



Not only for the dying

Palliative care and death denial

Þorgerður María Halldórsdóttir

Lokaverkefni til BA-gráðu í mannfræði

Félagsvísindasvið



HÁSKÓLI ÍSLANDS

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Abstract

People, with life threatening illnesses who enter palliative care early on in an illness-stage report greater quality of life and satisfaction. Furthermore, studies show that in some patient-groups, of people with similar prognoses, those who receive palliative care live on average longer than those who receive more aggressive treatments. Given these findings, one must ask. Why is palliative care not the standard care for people with life-threatening illnesses? To answer this question, I will take a look at the palliative hospice movement that was born out of the work of Dame Cicely Saunders. What is palliative care and how does culture play into discussions regarding death, dying and palliative care? The theories I will be drawing from are those of Michel Foucault regarding power, as well as the theories of Ernest Becker on death denial as terror management. I will incorporate anthropological ethnographies that have been conducted within the fields of palliative care, hospice care and dying in a hospital setting. In addition, I will be draw from material from philosophy, sociology, nursing and medicine.

Útdráttur

Rannsóknir sýna að fólk sem nýtur líknarmeðferðar (palliative care) snemma í sjúkdómsferli lífsógnandi sjúkdóma, telur sig njóta meiri lífsgæða er ánægðara. Jafnframt sýna tölur að í vissum sjúklingahópum þá lifa þeir einstaklingar að jafnaði lengur sem njóta líknarmeðferðar samanborið við þá sem undirgangast ágengari meðferðir. Í ljósi þessara niðurstaðna hlýtur sú spurning að vakna. Hvers vegna er líknarmeðferð ekki grunnmeðferð fólks með lífsógnandi sjúkdóma? Til að svara þeirri spurningu mun ég fjalla um líknarmeðferða- og líknardeildahreyfinguna (palliative hospice movement) sem varð til upp úr vinnu Cicely Saunders. Hvað er líknarmeðferð og hvaða hlutverki gegnir menning í umræðum um þá deyjandi, dauðann og líknarmeðferð. Ég vinn út frá kenninum Michael Foucault um vald, en einnig mun ég fjalla um kenningar Ernest Becker um dauðaafneitan sem óttastjórnun (terror management). Inn í ritgerðina mun ég flétta mannfræðilegar etnógrafíur sem unnar hafa verið í tengslum við líknarmeðferð, líknardeildir og andlát innan sjúkrahúsa. Jafnframt nýti ég gögn úr heimspeki, félagsfræði, hjúkrun og læknisfræði.

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Introduction

Picture a hospital-ward painted in lively colors in an attempt to make it look more homely. In one of the rooms, in a hospital-bed that seems almost too big for the frail body lying in it, there lies a disease-ridden person. Pale as ghost, protruding cheekbones and sunken eyes. The room is filled with pictures, flowers and cards and a family is sitting around the bed holding hands and waiting. A nurse walks in and says; “It won’t be long now”.

This is an example of the type of pictures that pop up in most people’s head at the mention of palliative and hospice care. Images of fatally ill people in their last days and hours of life. For most people, the word “hospice” conveys an idea of the place where death takes place. “Palliative” happens to be a bit more of a jargon, and therefore doesn’t have the same set of feelings attached to it, but coupled with hospice, ideas of death and dying reemerge.

Palliative care has been a subject of interest to me for numerous years. I used to work in a nursing home where ailing senior-citizens spent their last weeks and months. Most of them experienced, what appeared to me, relatively quiet and calm deaths in their rooms and in the beds they had slept in the previous weeks and months. At other times it would seem as if death was being interrupted by measures taken to prolong their lives without much consideration as to the kind of quality of life they had. Oftentimes it seemed as if these measures were simply prolonging the death-battle, and I was unsure as to who was to benefit from these actions. These experiences; on one hand, of death as a natural occurrence that was not as scary as I had previously imagined, –and, on the other hand, the feeling that some people were being cheated out of a “good death” – intensified my interest. The idea that quality of life was receiving greater appreciation than the mere length of life was something I felt I needed to look more thoroughly into. Initially I intended to dive into the budding field of palliative care of non-terminal patients. However it soon became evident during my research that there would not be enough data to support a full paper. Rather than being discouraged, I became interested in finding out why this was and decided to embark on a quest for the reasons behind this information-insufficiency. It could be said that this paper is an investigation into the tabooesque area of death and dying in the western world through the practice of- and attitudes towards-, palliative care.

My fascination with the medical field, as well as death and dying, goes back further than my practical experience in nursing homes: I have been interested in the medical field ever since I was a young child. TV-programs, movies, books – anything that had to do with medicine, was

either firmly planted in my hands, or I in front of it. Growing up I only experienced death and dying as a secret phenomenon that was to be addressed in quiet voices and hushed words. It felt like a big unmentionable subject and, as such, incredibly appealing to a curious child.

During my time of research I came across an article called *Letting Go*, by Dr. Atul Gawande (2010), about palliative care and the possible advantages associated with its incorporation. The article addresses a study that was done in Canada and it posed three interesting facts. First, it suggests that people who entered palliative care early on in their illness reported a higher quality of life than the comparative group. This is understandable since the main focus of palliative care is to focus on quality rather than quantity of life. Second point was that the medical cost of these patients was lower for both the individual as well as the medical insurance provider. The reason being that people who engage in palliative care are less likely to seek heroic measures towards the end of life than those not engaged in palliative treatment. A third interesting point the article raised pointed out that on average the people who were enrolled in palliative care program, lived, longer. Furthermore patients with congestive heart failure who were only enrolled in palliative hospice care lived on average three months longer than patients who were not enrolled, suggesting that people lived longer when the focus shifted from trying to live longer to attempting to live fuller lives (Hammes, Rooney and Gundrum, 2010). This conclusion brought up my thesis question – Given the benefits palliative treatment presents for patients and family-members;

Why is palliative care not the standard of care in the western world for people with life-threatening illnesses?

To answer this question I will take a look at the palliative care/ hospice movement. I will take a look at its beginning. What does it entail and who receives palliative care? I will discuss the way culture plays into people's decisions regarding palliative and end of life care. Power is a large part of discussions in medical anthropology. What is power? How does anthropology discuss and define power and how does power play into medical decisions? What is death? How is death addressed in western society? How does the medical field view and define death? How do people die within the medical field? What are common attitudes towards death? I will draw on the theories of Michel Foucault and Ernest Becker, regarding power and death denial and look at ethnographies that have been conducted within the fields of palliative care, hospice care and dying in a hospital setting.

