

**THE DEATH OF THE FEAR OF DEATH; *IMAGINING DEATH*
ABSENT FROM FEAR AND MEDICALIZATION THROUGH
*HOLISTIC APPROACH***

BY

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Abstract

This paper examines how western society has managed death within the 20th and 21st century and how this management has affected our death and dying experiences. While the majority of western society wishes to die at home, more than half of Americans continue to die in a medical setting. By implementing a holistic approach to death and dying within the medical as well as encouraging honest conversation surrounding death and end of life experience, a “good death” can be achievable for westerners. Using secondary analysis, a literature review is conducted and broken up into three chapters focusing on the medicalization of death, the hospice and palliative care movement, and achieving a “good death” through a holistic approach. Reflecting on the collected secondary data, this paper analyses how medicalization has stripped an individual of their ability to achieved a good death and thus, an incorporation of holistic principles in death and dying are needed. This paper concludes with illustrating the importance of *The Death Positive Movement*, *The Conversation Project* and Death Cafes which work to encourage the acceptance of one’s mortality and ultimately alleviate the fear of death.

Keywords: “Good death”, “Medicalization”, “Medicalization of Death”, “Death and Agency”, “Fear of Death”, “Fear and Dying”, “Holistic Death”, “Palliative Care”, “Hospice Care”, “Death Positive”

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Introduction

What do you see, nurses, what do you see? Are you thinking, when you look at me —
 A crabby old woman, not very wise, Uncertain of habit, with faraway eyes,
 Who dribbles her food and makes no reply, When you say in a loud voice — “I do wish you’d try.”
 Who seems not to notice the things that you do, And forever is losing a stocking or shoe,
 Who unresisting or not, lets you do as you will, With bathing and feeding, the long day to fill.
 Is that what you’re thinking, is that what you see? Then open your eyes, nurse, you’re looking at ME...
 I’ll tell you who I am, as I sit here so still; As I rise at your bidding, as I eat at your will.
 I’m a small child of ten with a father and mother, Brothers and sisters, who love one another,
 A young girl of sixteen with wings on her feet. Dreaming that soon now a lover she’ll meet;
 A bride soon at twenty — my heart gives a leap, Remembering the vows that I promised to keep;
 At twenty-five now I have young of my own, Who need me to build a secure, happy home;
 A woman of thirty, my young now grow fast, Bound to each other with ties that should last;
 At forty, my young sons have grown and are gone, But my man’s beside me to see I don’t mourn;
 At fifty once more babies play ’round my knee, Again we know children, my loved one and me.
 Dark days are upon me, my husband is dead, I look at the future, I shudder with dread,
 For my young are all rearing young of their own, And I think of the years and the love that I’ve known;
 I’m an old woman now and nature is cruel — ‘Tis her jest to make old age look like a fool.
 The body is crumbled, grace and vigor depart, There is now a stone where once I had a heart,
 But inside this old carcass a young girl still dwells, And now and again my battered heart swells.
 I remember the joys, I remember the pain, And I’m loving and living life over again,
 I think of the years, all too few — gone too fast, And accept the stark fact that nothing can last —
 So I open your eyes, nurses, open and see, Not a crabby old woman, look closer, nurses — see ME!

This infamous poem was written by a nurse in a nursing home in order to convey the feelings of a dying elderly woman. The poem has been used for decades to represent the experience of many elderly and dying individuals and spark empathy (“A Crabby Old Woman”,

2016). In the words of this poem, we see an individual crying out for respect and a consideration for their “wholeness” - mind, body and soul. But unfortunately, because of the ways in which the western world has “managed” and conceptualized death, this is not always the reality of a dying person's’ experience. In the western world, our shared fear of death has constructed a medicalized “management” of the aging body and death. Many scholars (Kübler-Ross, 1969., Howarth, 2007., Conrad, 2007., Lock, 2004., Aries, 1974., Robbins, 2011) have written extensively on western dealings with death and dying as well as the medicalization of death. The effects of medicalizing death have resulted in depriving an individual of a “good death” by conceptualizing death as a singular event that requires medical intervention rather than a continuing social process. Through a holistic approach to death and the dying process which includes palliative and hospice care an individual can alleviate fears related to death and reclaim their autonomy in death, free from the medical gaze. Thus, we need to reconstruct our approach to death and death management. This paper argues that the medicalization of death has prevented westerners from achieving their own notion of a “good death” and the importance of integrating a holistic approach to a dying individual in order for a good death to be achieved. It then argues that the information to this said approach of “holism” is still inaccessible to many groups and in order for a “good death” for all to be carried out, access to this knowledge needs to be implemented. I will begin the scope of this paper with a review of the literature presenting how death has been and is currently managed in the West in the 21st century under the guise of medicine. I will then talk about the notion of a “good death” and the idea of approaching death through a holistic lens and the benefits of this outlook. From there, an introduction to the birth of the hospice and palliative care movement which works to incorporate a holistic approach to

