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The Evolution of Palliative Care: A Social Paradigm

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ABSTRACT

Indisputably, palliative care practices within the United States embellish modifications contingent upon societal apprehensions regarding death and the dying process. Further, these malleable societal attitudes are heavily influenced by geopolitical catalysts such as world health crises and periods of armed conflict that result in mass casualties. As a direct result, rapid advancements to comfort care practices are established for patients experiencing discomfort from chronic ailments that may impede upon an amicable dying process. As such, a thorough examination of previously published research will demonstrate these fluctuations to the generalized public attitudes of morbidity in conjunction with the progressive degrees of value and importance given to those who have departed. The resulting increase in compassion given to such individuals in the final stages of life consequently stimulates advancements made to future healthcare related practices and technologies. Ultimately, this research aims to explore the key historical catalysts that have altered the societal and cultural perceptions towards death and dying, in correlation to the quality and effectiveness of palliative medical care over time. The subsequent findings will contribute to the general existing body of knowledge regarding palliative care interventions, providing standardized insights into the historic evolutions and current challenges to the implementation of palliative care interventions within the United States.

Introduction

Societal apprehensions of morbidity are vast, incomplete, and behold the distinct ability to change over time. Often, these fluid attitudes towards death and dying are amplified by historical events involving mass casualties such as public health crises and times of domestic or international conflict. As a direct result, these ever-changing societal norms associated with the dying process influence the accessibility and effectiveness of palliative medical care interventions overtime. A comprehensive analysis of these geopolitical forces that explores the key social, historical, and cultural advancements made within palliative healthcare is crucial for assessing the dimensions of the alternating public attitudes towards death and dying.

When further considering how humans are the only species alive that are able to conceptualize the process of death and dying, a slew of questions and unexplainable mysteries surround the circumstances to this phenomenon (Sinoff 2017). Additionally, when examining how improper communication of emotional processes often occurs during challenging periods of loss, individuals may find themselves limited in their ability to analyze the complex feelings that arise from death in a healthy manner. Without the guidance or reference on how to properly grieve loved ones, friends, other members of society, or even other species, the resulting drastic change that occurs within the life course leaves individuals unprepared for the emotional sequences that ensue. In part, because of improper public knowledge to a topic that fosters nonexistent grievance procedures for the inevitable circumstances of death.

Collectively, various cultures throughout history have standardized comfort care measures for the terminally ill, in addition to providing coping strategies for the living, in order to present some form of coping framework for individuals to inevitably follow. Yet, prior to the 1960s, the westernized conceptualization of the dying process arguably lacked any effective bereavement procedures. Consequently, individuals who experienced exacerbations of obstructive stimuli that may have further worsened their present chronic condition(s), were not presented with the same resources that are currently available today.

As such, the modern implementation of critical comfort care interventions that were designed to optimize the quality of life for patients were simply nonexistent within medical practice until fairly recently. Consequently, the minimal attention given to psychosocial care for terminal patients prior to the 1960s impeded upon a dignified dying process for individuals and their loved ones. Furthermore, the implementation of grief management strategies and comfort care interventions aimed at addressing the anxieties of patients and their family, ultimately provided comprehensive care standards for all psychosocial domains of an individual's health.

Essentially, the mounting severity and importance to this phenomenon of death thereby initiates awareness into the provision of total care for patients and their loved ones within the final stages of life. As more interest into this social phenomena grows, geopolitical catalysts and public health crises stimulate research into comfort care practices, thereby designating a newfound degree of value for terminal individuals receiving comfort care. Arguably, the degree of importance granted to this topic and the patients within it fluctuates over time, depending upon global events that produced mass casualties that therefore insinuate a generalized need for this medical discipline.

Literature Review

Grieving Processes: Historical Competencies

Systemically, generalized attitudes to this phenomenon vary immensely upon individual dispositions and the cultural competencies to which people follow (Sinoff 2017). All in all, the westernized conceptions of death are heavily reflected by demographic shifts and epidemiological trends, therefore molding an individualistic and variable approach to bereavement (Institute of Medicine 1984). More specifically, the westernized conceptualization of the grieving process prior to the publication of *On Death and Dying (1969)* was closely associated with the need for quick and private closure (Institute of Medicine 1984).

In turn, society continuously sought unanswerable examinations to mysteries surrounding death and the afterlife as emotions surrounding this phenomenon were suppressed from both individuals and the surrounding community at large. Death would then become regarded as a societal taboo to discuss publicly and privately, notwithstanding the increasing complexity and severity that poor communication from an inadequate social grieving cycle pose (Institute of Medicine 1984). As such, westernized cultures grasped onto individual coping and bereavement procedures as the standardized practice, inadvertently propagating generalized anxieties of death and the dying process upon future generations. Furthermore, the publication of *On Death and Dying* would soon critically introduce a multitude of grief management competencies to a society without one, thereby motivating public awareness into the domains of death care and social work.