Hospice and palliative care are concepts not too distant from anthropology and anthropological theory. Especially since nothing pertaining to people is unrelated to anthropology. Death is quite often relatively close at hand when an anthropologist carries out his or her regular fieldwork at a distant location as it is an inevitable part of human life. Few aspects of life appear to be under a similar cloak of mystique as death in our western societies. Therefore it is perfectly understandable that many anthropologists look to issues of death, dying and concepts of fatality when looking for research opportunities in their own environment. The tools of the anthropologist are ideal when researching such delicate matters.

1. Palliative and hospice care

1.1 - The beginning

According to the World Health Organization (WHO), the term palliative hospice care means to provide to people affected by life threatening illnesses a relief from pain and other symptoms that may plague them via support system that integrates multiple aspects of care by viewing dying as a normal process without hastening or postponing it. On their website it reads “Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.” (WHO, 2012: 1st paragraph). Palliative care was born out of the hospice movement in Great Britain that began as an experiment by Dame Cicely Saunders. In the 1960’s she founded St Christopher’s Hospice in England. Saunders was a social-science-educated registered nurse who studied the treatments available to terminally ill patients. While doing so she found the pain management and spiritual care of these patients mattered more to them than painful treatment-options that only seemed to prolong death. The philosophy of St Christopher’s Hospice has since then been to provide holistic palliative- and end-of-life care that acknowledges physical, social, mental and spiritual needs of their patients (Cicely Saunders International, 2012). The birth of the hospice movement can be traced to the time when Saunders was given a permission to give pain medication to four terminally ill patients. Even though people were skeptical regarding her work the results it produced intrigued them. The patients involved in the experiment, reported a better quality of life in their last days than did patients who received the standard care (Cicely Saunders International, 2012). Shortly after Dame Cicely Saunders founded her hospice in the UK, the concept found its way across the ocean to America. Under the care of

Florence Wald, Dean of Yale University and with assistance from Saunders, the first at-home hospice-service was started in New Haven, Connecticut. The second hospice that was established in the US was at St Luke's Hospital center in New York. St Luke's hospice integrated inpatient care, at-home care, clinic care, as well as offering bereavement counseling for families of the patients (Meghani, 2004).

Up until 1980, the pain suffered by cancer patients was a largely overlooked problem worldwide. Pain associated with cancer was considered an inseparable and unavoidable part of what happened when cancer took hold in a patient. The drastic changes that came about in 1980 and are by many considered to be the reason palliative care is what it is today, were the results of a decision made by a man named Dr. Jan Stjerneshvård who became Chief of the World Health Organization Cancer Unit. Having witnessed the suffering of incurable cancer-patients in East-Africa, he decided that the focus of the WHO cancer Unit would be pain management and palliative care. In order to gather all the information there was available, in separate parts of the world; he decided it would be most beneficial to create a comprehensive panel on pain management. The idea is that meticulous pain management is the most humane and sensible treatment option when cure is unavailable or unachievable. Several panels, conferences and conventions have since then been held on various aspects of pain management and they all contributed to this growing field. As more attention was being given to the subject, more researchers and research funders deemed the issue sensible and devoted time and effort to it (Stjerneshvård, Colleau and Ventafridda, 1996). During the 80's there was a great increase in the number of palliative hospices being built and opened all over the United States. What happened around the same time was that Medicare, the national social insurance program in the United States, began to pay for hospice care and thus it was recognized as a valid treatment option. It helped to move things along faster, that unlike new drugs that would have to go through complicated and time-consuming testing as well as numerous panels before becoming a valid treatment option, palliative care was more of a philosophy that incorporated already approved medicine and treatments but in a completely revolutionary way. Some might say that this fast acceptance on behalf of Medicare had more to do with the money it saved since in order to be approved into hospice care covered by Medicare, patients had to be seen as having less than six months left of life and had to forego other more costly life prolonging treatment options (Meghani, 2004). Around the same time as Medicare grew increasingly more appreciative of palliative care, WHO began to publish information booklets on palliative and hospice care in numerous other languages such as

Japanese, Italian and German to name a few. As well as publishing the literature WHO had a film made that became the organization's best-selling video, where palliative and hospice care were presented in a much more approachable manner (Stjernswärd, Colleau and Ventafridda, 1996). Palliative care has mostly been used as a treatment option for cancer patients and until recently it has been used as a last option for patients when there are no more treatment options.

It is understandable that people most often associate palliative care with cancer patients with incurable diseases in their last weeks, before the disease claims the life of the patient, since that is exactly the way the term palliative care was utilized up until the 1990's. Similarly in the US, when Medicare accepted palliative hospice care as a treatment option in 1982, it made the requirement that a doctor estimated that a patient had less than six months left to live, and would forego other treatment options, including palliative chemotherapy, which is often used to minimize discomfort even when hope for a cure is not realistic. Clinical trials were also out of the picture, were a patient to enter hospice care. Furthermore if a patient was to continue with curative methods, he or she would not be able to enjoy the expertise of trained palliative care professionals regarding pain and symptom management and bereavement counseling (Zimmermann, 2007). In more recent years, palliative care has been expanded beyond the final weeks of life, as well as having increased to being used for sufferers of other life-threatening illnesses besides cancer (Meghani, 2004). Ever since the early days of palliative hospice care, when Dame Cicely Saunders began treating terminally ill cancer patients, there has been an increasing interest in its theories and benefits. The panels of the World Health Organization (WHO) developed the field further and the information produced, spread the knowledge worldwide. Willingness of medical insurance providers, furthermore assisted in the philosophy's acceptance, and has made it what it is today. The benefits people have seen in patients who received palliative care have brought into question whether other patient-groups could benefit from this methodology. Next we will take a look at the way palliative care has been expanded beyond its original construction.

1.2 - Not just for the dying

In the field of palliative medicine, there is an emerging understanding of the benefits posed by palliative care and comfort care, when healing is not really an option but death is not an imminent threat either. Therefore there has been an increased interest in extending palliative care beyond that of the illnesses it is most often associated with. Some arguments are more financial while other arguments are more in tune with patient empowering. A study that was done in Belgium showed that spending regarding medical services dropped significantly, at the implementation of palliative care, while patient satisfaction rose at the same time. This is not a trend normally seen when spending goes down (Van Nes, 2011). The trend in medical spending is that there is usually a large upward escalation regarding cost when patients are nearing the end of their lives. This increase is the result of expensive invasive procedures used in order to prolong life. Previously mentioned study indicated that the patient's family felt the procedures did not add to the quality of life but lengthened the dying process for the dying person. Therefore, by focusing on quality of life, the number of expensive procedures went down and people were less limited to enjoy life. Palliative hospice care has most often been used for patients battling terminal cancers but soon after it started hospice care was extended to patients suffering from neurological diseases such as ALS (amyotrophic lateral sclerosis), sometimes referred to as Lou Gehrig's disease and MS (multiple sclerosis) as well as AIDS (acquired immunodeficiency syndrome), especially in the early years of HIV and AIDS when there was no known treatment (Byock, 1998). With all this in mind, medical officials in the province of Ontario, Canada decided to implement an integrative program where people were offered traditional curative methods as well as palliative care. Since patients rarely like to admit defeat, and foregoing curative methods to enter palliative care is by some seen as giving up, people are often reluctant to look into the possibilities palliative care offers. In fact, still to this day, it is rare that patients enter palliative care with more than a month left to live (Gawandi, 2010). By offering consecutive treatment-plans the patients and families can look beyond the perceived fatal predicament and reap the benefits the plan offers. What brought about this initiative were the results of findings that palliative care was being poorly used. When Ontario's government officials looked into reasons why people were hesitant to enter palliative care, they found that doctors in particular showed reluctance towards offering it to their patients. This caused patient to start palliative care much later in their illnesses and yielded the results that many of the benefits were not acquired. Ontario's officials decided to come together and come up with ideas on what could be done to make palliative care a more