dying. In my analysis/conclusion, I will then connect the idea that because the notion of a good death is aligned with the practice of holistic care that we see in a hospice and palliative approach, it is necessary that western society implements holism into the medical sphere. Finally, I will conclude with discussing death activism and the importance of an honest dialogue regarding death, dying and end of life wishes.

Thesis Statement and Research Questions

The thesis statement for this paper is as follows; In the Western world, our shared fear of death has constructed a medicalized “management” of the aging body and death. The effects of medicalizing death have resulted in depriving an individual of a “good death” by conceptualizing death as a singular event that requires medical intervention rather than a continuing social process. Through a holistic approach to death and the dying process which includes palliative and hospice care, an individual can alleviate fears related to death and reclaim their autonomy in death free from the medical gaze.

This paper was structured around answering the following research questions:

1. How has death been “managed” in 20th and 21st century west?
2. What is the medicalization of death?
3. What does the holistic movement toward death consist of, look like, and advocate for?
4. What is a “good death?”

Methodology

The literature review and analysis are structured around the methodology of secondary analysis. In her book *Secondary Analysis in Social Research*, sociologist Catherine Hakim defines secondary analysis as “any further analysis of an existing dataset which presents interpretations, conclusions or knowledge additional to, or different from, those presented in the first report on the inquiry as a whole and its main results” (Hakim, 1982, 1). Secondary analysis involves formulating research around specific research questions then gathering the pre-existing data to answer, explain and analyze such questions. Research was gathered through the Purchase College Library discovery search which led to several databases and peer reviewed journals. The key words used in this research were as follows: “Good death”, “Medicalization”, “Medicalization of Death”, “Death and Agency”, “Fear of Death”, “Fear and Dying”, “Holistic Death”, “Palliative Care”, “Hospice Care”, and “Death Positive”. By using these keywords listed, the scope of the research was narrowed to fit the needs of the topic. For this particular topic, mostly peer-reviewed journals (academic journals) and scholarly papers/articles were reviewed and analyzed.

To integrate the data found, a literature review describing the research that has already been conducted on the topic was composed. The literature review revolves around the ways in which western society has managed death. Specifically, three chapters were created within the review. The first chapter is titled *Medicalization of Death* which describes how the medical gaze has affected the way in which we handle and manage death in western society. Chapter two is titled *Alternative Approach* and details the beginning of the hospice movement as a response to the medicalization of death. Lastly, the review ends highlighting the success of a holistic

approach to death and its connection to the concept of a “good death” with the chapter *Holistic Care and a “Good Death”*.

After thoroughly describing and contextualizing the main research topics of medicalization, hospice care and holistic approach to death in the literature review, the ways in which medicalization has stunted western society from achieving a “good death” were analyzed. Then follows a discussion on how holistic methods and ideas in death are necessary in order for western society to experience a fulfilling and meaningful “good death”. For the concluding analyses, discuss death activism, from *The Death Positive Movement* to *The Conversation Project* and Death Cafes, and highlight the importance of prioritising the conversation of death is discussed.

Literature Review

Medicalization of Death

In order to illustrate how death has become medicalized, it is first important to define the term “medicalization.” Many scholars and academics have defined and redefined “medicalization” which essentially refers to introducing what was not organically medical into the medical field. The definition for this paper that I will be directly referring to comes from Conrad’s “Medicalization and Social Control” and defines medicalization as “a process by which nonmedical problems becomed defined and treated as medical problems, usually in terms of illnesses or disorders.” (Conrad, 1992, 209). In the following paragraphs, I will talk about the evolution of the dying experience in the west and how scholars theorize this change.

