promoted, leaving him without a personal

nurse for two weeks. Though he said Hospice Austin did what they could to make this transition easy on him, he still spoke to the fact that he wished the staff transition went smoother for him in terms of his care. Thus, one thing Hospice Austin can watch out for is to make sure staff transitions do not effect patients in a negative way.

Finally, for individual such as Ray and Derrick, Hospice Austin provides something that socially and economically disenfranchised individuals may have not ever had access to: a support network, a sense of security and control, basic amenities, and people that treat them as living humans with meaningful lives. Though all participants spoke to the phenomenal level of care they received while under hospice care, Ray and Derrick were especially appreciative of the care and respect they received at end-of-life. “They not lookin’ at my situation,” Derrick explained. “They treat me like a person.

APPENDIX SECTION

Focusing on Life

- Focusing on life in the face of inevitable death is extremely beneficial for patients
- Allows them to find some solace at end-of-life and to focus on their remaining time
- Trevor: “They don’t make it seem like you’re dying”
- Derrick: “They treat me like a person”
- Paige: “I call them my angels”

Control Matters

- Returning control to patients over aspects of daily life, and over some aspects of care, was greatly appreciated
- In a time characterized by a rapid loss of control, patients found this to be important
- Derrick: “That’s their question- what do *you* want?”
- Ray: “I call it special treatment”

Nonprofit Hospices and the Disenfranchised

- Ray and Derrick were both great examples of what nonprofit hospices can provide for the socially and economically disenfranchised at the end-of-life
- Derrick: “They not lookin’ at my situation”
- Comfort, love, respect, basic amenities, etc. for possibly the first time in an individual’s life
- Both Ray and Derrick were very appreciative of this aspect of their care

Staff Transitions

- One issue that came up was the effect that staff transitions have on patients
- Ray’s nurse was promoted, leaving him without a personal nurse for two weeks
- Though Ray was not upset, he did mention he wished it would have “gone smoother” for him
- One thing to watch out for- that changes in staff do not effect patients

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