appealing option in the wilderness of treatment plans and options. The idea to not limit the availability of palliative care to those not seen as imminently perishing, seemed simple enough. The results yielded by these initiatives were beyond what Ontario officials had dreamt of. The simultaneous utilization of curative methods as well as comfort focused treatment brought about increased patient satisfaction and when the time came that a cure was not a realistic option the patient involved in this initiative were more at peace with decisions to forego the curative plan and focus entirely on comfort and quality of life. The results of the Ontario-initiative brought about another interesting fact. While most people would think that palliative-care-ideology would cause a decreased life-expectancy of a patient, an opposite trend emerged. Patients who entered the consecutive treatment-plans, on average witnessed an increase in life-expectancy. This increased life expectancy did not come at the hands of poorer quality of life. On the contrary, the patients reported higher quality of life than the comparative group. Since the patient who received the concurring treatment-plan declined expensive curative initiatives sooner and entered simple palliative care there was a decrease in the medical cost for these patients (Hammes, Rooney and Gundrum, 2010). These results seem almost too good to be true, what with increase in life expectancy, self-reported higher quality of life and lower costs. It is therefore understandable that government officials elsewhere have shown a greater interest in implementing the methodology of palliative care elsewhere and extending it to more patient-groups.

Patient-groups are not homogeneous. Not even when they are made up of people who all deal with the same illness. Some illnesses are very limiting and quality-of-life-restrictive and even though they may be incurable, they may not pose an imminent threat to the patient's life. Other illnesses are not highly visible and do not come with dramatic visual symptoms even though they pose a danger to the influenced party's life. That makes the group of people who would benefit from extended palliative care very diverse. Patients who suffer from heart- and lung-diseases are an excellent example and could fit within the descriptions of both previously mentioned groups. While advanced lung-diseases and many types of advanced heart failures are very limiting for the patient and lessen his/her quality of life dramatically, the terminality of the illness is not often obvious, not even to the doctors unless in the final stages (Ward, 2002). Christopher Ward (2002), an American cardiologist, published an article in the British Medical journal on the need for palliative care for patients with congestive heart failure. As he points out, the needs of those patients are very similar to the needs of patients with malignant diseases with regards to spiritual, mental and social needs. Ward found that while social and

emotional needs of cancer patients were most often seen as equally important as medical needs, they were not as readily acknowledged when it came to cardiac patients. People with heart diseases did not get the same emotional support as cancer patients and when it came to hospitalization, majority of the patients felt symptom management was inadequately addressed. The patients themselves were rarely asked what symptoms they felt were most bothersome. Probably the most distressing results of the study Ward reported on, was the fact that the patients felt they were not being included in decision-making regarding their own health. When he decided to offer a more palliative-like approach to treating heart-patients, a large number of the patients chose comfort in lieu of aggressive treatment options. Ward concludes that the improved communication about prognosis and the patient's own wishes are key points in quality palliative care as well as proper pain management. Both treatment options offer rewards that cardiac patients should not miss out on. An example of improved pain management is the use of morphine to combat dyspnea, a particularly distressing symptom, sometimes called air-hunger, where the patient feels as if he/she is suffocating slowly. This happens when the blood is not properly oxygenated. Since morphine is a respiratory depressor some could see its usage to combat dyspnea as unethical, but in terminal care, when the focus has shifted from curing or treating the patient to making the final moments the most comfortable without the focus on prolonging life, the use of morphine can be seen as beneficial. Since patients suffering from heart-diseases often suffer prolonged dying with troubling symptoms related to a decreased heart- and lung-function they make up a patient-group who would benefit greatly from increased awareness of palliative care (Ward, 2002). Patients who suffer from other diseases sometime come into contact with professionals of the palliative hospice field, despite not being classified as palliative patients. They do so in order to receive symptom management, most often pain management. These patients seek assistance for many different types of ailments. Patients who suffer from arthritis, whether it is rheumatoid arthritis or osteoarthritis are a particular group who can benefit greatly if quality of life is a main concern regarding medical decisions due to its incurability (Kite, Jones and Tookman, 1999). As in Ontario Canada offering a focus on quality of life, instead of aggressive cure can have many benefits, not just for the patient but the whole community.

In this era of skyrocketing medical cost, would it not be ideal if there was a way to lower cost and increase patient satisfaction? Those are in fact the same results government officials in both Canada and Belgium came across when they decided to put a greater emphasis on palliative care for the elderly and others with shortened life expectancy. When innovative

doctors decided to offer palliative care to patient beyond the previously understood group of ideal recipients of palliative care, such as people with congestive heart failure, they too discovered that the patients reported greater satisfaction and spoke of feelings of empowerment. They felt they were being given more choices and with the choices they felt they had a greater power over their future as well as life today.

2. Power

Let's take a look at some definitions of power. "Power" is a reoccurring theme in anthropology and has been viewed in many different ways. Power plays a pivotal role in discussions of illness, patients, death and dying. The political anthropologist, Ronald Cohen talked about power "as the ability to influence the behavior of others or gain influence over the control of valued actions" (Cohen, 1970:31). Despite this clear definition there are more concise ways to classify power. There is "private power", which is the type of power a person holds due to his or her position in certain group, but does not grant superiority outside that particular group, for instance a dominating father in a family. "Public power" is what we grant institutions and agencies with the hopes that the authority is warranted and will not be abused. An individual can have great influences due to some favorable characteristics such as some unique skill, knowledge or even simply because the individual is a charismatic one. When a person has this ability it is said that he or she holds "independent power". The opposite of independent power is "dependent power". An individual who has been granted independent power can advance that control over to some other person. Groups or individuals can grant their power to other groups. However in order for anyone to utilize power, first there needs to be an agreement of some sort regarding consequences. For example if an individual breaks the law, people have agreed to grant disciplinary power to the appropriate establishments. Disciplinary power is therefore an example of a dependent power (Lewellen, 2003).