Writing in the 2004 *Encyclopedia of Medical Anthropology*, medical anthropologist Margaret Lock theorizes the catalyst(s) of medicalization. Lock explains that anthropologists and sociologists pinpoint the beginning of medicalization to western modernization which is to be understood as the development and application of science and technology to aspects of daily life beginning in the 17th century (Lock, 2004). Glennys Howarth explains that this shift was a replacement of common religious doctrine which used to dominate societies political, social, and economic spheres, with a more scientific or secular approach to death and dying (Howarth, 2007). Howarth explains that this was a result of “doctor’s replacing priests at the deathbed” (Howarth, 2007, 121) and as a result, has pathologized death as a “scientific problem that might be ‘solved’ by appropriate intervention and medical technology” (Howarth, 2007, 121). Peter Conrad further supports Howarth’s proposition of a shift in the dispositions and spirituality of the western people writing “Analysts have long pointed to social factors that have encouraged or abetted medicalization: the diminution of religion; an abiding faith in science, rationality, and progress; the increased prestige and power of the medical profession; the American penchant for individual and technological solutions to problems; and a general humanitarian trend in Western societies.” (Conrad, 2007, 8).

As we moved from primitive society and advanced so too did our experience of death, both from the perspective of the “dyer” and of the family. This change paired with the now dominant culture norm of approaching death through valuing science and doctors over priests and spirituality, also perpetuated the the treatment of death through the guise of the medical. In his pivotal work, historian Philippe Aries penned *Western Attitudes Towards Death* which chronicles and theorizes the shift in this cultural view, dealing and perception of death in the

west. Aries begins his writing divulging between 'tame' and 'wild' death, tame referring to pre-modern times where death was calm, public (in that it happened in front of others thus encouraged others to be familiar with death and think of their own), "ceremonious" where death was absent from "theatrics" and the dead and the living had a higher degree of coexistence. Wild referring to modern times where death essentially encompasses the opposite of the defined tame death. In regards to the medicalization of death, Aries expands on how the change in the culture of death has affected the family and death, our dealings of the dead body itself and the internalization of the notion of dying. The above has lead to another important transformation of death, the "site of death, from the home to the hospital" (Aries, 1974, 87). To reiterate this idea further, Aries writes "death is a technical phenomenon obtained by a cessation of care, a cessation determined in a more or less avowed way by a decision of the doctor and the hospital team...Death has been dissected, cut to bits by a series of little steps, which finally makes it impossible to know which step was the real death, the one in which consciousness was lost, or the one in which breathing stopped" (Aries, 1974 , 88).

Expanding on the idea of a "tame" and "wild" death psychiatrist Elisabeth Kübler-Ross theorizes her own version of "tame" and "wild" through the lens of her childhood upbringing and death as well as the dealings of sick and dying bodies in her book *On Death and Dying*. Kübler-Ross explains how the "dyer" is removed from their own dying process when thrown into the lonely, frantic state of a hospital- from the process of arriving their in a loud, rushing ambulance to the experience of being poked and prodded and having a multitude of tests and procedures done without clear understanding of the entire process (Kübler-Ross, 1969). It is within this unknowing and unseen process of death where we are then able to conceptualize

death as an event beyond our individual body in this “unknown” fear is born. It is not something we go through and experience but yet something that “happens” to us.

Kübler-Ross also details how her experience growing up in a European country influenced her understanding of death by describing the experience of a neighboring farmer’s dying process which included him dying at home and spending his last few days being visited by family member and friends. Kübler-Ross, although a child, was as much involved in the dying and mourning process as any adult and visited the farmer and compares the grooming of Western embalmed corpses, which are highly manicured and falsely presented as “sleeping” to that of the farmer’s body, which was untouched, uncovered and laid in his home for final goodbyes. She writes “The fact that children are allowed to stay at home where a fatality has struck and are included in the talk, discussions, and fears, gives them the feeling that they are not alone in grief and offers them the comfort of shared responsibility and shared mourning. It prepares them gradually and helps them to view death as part of life, an experience that may help them to grow and mature.” (Kübler-Ross, 1969, 6).

As a result of this “modern” cultural shift towards a fascination and dependence on technology and science, human health was largely affected by these advancements. Margaret Lock explains, “health came to be understood by numerous physicians and by the emerging middle classes alike as a commodity, and the physical body as something that could be improved upon. At the same time, legitimized through state support, the consolidation of medicine as a profession was taking place, together with the formation of medical specialties and the systematic accumulation, compilation, and distribution of new medical knowledge (Lock, 2004,

116-117).” Lock goes on to further describe how this “medicalized” view of life began to leech into daily routine, for example, individuals beginning to receive medical training for what was so long a “home” even, birth giving, which gave way to a whole new sect of medical speciality, obstetrician (Lock, 2004). Drawing comparisons to Michel Foucault’s idea of “governmentality” which describes the notion of government’s total power over its people, categorizing a multitude of daily experience as “medical” work “to regulate the health and moral behavior of entire populations” (Lock, 2004, 117) thus, essentially giving the government more power over it’s governed.