Few if any have influenced the ideas and conversations on power and embodiment more than the French philosopher Michel Foucault. Interest in his works surged in the 1970's as it suited the ideologies of that era perfectly. Foucault studied power extensively in many different settings. His ideas and theories on power have been adopted by many anthropologists and have become a sort of a dogma in the dogma-free era of post-modernism. He saw power in the way that it was not something a person could hold or own but more as a potential, the capability to change and influence the systems in which an individual lives. As well as the

ability to change structures, Foucault also regarded power as the capacity to impact how resources and goods are distributed, for personal gain. An example of such resources and goods could be the access to water, food or financial resources. This is not the only way Foucault believed power emerges in our day to day life. As well as the more economically associated power or “economic power”, previously mentioned, he spoke about the power of discourse. “The power of discourse” is the way the words of certain groups of people carry greater weight and merit in the public arena than the words of some less powerful groups. The people or establishments that hold such power may in some instances not hold other more traditional powers. They are in turn granted authority on the basis of intellectual or educational advantage (Barnard, 2000). The power of discourse fluctuates based on topics at hand. A geologist has discourse-power on matters pertaining to geological issues whereas he most likely will have very little regarding fashion. In turn, the authority, carried in the words of a dean of a university beyond the establishment’s walls depend on its reputability. The words of a Harvard- or a Yale-dean are thought to hold a greater merit than for instance, the words of a dean of for-profit college such as ITT Technical Institute or American Career College. The ability to control an individual’s access to information is power of immeasurable substance often utilized via censorship by governments and even major corporations (Nanda and Warm, 2009). Another way, in which power of discourse plays a large role in discussions regarding matters of medicine, is when it comes time to discuss issues of life and death, - who holds the permission to talk about these specific topics? Who is allowed to make decisions regarding end-of-life? Who is allowed to bring up the topic of making the move away from curative and towards palliative treatment? Or even to utilize both simultaneously (Freundlieb, 1994).

Disciplinary power is not only a power held by correctional-institutions. We have given the medical field a form of disciplinary power in the sense that doctors, hospitals and other medical staff have been given the task of disciplining a body that acts out of order, via illness, injury or old age. Acting against this disciplinary power can be seen as an act of defiance and based on the level of defiance or position of the defiant, can be seen as a medical infliction under theories of medicalization (Driver, 1994). The modern medical world inflicts disciplinary power onto the body by many means. One aspect, not removed from such actions is how a medicine has taken death out of the concept of being a natural occurrence in the cycle of life, and began to see it as a failure of medicine, which is an idea that will be discussed further, later on.

Lastly, there is “biopower”. Foucault’s definition on biopower has become renowned. He is quoted as to having said that biopower is “what brings life and its mechanisms into the realm of explicit calculations” (Foucault, 1980:137). This concept of biopower is known as the historical change that allowed authoritative figures such as medical professionals, to exercise influence and authority by producing knowledge regarding life, health and death and controlling access to it (Kaufman and Morgan, 2005). According to Foucault, there are two types of biopower. Most scholars will discuss the concept as a life-affirming power intended to make life grow by devoting resources to its continued development. The other side of biopower according to Foucault; is when means are taken against preserving life or even eradicating life, perceivably for a greater good of some sort (Inda, 2005).

The term “biopolitics” has been used to describe a type of meeting point between states and institutions as well as individual experience. Biopolitics address the changing ideas of what is considered normal and what is pathological. Biopolitics are not too separate from the idea of biopower. It could be argued that biopolitics is simply the implementation of biopower in practice. That, while biopower is a terminology used to describe the ideas, biopolitics are the results of governing via biopower (Kaufman and Morgan, 2005).

The Sociologist Mitchell Dean (2002) describes governmentality, as “the conduct of conduct” which roughly translates into the action of leading. Foucault describes it as “the art of government” or the powers that are utilized to control. What they mean by the term governmentality is to describe the way people are ruled and governed, and how they are affected by the types of control that is incorporated. One of these is the aforementioned, biopower. Formal governments are not the only types of governments that are at play in situations of health and medical decisions. While the government might make rulings that are to be followed regarding reproductive health and other moral issues with wider implications, hospital-administrators, insurance companies and medical professionals might act as a small government over decisions regarding a patient’s treatment options. Governmentality and biopolitics are not the same even though they might often become indistinguishable from one another. Dean (2002), talks about a delegation of sovereignty among decision-makers. Decisions regarding whether to continue full treatment, discontinue active treatment or let die are all decisions that can go through an array of complicated bureaucracy of biopolitical power-players exercising their biopower (Dean, 2002).

Bruno Latour was a French philosopher like Foucault, as well as being an anthropologist of science. He is credited with influencing other anthropologists with his idea on the construction for scientific facts; More notable the separation of nature and society as well as the split of life from life-sciences. Political discourse in the West is now, in large part due to Foucault and Latour's influences, changed so that biopolitical subjects are central to the discussions. Additionally, life and death are understood because of their biopolitical definitions and negotiations (Kaufman and Morgan, 2005).

The medical industry has been granted power of discourse due to superior knowledge of medicine and bodies. Because of this power we rarely take a step back and question the validity of claims made by those who hold this power. The medical industry governs in ways that we can often not identify. The biopolitics of end-of-life have gone through a great deal of change as a result of the technical advancements that have taken place over the last few decades and have blurred the line between life and death. The changing attitudes regarding palliative care have been influenced by life-affirming biopower that, at least to a point, is being implemented by the government in charge. As mentioned before, the government in charge can be on a small scale like the hospital administration or on a large scale. The biopolitics for and against palliative care, depend on the powers that are in charge. What is considered by some to be patient empowering via the right to choose or deny treatment and focus on quality rather than quantity of life, can be seen by others as not exercising all powers to keep an individual alive for as long as possible and be understood as the eradicating form of biopower.