This medical definition and management of death is not only evident through our social, cultural and scientific societal changes but is also perpetuated through medical practices as well as medical discourse and education. Psychologist Brent Robbins of Point Park University, uses evidence to examine this notion of how medicine and medical education has perpetuated the “denial of death” (Robbins, 2011). Because medical professionals are constantly witnessing death and dying, they, even more so than the laymen, have in turn developed advanced psychological techniques to cope with the inevitability of death (Robbins, 2011). Robbins contextualizes this argument by explaining that in order for medical professionals to be able to continue their daily prejectories absent from constant emotional attachment and distress, their training teaches them to view death through a “concretization” (Robbins, 2011) which he defines as “a form of physiological reductionism which confines the meaning of death to that of mechanical malfunction of the anatomical body. Such a reductionism conceals the existential reality of death as the loss of the possibility for embodied being-in-the-world.” (Robbins, 2011, 134) Through this compartmentalization, death is conceptualized as an “event” rather than a

process, allowing removal of the existential from death thus, continuing the denial of the true experience of death for the individual (Robbins, 2011). To further examine the fueling of medicalized death via medical education and principles, Philip Fung and Miguel Paniagua studied the education and training of doctors. and Paniagua and Fung explain that the development of “life-sustaining technologies” such as artificial organs and oxygen ventilators to revive for those whose biological organs fail have transformed the ways in which we as a society view healthcare as a whole- specifically, what is and isn’t “successful” (Paniagua and Fung, 2016). Relating to death and dying, Fung and Paniagua have translated these advancements to influencing the now common perspective both in the medical field and amongst the laymen of “death as failure” (Paniagua and Fung, 2016, 12). Expanding on death as failure, Fung and Paniagua write “A pervasive attitude exists in medicine as an institution (and it is stronger in certain medical or surgical specialties than others) that for a patient to die is for the physician to have failed” (Paniagua and Fung, 2016, 12) [and therefore,] “Death is not anticipated or embraced as a part of the human experience, but it is seen as an enemy to struggle against and hopefully defeat” (Paniagua and Fung, 2016, 12). Fung and Paniagua describe how the perpetuation of death as a pathological problem with measurable rates of “success” or “failure has also had deep affects on the way in which culture, patients and their families believe death should be carried out. Death has not “failed” if the person is still alive, even if that life is completely sustained by medical intervention(s) and this has lead to popular belief that all medical intervention that can be done (in order for “success) should be done, regardless of whether or not such intervention is worth it or even wanted. As Fung and Paniagua point out, this

has lead to an alarming precedent in our medical system and the ways in which we think about death.

With the above representing the ways in which the medical has permeated throughout our culture as well as in the medical education and discourse itself, it's important to represent statistical information about the outplay of medicalization's role in death and death management. Dr. F. Amos Bailey and Dr. Vyjeyanthi (VJ) Periyako, director of the Stanford/VA Palliative Care, study Home/ Home Hospice: Home Care of the Dying Patient investigated Americans actual wishes when it comes to end of life care and the reality. Bailey and Periyakoil examine the requirements or "admission criteria" in order to receive home hospice care, the benefits of home/home hospice care, discrepancies in the healthcare system that allow for these wishes (or admission entirely) not to be carried out such as physician's error in recommending patients to hospice or dying at home care. Their study, issued by Stanford School of Medicine, shows that although 80% of Americans wish to die in their own homes, only 20% actually do (Baily, Periyakoil, 2013) . The other 60% die in hospital settings (i.e. hospitals, nursing homes etc). Coinciding with the Baily and Periyakoi study, Broad et. el confirmed that although the majority of people prefer the site of death to be the private home, the reporting shows individual wishes are not always aligned. Surveying the existing published reports and surveys, Broad et. al examined the location of death globally in regards to percentages in hospitals, residential care and other ("including private home") (Broad et. al, 2013). Specifically, in the United states, 47% of people die in a hospital and 22% in residential aged care (Broad et. al, 2013, 260). That's almost 70% of people dying in an institution, which compared to the Stanford study where 80%

of Americans prefer to die at home, death site ratio is out of proportion. Clearly, the medicalization at play does not allow for an individuals' end of life care wishes to align with what actually becomes their end of life reality.