3. Death and dying

3.1 - Physical death versus social death

Traditionally throughout the ages, people who have died as a result of an illness have died at home surrounded by family. Since the main cause of death tended to be infectious diseases, people remained relatively healthy until they died from said diseases. New discoveries in science and medicine lessened the effects of epidemics of infectious diseases which in turn moved death away from homes and into institutions. Slow-progressing chronic ailments

replaced acute illnesses as the leading cause of death and people began to view death as an occurrence only when the science of medicine failed. This caused a certain rift concerning the notion of death as a natural occurrence. The modern hospice movement was a reaction to this split in ideologies (Lawton, 2000). It is difficult to discuss the beginning of altered attitude towards the treatment of the dying without mentioning the psychologist Elisabeth Kübler-Ross, who revolutionized medical profession's attitudes toward the mental well-being of terminally ill patients with her book *On Death and Dying* first published in 1969. In this book Kübler-Ross first presented the now widely accepted and publicly known five stages of grief. The five stages are: denial, anger, negotiation, depression and acceptance (Kübler-Ross, 1997 [1969]). Although the stages were originally designed to describe the emotional roller-coaster she witnessed the dying person go through, they have since been associated with any type of loss. Be it the loss of a loved one, a job and so forth. One could argue that these two women, Elisabeth Kübler-Ross and Dame Cicely Saunders, were pivotal in changing people's attitudes regarding treatment at end of life.

Before going further it might be helpful to discuss what is meant by death. Medicine has changed a lot over the last 40 years. The new treatment options as previously mentioned have given doctors the ability to take over many of the tasks normally carried out by organs in the body. These technological initiatives, such as ventilators, heart and lung bypass as well as drugs that raise or lower a patient's blood pressure, have been a real game-changer. The new technical advances have produced a new set of ethical questions regarding the boundaries between life and death. Prior to these improvements, the moment of death was evident by lack of heartbeat or breathing (Árnason, 2003). Those classifications no longer applied when heartbeat and breathing could be maintained mechanically. Thus was born the term "brain-death". When the term brain-death was defined in 1968, the line between a living body and a dead one became blurred. The need had risen for more than one definition of death that addressed this change. Next people had to decide what "life" was and "person" (Kaufman, 2005). Around the same time terms such as "quality of life", "dignity", and "suffering" made their way into treatment-discussions. As with anything else that has to do with ethics, there is no black or white, there are many different opinions regarding end-of-life. Other more complex definitions of death are: an irreversible loss of flow of vital fluids, irreversible loss of the soul from the body, irreversible loss of the capacity for bodily interaction and irreversible loss of the capacity for consciousness or social interactions. For irreversible loss of flow of vital fluids, the idea is that when blood-flow stops, so does life. And for many years, that was

true. This could also mean other fluids such as urine. Modern technology has given us the option of maintaining the flow of fluids mechanically with mechanical pumps, ventilators and dialysis. There are several different mechanical pumps that maintain flow of multiple fluids, for instance; heart and lung-bypass. Ventilators can maintain the breathing for a person who is unable to do so him-/herself. When respiration is maintained, the heart is able to perform its task of maintaining blood-flow. In the case of total renal failure, a dialysis-machine rids the body of toxins that would otherwise be removed from the body via urine. Irreversible loss of soul from body has become more of an idea for theology to debate although in the setting of social science it could be argued that it is closely related to the idea of irreversible loss of the capacity for social interactions and consciousness, mainly irreversible loss of consciousness. In the case of brain-death, whether it is total or loss of higher function, the argument for end of care is often that the person is no longer the person they once were. That what made them that person is no longer there. So it could be said that the soul and consciousness are somewhat the same. As for irreversible loss of the capacity for social interaction, that is sometimes referred to as *social death*, the time when a person is completely or almost completely removed from social life due to illness or handicap. Social death is often a prelude to ending curative or life-saving treatment. It is condition characterized by active or passive removal from life. A patient might pull away from family and friends or even stop participating in conversations altogether because he or she feels there is no point in investing time in frivolous time-killers when it is uncertain how much longer a person has left (Lawton, 2000). For people with progressive terminal illnesses social death might happen weeks prior to the time of physical death. At this point there is a question of when a person is no longer a person but simply a mere body. The fourth point, irreversible loss of the capacity for bodily integration is not so different from the previous two, since that point is concerned with awareness of a physical body. As with the previous one there is a question of consciousness (Veatch, 1989). Simply with regards to physical death, if social aspects are overlooked, there are four levels of life: 1. A living person with functioning body and mind. 2. A living person with brain-death of cerebral cortex. Since brains-stem is still active and maintains physical body-functions but there is very limited mental awareness, that person will never gain consciousness. 3. A brain-dead person. Complete brain-death and no mental awareness. Body-functions are artificially maintained. At this point organ are harvested for organ transplantation. 4. Dead body. No physical or mental functions remain (Árnason, 2003).

Technical innovations have caused us to have to come up with new definitions of death, since the old ones did not fit anymore. When breathing and blood-flow, whose absence had previously been used as an indicator of death, could be maintained mechanically, new definitions emerged. The process of dying, also received greater attentions which has broadened the understanding of the many ways an individual can die before an actual physical death takes place. When the term brain-death was coined, new ideas of what it meant to be alive also developed and people began to look further into ideas of quality of life and personhood. The biopolitics of organ transplants and medical ethics concerning the boundaries between life and death, which came with the new technology, created a need for a new vocabulary regarding life, living bodies, death and dead bodies. The new vocabulary is an example of the biopower the medical profession needed to establish with the emergence of this new technology. With all this new technology that is almost able to stave off death indefinitely there is one thing that improved technology has not achieved. It has not lessened in our collective fear of death and dying.

3.2 - Death-denial.

The fear of death has plagued humans for a long time, but as natural death became more removed from people's everyday life, violent deaths became a more permanent fixture in their lives. As deaths as a result of illnesses became less likely due to advances in medicine, violent deaths soared proportionately in return. This happened as a result of modernized warfare, concentration camps and gang violence that took the lives of young people in their prime (Gorer, 1995). War has accompanied people since the beginning of ages, but what changed in recent years is that due to technology that brought us photography and war-journalism, the horror of violent deaths was brought to the people. People could see terrible images of the way people died in a brutal manner. Cinematography took this idea and created violent films where heroes and villains died graphic deaths. At the same time deaths were taken out of the homes of people and placed in hospitals and other institutions where family members might not even have been welcome to take part in their loved-ones final hour when they died peaceful hospital deaths (Becker 1995; Veatch, 1989). Thus death became something so far removed from people's lives that irrational fear festered and a new set of problems emerged.