Alternative Approach

Individuals' concern of the degree of medicalization of death was steadily increasing. As a response to this growing medicalization of death, more and more people were becoming aware of the extent to which the medical influenced death and death management. They began to feel their death and dying bodies were falling short of the experience they wanted their death and death care to emulate. As a result, the hospice and holistic movement was born.

David Clark explores the important timeline and reasons leading up to the birth of the hospice movement from 1948-1967 in Britain. Although the establishment of the National Health Service (NHS) in Britain was supposed to attend to care for the individual from "cradle to grave", attention to terminal care or end of life care seemed scarce (Clark, 1999). Through a review of surveys and studies at the time, the social conditions and care for the dying were inadequate, "often delivered by nuns and untrained nurses, and medical involvement was limited" (Clark, 1999, 238) and unguided, mainly occurring in religious or charity homes was (Clark, 1999).

Though, approaching the 1960s when a shift in the medical discourse about end of life care prompted provisions on terminal care of the dying, the key reformers of end of life care began to synthesize their ideas on caring for the dying and the modern hospice movement began its momentum (Clark 1999). Clark explains that there was a “growing clinical interest in questions of terminal care which served slowly to draw further attention to the needs of those in the final stages of life” (Clark, 1999, 231). Specifically in the US hospice movement, Stephen Connor points out the need/want for this new approach to death and dying and writes, “this reflected a number of U.S. factors including a desire for independence, a distrust of medical institutions, and a lack of resources for non-profit hospices operating outside mainstream medicine” (Connor, 2007, 90). Connor explains that the adoption of hospice within the US during the 70’s illustrates a larger theme that was permeating in the US- one of questioning social constructs and institutions as well as the desire for autonomy-an idea within the foundation of the hospice principles (Connor, 2007). Connor explains that “early pioneers in hospice care also included many physicians who, like their other professional colleagues, shared a concern for how the health care system was caring—or more accurately, not caring—for the dying” (Connor, 2007, 90).

One individual that was particularly inspired by this shift in the medical was Cicely Saunders. Through her work, Saunders essentially formulated the basis of an alternative care approach to death and it’s principles. Over the course of a decade working as a volunteer in several early model hospice homes (mainly in charitable and religious homes), Saunders was able to keep critical notes and observations about the successes and negatives of each facility,

ultimately leading to her inspiration to implement her own hospice program/home. When Cicely proposed her own home, based off of her observations on what was needed, specifically, catering her approach to care around this concept Saunders' essentially copywrote of "total pain" as Clark describes" is taken to include physical symptoms, mental distress, social problems and emotional difficulties" (Clark, 1999, 234). There would be 3 crucial elements to be enacted as the foundation for the modern hospice movement. Clark synthesizes Saunders' vision and writes "First, there would be the delivery of high quality terminal care, the "total care" to which she had referred in her writings, which would encompass physical, social, psychological and spiritual dimensions. Second, there would be an emphasis upon teaching in this developing area of work, so St. Christopher's would be a centre for education, not just of doctors and nurses, but also for social workers, chaplains, volunteers and others. Third, it would be a place for research into pain and symptom control and into the wider view of terminal care which was emerging." (Clark, 1999, 240-241)

With the principles laid out by Saunders' work and the notion of addressing "total pain", the hospice movement began to spread and, to manage "total pain" a holistic approach to dying bodies was adopted throughout the west. Individuals now had options to explore in terms of their terminal care and death experience and the hospice movement and its principles were instrumental in providing such options and knowledge for people. The National Hospice and Palliative Care Organization explain that their approach to long term illness and death does not revolve around *cure* but rather *care*. NHPCO defines hospice care as "compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to

expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so” (National Hospice and Palliative Care Organization, 2019). By this definition and the rest of the description on the website, Hospice care emphasizes including other social resources in the individuals’ life, such as family, friends, religious leaders, doctors etc, to be apart of the hospice process as much as possible. Hospice will guide the individual’s social network in pain management and care for the individual that is aligned with the recipient's wishes, provide support beyond the physical, regarding the emotional and spiritual experience(s) of the recipient and also provide counseling and support for the social network of the individual during the process as well as if the individual dies in hospice (National Hospice and Palliative Care Organization, 2019). In *Palliative care* vol. 10, Pippa Hawley further expands the principles of hospice and palliative care by describing the core values as follows; “1. meticulous prevention and management of symptoms, including pain; 2. excellence in communication, in discussion of goals of care and advance care planning; and 3. an extra layer of support for practical needs, particularly with respect to care provided at the patient’s home.” (Hawley, 2017). The difference of Palliative care and hospice is that Palliative care specifically focuses on medical intervention to ease pain and Hawley explains that palliative pain management can be received by any individual alongside their other medical treatments as well that are more specific to the sufferer’s condition (Hawley, 2017). Though, as Hawley’s article explains, although studies have shown that palliative care improves the “quality of life” of patients suffering or dying from medical

conditions, there are numerous factors at play that inhibit universal access to palliative care.

“Nearly one-third of US hospitals with more than 50 beds do not have any palliative care service” (Hawley, 2017) and Hawley attributes this disparity to five underlying problems defined as follows; “resource availability, ignorance and lack of awareness of resources, referrer reluctance, patient and family reluctance, and restrictive program eligibility” (Hawley, 2017).

Holistic Care and a “Good Death”

Noting the introduction as to what exactly hospice and alternative care is as outlined above, what will now be explored is the positive effects of the holistic approach to dying that hospice and alternative care advocate for and how these approaches are related to the notion of a “good death”.

In the *Journal of the Multinational Association of Supportive Care in Cancer* vol. 23, John Cagle defines a good death as follows; “A good death generally consists of: good pain and symptom management; clear decision-making; respect for one's personhood; trust in health care providers; a sense of closure, completion or preparedness; minimizing family burden; being able to contribute to others; and maintaining control” (Cagle et al., 2014, 2). Expanding on Cagle et al.'s characterizations of a good death, in Steinhauser et. al.'s study they confirm the fundamentals of a good death through their interviews of dying patients, their family members and their caregivers/physicians. They conclude that these good death truths are “pain and symptom

management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person” (Steinhauser et al., 2000, 185).

Following Cagle’s definition of a good death and the principles of hospice/holistic care already previously discussed, these next studies mentioned will illustrate how the fundamentals of holistic care and a good death align.

Cagle et al. conducted a national survey to determine the role hospice care had in carrying out a good death for cancer patients. Cagle et al. define similarities between the concept of a good death and an overall holistic approach to care are clearly present which is why Cagle et al. wanted to further investigate how holistic care such as hospice care affected a patient and family’s overall perception of a good death- and whether or not they hospice care aided a good death. What the study found was that empathetic care carried out by hospice was a positive contributor to a good death in that it enhanced the quality of life of the individual (Cagle et al., 2014). Cagle et al. found that the family oriented model and the prioritization of patient’s wishes as well as “attention to non-medical factors” (Cagle et al., 2014, 8) that hospice care perpetuates had an overall more positive contribution to an individual's “good death” than an alternative approach of highly medicalized and institutionalized intervention. Similar to Cagle, Zamanzadeh et al. describe the philosophy and importance of a holistic approach to medical care in order to achieve the experience of a good death. In their study, Zamanzadeh et al. discuss how holistic care not only centers around the patient’s needs, both biological and metaphysical but includes the patient as an integral part of the medical decision making (Zamanzadeh, et al., 2015). By

considering an individual's entire being and going beyond just treating the symptoms, their argument is that a holistic approach maintains and advocates for an individual's autonomy and dignity in their medical (and dying) experience. Zamanzadeh, et al. write, "providers of holistic care consider a patient as a whole within his/her environment and realize that a patient is made up of a body, mind, and spirit. Respecting the patient's role in the treatment process, having him/her take part in the process and encouraging self-care is another aspect of holistic care which leads to therapeutic consultation, hope, dignity, self-discipline, social growth, a sense of autonomy, vigor, and vitality" (Zamanzadeh, et al., 2015, 214). Thus, when the foundational truths of a good death are considered throughout the patient's care, a good death is able to be achieved by the patient.