One of the problems that arose when death became medicalized was death denial. People have not come to a mutual understanding on whether death denial is harmful or beneficial. Elisabeth Kübler-Ross classified denial as the first of the five stages of grief, and felt that as such it held an importance as one of the steps that were needed to be taken on the way towards acceptance (Kübler-Ross (1997). Ernest Becker was a cultural anthropologist who wrote extensively about death and death denial as a driving force in people's lives (Becker, 1995). Death denial is considered a tool of terror management which is an idea of Freud's and Kirkegards's. It is a psychological tool people implement in order to push aside their paralyzing fear regarding mortality and perceived irrelevance in the greater scheme of things. Death denial is believed to be a part of the Id's defense mechanisms in the works of Freud. Terror management is seen as evolutionary beneficial since it increased the likelihood that an individual was able to focus on the task ahead rather than focusing on the prospect that a fatality might transpire as a result of imminent threat such as from a predatory animal. Consequently, that individual would be more likely to pass on his/her genetic material on to future children. An individual who fears death would be more likely to find ways to lessen the possibility that he would get killed while hunting or travelling since he/she would not make the same risky choices as an individual who is not fearful or even aware of his own mortality. Despite its benefits, death awareness can be detrimental if it results in paralyzing anxiety that renders the individual unable to gather food or tend to other aspects of life. Abovementioned death denial is a widespread coping mechanisms used to tackle this possible detrimental fear (Arndt and Vess, 2008). Gregory Zilboorg, a psychoanalyst, pointed out that a fear of death was a mechanism of self-preservation since individuals would not go to the same great lengths to maintain life through the means of food-production, food-consumption and reproductions without the constant awareness of life's fragility. Zilboorg also pointed out the transformation our death-awareness goes through in the course of our lifetime. In early childhood there is a complete lack of awareness that consist until the child develops both an understanding that not everything is a constant as well as the understanding of the finality of death. At this time there is often the emergence of a grave fear of death that accompanies awareness. For the child not to become an individual unable to function due to this fear he/she must acquire the skill of blocking out this fear. The most common result is death-denial. However Becker felt this was an oversimplification of children's psych. Incidents that take place in children's lives and how they witness adults deal with those incidents has a far greater influence, making some children overly focused on death, while others lead much more optimistic lives. The core of ideas regarding death-denial is how people go about their

lives seemingly oblivious to their fate and since fear of death can so easily be absorbed and drowned out by the loudness of what occupies our day to day life (Becker, 1995). Dr. Camilla Zimmermann PhD, MD. (2007) a palliative specialist, studied the way the issues of denial and perceived denial were approached by medical professionals in her literature study of clinical literature regarding palliative care. Zimmermann relied on Foucault's "genealogical questions" regarding discourse. Mainly, how discourses are used and what role they play in the society. She studied ideas that were present in medical literature regarding death and denial. Two main themes were identified; Denial as a coping mechanism and denial as an obstacle in palliative care. Within the idea of denial as a coping mechanism, there were three sub-themes; Denial as an unconscious defense mechanism, denial as beneficial, and denial as temporary. In the literature death denial has been seen as an obstacle regarding five aspects of palliative care, which are; open discussion of dying, dying at home, advance care planning, symptom management and stopping 'futile' treatments. Zimmermann points out that labeling a patient or a family-member as death denying can in some cases, be an attempt on behalf of the medical professional to discipline the opposition, mainly the patients and or family. Since they are being seen as a hindrance on the road to the goal which is a "good death", by fashion of Foucault's power of discourse Zimmermann points out that the subject of death as a taboo has replaced sex as a taboo in the recent years (Zimmermann, 2007).

Denial of impending death is not only something a patient does. Medical staffs take part in such behaviors as well since they are no different from other people in the sense that death and discussions of impending death are rarely something people engage in actively or willfully. For that reason a nurse or a doctor often look for clues that a patient understands that he or she might be dying, rather than addressing it specifically. Often nurses will feel unsure whether a patient in fact wants to discuss an impending death. When they do, they are often met with anger from the families of patients who feel as if the nurse and therefore the entire medical staff are giving up on the patient. Studies have shown that many patients encompass an incredible ability to flash cues to the hospital-staff that they do in fact wish to discuss imminent death. At that same time staff often feels the patients are better off not knowing or thinking about it. This type of interaction is referred to as "pretense interaction" (Glaser and Strauss, 1995). Up until the more recent years, doctors would not disclose of terminal diagnoses to patients if it was at all avoidable, because it was seen as detrimental to the patient to know of a fatal diagnosis. In the spirit of paternalistic ideas of the all-knowing doctor, the opinion was that a patient, who was aware of impending death, would lose the will

to live and give up. This was seen as being in line with the Hippocratic Oath, - to avoid harm to the patient. On the other end of the spectrum is the belief that the patient should always be told if her or she has a terminal disease. This is seen as an important part of allowing the patient to best prepare mentally for what is about to happen (Veatch, 1989).

When a situation known as “open awareness” is achieved, all parties involved are aware of the situation. They may however revert back into the pretense interaction at any time for whatever reason. But most often the open awareness allows for a greater understanding of needs and wants of the patient. This is a time when people do in fact “get their affairs in order” since they are not living in denial regarding death. When a patient is able to transcend into open awareness but family members remain in the pretense interaction, open awareness might be regarded negatively by family members. Family members might feel as if the patient has lost the will to live and has given up. Doctors and nurses might even feel the same as the family members since death is often viewed by some medical staff as sign of failure for medicine. Some of the consequences when people stay for an extended time in this state of mutual pretense are that people might miss out on the opportunity to strengthen relationships with family and lose out on valuable time where petty issues are set aside and people focus on what really matters (Glaser and Strauss, 1995). Unlike emergency hospitals where deaths tend to be more acute, deaths that occur in nursing-home settings are more readily expected. That dramatically changes the way in which people, staff and residents alike, view death. People in nursing homes are always aware that death is a constant in their lives. The staff becomes seasoned in dealing with deaths since they witness them regularly and the residents understand that the next person to die could be their friend or neighbor or even them. Thus the awareness is different from that of people working in other medical institutions where death is less present. One could argue that people in nursing homes spend much more time in a state of open awareness and less time pretending they are not dying (Glaser and Strauss, 1995: Guðmundsson, 2000). Jaber F. Gubrium, a sociologist who conducted a field study in a nursing home known in literature as Murray Manor, concluded that the people in his study, staff and residents alike, defined their futures in terms of death. That is not to say they all felt as if they were likely to die the following day. They did however feel like death was a given fact even though the actual timing was uncertain. People at the manor did not really differentiate between death itself and dying although to some extent they viewed actual physical death more positively than the dying process. Dying is often seen as a lengthy event

characterized by pain and suffering. Death then in turn was seen as merciful. An end to the suffering dying brought on (Gubrium, 1995).