Studies comparing the quality of life and achievement of good death between patients who enroll in hospice care vs. those who did not have also been conducted to illustrate the ways in which a holistic approach improves the dying experience. Looking in over 800 nursing homes, Miller et al. 2002 examined the differences of utilizing analgesic pain medications between residents who were enrolled in hospice and residents who were not and whether or not hospice intervention better delivered pain management through the administration of analgesics. The study found that nursing home residents that were enrolled in hospice were more likely to receive analgesics, receive analgesics that were stronger, such as opioids, than those not enrolled in hospice, and receive analgesics beyond, received analgesics simply as needed (not excessive or unnecessary amounts) and receive daily pain management treatment (Miller et al. 2002, 510). Overall, residents enrolled in hospice care received better pain management options than those

not enrolled thus, improving their quality of life. Miller et al. write, “This study supports the hypothesis that hospice care delivered in nursing homes is associated with superior pain management via the regular administration of analgesic treatment...and with family reports of higher-quality symptom management in nursing homes after hospice enrollment” (512). Similar to the purpose of the Miller et al. study, Xie et al. looked at the effects of implementing a holistic approach to patients with Pituitary tumors to engage whether or not holistic care improved quality of life for patients. Looking at a sample size of 100 patients who were to undergo surgery for removal of the tumor, Xie et al. divided the patients in half. One group of 50 patients received holistic care prior to their surgery consisting of an “integrated team” of nurses and family members as well as in depth education about the tumor and surgery (Xie et al 2019). While the other half received conventional care consisting from solely staff nurses and focused more on lifestyle variables like diet and health (Xie et al 2019). The holistic care recipients also received conventional care along with their holistic approach (Xie et al 2019). Using a 20 question questionnaire and self-rating anxiety scale, Xie et al were able to measure the anxiety and fear of the pituitary tumor patients in regards to the specific care they received. Not only were the anxiety and depression baselines for patients who received holistic care significantly lower than those who only received conventional care, holistic care recipients were also more satisfied with the overall medical treatment they received from the hospital and hospital staff (Xie et al 2019). However, an important note touched upon in the Miller et al study is that, although hospice residents generally receive more positive levels of pain management and access to analgesics, there were still a staggering number of nursing home residents (as well as other patients with chronic illnesses, in hospitals, going through surgery etc) in daily pain not receiving

analgesics or receiving analgesics that were not approved or not appropriate to treat their chronic illnesses/disease. Miller et al then stress that a focus on pain management for all residents in nursing homes (hospice and not hospice) need to be priority in order to maintain quality of life.

Analysis

Once the advancements of the 21st century in technology and science changed the course of human existence forever so too was our conception and treatment of death also radically altered. As the above research illustrates, medical developments transported death from the home to the hospital and in turn, stripped the individual of our “personhoods” disconnecting the lived experience of the individual from the illness/medical problem in which they faced. This idolization of science and “doctor’s replacing priests at the deathbed” (Howarth, 2007, 121) made death into a medical act. Death and dying were no longer seen within the spaces of a community or a home but rather behind hospital walls and in institutionalized settings creating a place where death happened that was separated from the rest of life. In this separation, the larger conversation and thus, understanding, of death as a life process is lost. This medicalization of death perpetuates the western idea of death as a medical phenomena that requires medical intervention rather than an inevitable and natural physical, emotional and spiritual experience. In this interpretation of death and dying, a “good death” cannot be achieved because the foundation of a good death involves empowering the individual through their dying process by encouraging the outlook of death as a life process encompassing the spiritual, physical and emotional.

Referring back to John Cagle’s definition of a good death; “A good death generally consists of: good pain and symptom management; clear decision-making; respect for one's

personhood; trust in health care providers; a sense of closure, completion or preparedness; minimizing family burden; being able to contribute to others; and maintaining control” (Cagle et al., 2014, 2).

Managing death as a medical act rather than a process blocks any possibility of considering the complete lived experience of the dyer and thus, the notion of a “good death” personal to the individual is lost. How can one feel satisfied and at peace with their own mortality if their “success” is solely being measured under the guise of medical regulations and conceptions rather than if their mind, body and soul is prioritized in their dying? Because of this reality, the movement of hospice and palliative care was spurred and an approach to death that allows for the recognition of the wholeness of a personhood was adopted to fulfill a “good death”.

The birth of the hospice movement and its principles proved that the 21st century approach to death was falling short of providing westerners with the tools and experience of a meaningful, fulfilling death. For the first time since the technological and scientific shift of the 20th and 21st century, dying and death was brought back into the hands of the individual and prioritized their familial connections, spiritual wishes, and physical/mental pain in their dying process. Dying could be an experience of empowerment in that it focused completely on the individual. As illustrated, bridging the gap between the medical and non-medical in death or a dyer’s wishes being met, pain relieved, family connected and control over their medical treatment resulted in an overall higher satisfaction, comfort and understanding of death and dying both for the person and their loved ones. Rearranging the notion of “success” in death

from just stopping death with medical intervention to prioritizing a “good death” and incorporating a holistic approach reduces fear, depression and anxiety while also restoring autonomy, fulfillment and purpose in death.

If holistic approach and prioritizing a “good death” has proven to be a transformative model to understanding and experiencing death, why isn’t such an approach mandatorily implemented within the medical sphere? Why are we as westerners essentially denying ourselves access to and an experience of a fulfilling and empowering life event? Especially one in which all of us will collectively experience.

This paper is not simply arguing all medicalization is inherently bad. But rather, the lack of “holism” that is present (or rather, not present) in the medical diminishes the dying experience for the individual and their family and in turn, death is not the experience it can be when holism is applied.

It is clear through the above research that not only is a “good death” the primary concern of an individual but that the principles of a “good death” and the foundation of holistic care and holism are directly intertwined. Thus, when holistic care is practiced, an individual is able to achieve a “good death”. Culturally, institutionally and economically, we then need to implement these findings into the medical.

Conclusion

In order to enact cultural, institutional and economical change in the world of death and dying, a larger dialogue and understanding of death and the dying experience needs to be

facilitated in the western world. Adopting a holistic approach within the medical, ultimately leading us to achieving our “good deaths”, can only arise from a drastic cultural shift that involves normalizing death and dying thus, demystifying death and the fear of death.

Our collective fear of mortality has permeated throughout our culture. Thus, we don’t approach or discuss the process of death and dying until it has directly affected us or a loved one. This reality has not only catalyzed the pathology of death, as extensively discussed throughout this paper but, in turn, has created a phobia-like conception around death and dying. In the west, we don’t want to talk about this ugly, scary, and upsetting life event. And because of this reluctance to have these conversations about death, a “good death”, which exists through open communication, is even more elusive and achievable.

Many, from sociologists to funeral directors, are thus working to implement the normalization and acceptance of death as well as radically alter the ways in which we discuss and carry out death.

In 2011, frustrated with the “death-phobia” that seemed to infect our culture, mortician Caitlin Doughty founded *The Order of the Good Death* or what is now known globally as *The Death Positive Movement*. According to their website *The Death Positive Movement* mission “ is about making death a part of your life. That means committing to staring down your death fears- whether it be your own death, the death of those you love, the pain of dying, the afterlife (or lack thereof), grief, corpses, bodily decomposition, or all of the above. Accepting that death itself is natural, but the death anxiety and terror of modern culture are not” (Welcome to the Order, 2019). Doughty and the other members of *The Death Positive Movement* advocate for

normalizing death and dying through conversation, art and academics. They encourage individuals to reflect on their lives and decide what will be important to them in death as well as generally confront their own mortality.

Other movements attempting to shift the western conception of death and dying are *The Conversation Project* and death cafes.

Wanting to normalize talking about death and end of life experience, Ellen Goodman developed *The Conversation Project*, a public engagement campaign that focuses on starting the conversation of death and dying right at “the kitchen table” to assure an individual’s end of life wishes and wants are heard, understood and respected by their loved ones (The Conversation Project, 2019). Goodman discovered that although many Americans have specific end of life wishes, the majority have not communicated such wishes to their loved ones. Thus, *The Conversation Project* was born and provides families and loved ones with the tools and resources to facilitate the dialogue casually yet meaningfully.

Death Cafes are another mission of activism within the death positive community that began in order to facilitate a space for honest dialogues about death. Jon Underwood and Sue Barsky Reid started the first Death Cafe in London with the mission “to increase awareness of death with a view to helping people make the most of their (finite) lives. A Death Cafe is a group directed discussion of death with no agenda, objectives or themes. It is a discussion group rather than a grief support or counselling session” (What is Death Cafe?, 2019). By providing a non-judgemental and confidential space for individuals to gather, either with loved ones or with

other strangers attending the cafe, Death Cafes allow for important conversations revolving around death, dying and end of life wishes without pressure or fear.

Radical acceptance and advocacy of the values and principles of missions such as *The Death Positive Movement*, Death Cafes and *The Conversation Project* allow for the beginning conversations of the empowering and fulfilling experience death has been proven to be through holistic approach which ultimately, propels western society closer to universally achieving a “good death”. Prioritizing a “good death” shifts the idea of death as a medical circumstance to an affirming life process which could essentially be the answer to alleviating the west’s misunderstandings and fears of death.

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