From the day we are born, there is only one thing that we can be sure of, and that is that we will all die one day. This information does not seem too comforting to people. In fact rather than accepting it, many people go about their lives denying death's existence. In our society death is hidden in hospitals, diseased family members are made to look like they are sleeping in their caskets and euphemisms are used to describe what has happened. Death is prettified at the same time it is pornified through news and popular culture. Ernest Becker wrote extensively about this tendency of death denial in our society which is believed to have been a part of an evolutionary beneficial coping mechanism called terror management. Elisabeth Kübler-Ross saw denial also as a coping mechanism-stage of grief on the way towards acceptance. Being death-denying in today's society has ceased being beneficial when it prevents people in seeking out palliative care treatment of the fear of what it could mean, and instead continues with futile treatments. Medical professionals are not exempt from being death-denying. In fact they might sway from discussing impending death with a patient out of self-preservation. Even though it might seem as people would be most frightened by the finality of death, what field-work at Murray Manor showed was that people were much more frightened by the process of dying than the death itself. When anthropologists conduct field-work in hospitals, nursing-homes and hospices, the information that is produced can give great insight into the world of death and dying, and the views that shape our opinions regarding these matters.

3.3 - Death in action

Several field studies have been done in the field of palliative care. The British anthropologist, Julia Lawton (2000) conducted her research at an unspecified Hospice-ward in Britain during the 1990's. At the beginning of her book, *The dying process*, where she publishes the results of her field-work, she says that the book is an attempt to get people to think about their "Westernized self" by conducting a research on the experiences of people during the weeks and months leading up to their deaths or the deaths of their loved ones. This is done by looking at how far the physical self reaches, since as it is with other sciences, the best way to understand how things function, is to look into their absences. The main focus of the research was to examine the way patients experienced their personal "self", their body, time, locale and

the changes they underwent from diagnosis until they died as a result of their disease. Lawton also studied what effect physical deterioration had, not only on the patient but also on the family-members and care-givers. The Hospice-ward where the research took place was separated into two parts so Lawton did the same with her research. First there was an outpatient day-clinic, where people came and spent their days early in the disease. At the day-clinic, patients received treatment to combat easily treatable symptoms as well as receiving mental stimulation. There was grief-counseling, art therapy and the simple mental benefits of being around people in similar situation where instead of being the ailing family-member or friend, they were able to be individuals first and foremost. The inpatient-care-facility closely resembled a hospital-ward. The patients came there for symptom management such as pain-relief, wound-care and other more specialized treatment. The inpatient-part of the hospice was also the place where many patients drew their last breath. At the in-patient portion of the hospice, Lawton witnessed what she referred to as “dirty dying”. Dirty dying was when the dying body could not be controlled due to the symptoms of the fatal illness and the symptoms became too much for the medical staff to manage. The uncontrollable body was sometimes brought under control, not for the well-being of the patient, but for the emotional well-being of the families. Patients were sometimes put into medical induced comas even though it was not evident if they were in fact suffering, but because their symptoms caused bystanders mental anguish (Lawton, 2000).

The medical anthropologist Sharon R. Kaufman (2005) conducted a different kind of research. Kaufman did her work at an emergency hospital in the United States. Her book *“...And a time to die – How American hospitals shape the end of life”* details the study. Largest portion of her work took place in an intensive-care-unit (ICU), and the aim was as the title of book indicates, to look at the way in which different professions at the hospital affect and shape the end of life of patients who receive treatment there. Insurance-companies influence health-care in America greatly, since they require detailed treatment-plans and diagnoses in order to put a price-tag on services provided. Therefore, doctors and other staff are under pressure to provide certain treatment and to make sure patients move along a procession of sorts. Most often the ultimate treatment goal is a cure.

Kaufman did not miss out on witnessing the dissimilar attitudes doctors, nurses and family-members had towards treatment-options and what medical interventions should be applied. Ideas about when treatment should be stopped varied considerably, and contrary to popular belief, it weren't always the family members who pushed for treatments that delayed

inevitable deaths. The doctors seemed particularly threatened by possible law-suits at the hands of family which made them often opt for more aggressive treatment options. Power is an intricate subject and it was very evident in Kaufman's book. Insurance-companies have the power to decide whether a patient undergoes a particular treatment. Hospital officials have the power to pressure doctors into making sure a patient doesn't stay in the hospital without a treatment-plan that translates into billable hours. The doctors had power regarding knowledge about ailments and progress. Family-members and patients alike, had the power to decide if doctors should discontinue treatment, but patients were often in the situation where they lost power over their body into the hands of disease (Kaufman, 2005).

Hospitals often exercise great power over the type of end-of-life-plan that is made available to patients. Other times the power exercised is that of the illness itself. The place where a person draws his or her last breath can greatly influence the way death happens. Hospice-units differ greatly from Intensive Care Units (ICU's), since the role of hospice is to provide comfort-care without hastening or prolonging death, whereas ICU's have a main goal is to keep an individual alive. There are more components that affect a person's attitude towards their exit from this world, than hospitals and hospice-units.

3.4 - Culture and dying

Culture shapes people in multiple ways and health is an imperative part of people's lives. Attitudes regarding the kind of medical initiative, a person chooses depend highly on that person's cultural background. Studies show that different groups of people have multiple attitudes toward medical practices and that these views should be addressed in order to bring about a greater quality of care (Lupton, 2012). In the ever-increasing diversity of cultures we are faced with in our multicultural societies, it is pivotal to think about our own ethnocentrism and attempt to understand different cultures as well. Someone might think that since death is a universal occurrence, that there wouldn't be so much of a difference in our attitudes towards it. Nothing could be further from the truth. This was a problem understood by Australian health-officials. In 1999 Palliative Care Australia produced a book, funded by the Commonwealth and Department of Health and Age Care, named *Multicultural Palliative Care Guidelines* (1999). The book listed cultural attitudes and traditions, regarding death and dying among the most common groups of people of non-English speaking backgrounds. A disclaimer at the beginning states that the book is only a guideline and not meant to be

stereotype-producing. The authors stress the importance that each family is different and that two individuals can vary greatly, despite having the same cultural background. There is a great emphasis placed on the importance that the healthcare provider approaches each scenario without preconceived notions of the people he or she will be working with. Initially the project was simply meant for updating information in one part of Australia. However, after some investigation the researchers came to the realization that this project needed to be taken nationwide. Study showed that while community awareness in Australia, of the existence of palliative care, was 52% overall, it dropped to 37% among Australians born outside Australia. Additionally they found that of the 3,000,000 Australians who spoke languages other than English at home, 17% had little or no proficiency in English. There was great need for culturally sensitive, accessible information on palliative care for this large group. Furthermore there was a need for accessible information for the professionals who were likely to come into contact with these groups of people and whose job performance depended on the ability to approach the sick and the families in the most culturally sensitive way. By reason of an individual's own ethnocentrism he or she often overlooks the cultural differences in practices regarding death and dying. Not because of some malice intent, but simply due to the fact that people are often not aware of their own culture and belief-systems until they are faced with opposing ideas. The information contained in the book includes difference in attitudes regarding approaching the subject of impending death. Among the diverse cultural-groups that inhabit Australia, the attitudes can vary greatly. There can be certain rules regarding, who is to be addressed when it comes to discussions on the medical needs of an ailing family or community member. In some cultures, the oldest son is expected to be in charge, whereas in others, the oldest daughters is in charge of issues pertaining health and family, and sometimes even, it is the youngest daughter who is supposed to be the medical proxy concerning these issues. Even though there are often strong rules regarding who is permitted to talk to about health and matters of death on behalf of the family, there is sometimes an issue of who does the talking. The professional must be aware of attitudes regarding gender or professional position. In some cultures women should not talk to men in an authoritative manner or from a position of power, other times it is considered improper for men to discuss female anatomy of bodily functions as is sometimes needed in these situations. A female doctor or a male nurse could sometimes pose a problem in cultures due to strong gender-roles. Who is allowed to bring up death in the conversation? In some cultures it can be seen as "actively bringing about death" to simply discuss it. Different cultures can also have dissimilar attitudes as regards to where treatment takes place, such as hospitals, hospice units,

senior care facilities or at home. There can be variations pertaining to views on pain management as well. For instance in many cultures, such as Bosnian, Greek and Chinese, administration of morphine is seen as a sign that death is approaching, so there might be some apprehensions and in some cases, reluctance regarding pain management via morphine. When treating Jewish, Muslim or Hindu people, it needs to be taken into consideration if the drugs used are made using or might contain some animal products prohibited by these faiths. There does not seem to be a great cultural variation with regards to taboo-words. Cancer, death and dying are the most common taboo-words mentioned in the book. For people of many cultures, the word cancer is synonymous with death, so it is often avoided in general discussions, sometimes replaced by terms such as “that disease” and “the terrible illness” (Taylor and Box, 1999).

In times of hardship, most people seek solace in the in the arms of their families and the familiar. Traditions become very important as does knowing that you are understood. We often do not realize how greatly our culture shapes us. In today’s world of multiculturalism and vanishing borders, people often find themselves living and residing in countries where they are not from, originally. Therefore it is crucial that people who work in the field of palliative medicine are aware of the cultural differences that can exist in the communities they service. Palliative Care Australia realized this and published a guide for people in the field. The guide contained notes on customs and traditions regarding issues of death, dying and terminal illness.

Conclusion

Diseases and illnesses strip people of their power in many more ways than by ending their life. Prior to the time of death, a disease such as cancer, has often negatively affected the person’s quality of life profoundly. The person might have had to limit his or her life to the confinements of a wheel chair and or a medical institution of some sort. Communication and interactions with family and friends often change as a person is now dependent on people he or she might have taken care of at a previous time. In this paper I have been looking into the reason why palliative care is not a standard care for people with life-threatening illnesses.

Palliative hospice care began as a brain-child of Dame Cicely Saunders, who founded St Christopher’s hospice in England in the 1960’s. Coupled with increased public awareness for

the mental needs of terminal patients as a result of the revolutionary work of Elisabeth Kübler-Ross, there was a great change in the way these patients were being treated. Another change came about in 1980 when Dr. Jan Stjernesvärd became the head of the Cancer Unit of the World Health Organization (WHO). Stjernesvärd decided that greater effort should be put into symptom management and treatment of the largely overlooked patient population that was terminal cancer patients, and a research-panel was established. The AIDS-epidemic was also unfolding at this time and there was yet little anyone could do for those patients. Additionally there was an increasing population of people with degenerative diseases like ALS and MS. Interest in the matter increased and more and more hospices were being built. The idea is that meticulous pain management is the most humane and sensible treatment option when cure is unavailable or unachievable. As recognition grew, so did Medicare's understanding and appreciation of the ideology which brought about greater awareness which has made more and more people look into palliative care as a treatment option. Professionals of other fields besides oncology and neuropathy have since started taking greater interest and begun considering palliative care as an option alongside curative treatment options. Public acceptance of palliative and hospice care has been affected by culture. Interestingly people from cultural backgrounds that tend to favor great familial involvement are often the ones that seem most reluctant to discuss palliative care, since they feel that by doing so they could be hastening death by acknowledging it.

Seeing as such a large part of life-threatening illnesses has to do with losing power, it is beneficial to look at power and how it can play out within an illness. Michel Foucault coined the term biopower. Biopower is the ability of those with power of discourse to create and control access to information regarding knowledge of for instance, medicine, health, illnesses and treatment options. By governing through biopolitics, those in charge have a great deal of power to decide what is normal and what is pathological. Technological initiatives have changed the old view of what death is, when it happens and how it happens. Drawing from Latour's ideas this rift between actual normalcy of death and the perceived unnaturalness of death is an example of when life becomes separate from life sciences. This has created a great deal of anxiety related to death and dying, for many people. This rift between the death that is published in movies and the news, and the normalcy of death, is something that needs to be addressed. Given how popular culture portrays palliative care, as solely hospice care for the soon-to-be dying, and only individuals ravaged by certain diseases, it is understandable that people are not eager to consider palliative care. With innovative medical inventions that have

the ability to take on almost all tasks of the body the time has come to take a greater look at what it is that we want medicine to do for us. Whether it is popular culture, government officials trained under the medical model of never giving up or some other power-players, biopower is being employed in an extremely life-affirming way, making it seem as if great emphasis on palliative care is the same as making a case for death.

Why is palliative care not the standard care for people with life-threatening illnesses? I believe it is because we live in a death-denying society that will try almost anything to keep death hidden in the hope that by doing so, we will not have to deal with it. The medical industry has begun to see death as a sign of failure of their part, which plays right into our death-denying hands. . Many people shy away from the idea of palliative care because they believe that palliative care and hospice care are one and the same thing, and that palliative care should only be put into practice, when there is a certainty that a cure is not possible. In other words, if it is evident that you will not survive, then you can look into that treatment option. As evident by the writings of Hammes et.al., palliative care is not simply for terminal cancer-patient. Perhaps, this information is what is missing from public discourse. It is my experience that people are not sure about the difference between hospice care and palliative care. The terms are often mistaken for each other, and used interchangeable. Even among people in the healthcare industry, have I discovered that there is a confusion regarding palliative- and hospice-care. Even to the point where people will be talking about hospice care or end-of-life care but use the term palliative. I have a feeling things are changing regarding death being such a topic of taboo, and that in a few years we will be talking as freely about death, dying and our wishes regarding death as we now discuss the previously big taboo of sex. While things remain this way, it is understandable that people are not keen on giving palliative treatment a chance when they see it as quitting or giving up. I feel in order to make more people aware of the benefits offered by palliative care, medical-professionals need to take a greater responsibility in presenting these options and exercise their powers of discourse in favor of palliative care and quality of life. We need open up the dialog regarding our exits from this world, the options we have and how we intent to achieve our wishes.

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