Grieving Processes: Dismissal of Comfort

For additional context, the historic prediction of inadequate grieving strategies in westernized cultures can be concentrated on the separation of terminal patients from their physical means of comfort during the dying process. In other words, terminal patients are regularly removed from the boundaries of their comfort, including their physical home locations and other surrounding social support systems that provide care and reinforcement in times of need. Substantially, the way of life for terminal individuals becomes deeply compromised from normalcy, thereby subjecting them to inequitable coping strategies as a result.

For further clarification, western bureaucratic institutions essentially removed death from the home setting, thereby concealing facets of death and dying from patients and their families (Institute of Medicine 1984). Similarly, removing terminal patients from the comforts of their home, to then be placed at a new location with strict limitations of visitation, further poses severe psychosocial traumas upon individuals and their families. Therefore, this notion posits that survivors are less well equipped to deal with the aftermath of death as evident by the physical separations to means of comfort (Institute of Medicine 1984). Propagated by modern bureaucratic institutions, this facet can clearly be linked to the physical separation of social support, fundamentally creating multiple environments of fragmentation and grief for individuals to process.

Additionally, bureaucratic macro-institutions such as law facilities, workplace environments, funeral homes, and medical care systems further complicate this matter due in part to their uniform disposition to explicitly place constraints on individual bereavement behaviors (Institute of Medicine 1984). Conditionally however, these macro-agencies' perceptions are subjected to constant change, especially when considering the generalized alterations to the social phasing's of the mourning processes in the United States. One such example includes the historic expectation to wear dark colored clothing in conjunction to being publicly absent as adequate mourning strategies. However, some current apprehensions may deem the displayance of any form of grief in public as taboo, further dividing individuals' private lives from the public sphere and fragmenting their degrees of individual comfort (Institute of Medicine 1984).

Sequentially, these conflicting societal attitudes can be rationalized as death anxiety, or thanatophobia (Sinoff 2017). Notably being one of the most fundamental emotions of humanity, thanatophobia is also regarded as being the root of all other generalized anxieties (Sinoff 2017). Kubhler-Ross further elaborated upon this notion, stating that the issues surrounding the exacerbations of thanatophobia stem from the departure process itself, in addition to the psychological adjustments that individuals must adapt to when in said grieving process (Sinoff 2017). With all aspects considered, the removal of terminal patients means of comfort undoubtedly adds to thanatophoric feelings regarding grief, thereby perpetuating additional fears derived from improper communication.

Grieving Processes *On Death and Dying (*1969)

In totality, the publication of Elisabeth Kübler-Ross' *On Death and Dying* (1969) stimulated public awareness towards the care of patients receiving end of life treatment services. Additionally, the publication of *On Death and Dying* put forth numerous psychodynamic grief management strategies for a society that widely overlooked individuals who inadequately failed to process the death of a departed loved emotionally and psychologically.

Within this research, Kübler-Ross detailed the changing stages of grief that individuals experience, starting with emotions of denial after the loss of a loved one (Byock 2013) These emotions soon transform into actions of isolation, anger, bargaining, depression, and finally acceptance of the circumstances (Byock 2013) These emotional states comprehensively describes the psychological states to which terminal patients commonly experience, in addition to various adaptive mechanisms that are utilized to make sense of the inevitable circumstances (Byock 2013). In essence, Kübler-Ross characterized words to emotional sequences, that may or may not follow a set order or occur at all, to grief management situations that arise after an individual passes away. By doing so, Kübler-Ross detailed the individual experiences of patients diagnosed with terminal conditions, thereby asserting patient rights of agency and autonomy to end of life medical decisions.

Beyond the clear sociological advancements that *On Death and Dying* cultivated, such as an increase of public awareness into death care and social work, Kübler-Ross's publication simply designated words to complex emotional situations that all humans experience. In other words, Kübler-Ross manufactured a process of effective grief management, based upon empirically reviewed data, to a social phenomenon that was widely ignored. This grieving process thereby granted society with a new and extensive psychological framework that is easily comprehensible and free from bias, serving as an ideal mourning structure for the general public. In turn, individuals within this mourning process inadvertently designated a new set of civil liberties to those who have departed, essentially recognizing death as an important event in an individual's lifespan.

Kübler-Ross Influence to Clinical Practice

This publication further sparked alterations to the assumptions and expectations of terminal patients, influencing the overall relationship between terminal patients and their providers. In other words, this publication reasserted personal sovereignty over illness and dying, further influencing overall societal apprehensions to death and the dying process (Byock 2013) As a direct result, the cultivation of open communication channels between patients and their providers granted patients with a newfound relationship that respected and aimed to understand the feelings and emotions experienced by terminal patients. As such, clinical practices prioritized societal attitudes and perspectives towards death, therefore influencing a newfound understanding of morbidity associated with terminal medical conditions.

Furthermore, this mourning process was not only designated to serve as a theoretical framework for future psychosocial conceptions of the dying process. The various stages of grief management also provided an adjusted cognitive framework for individuals. In theory, Kübler-Ross proposed a substantiated process for individuals within the grieving process that encompassed all dimensions of tumultuous psychosocial realms, establishing categorical titles of emotional sequences for the various episodes of coping management. Following this publication, evident influences to the medical community at large transpired, inciting providers to specialized developments made for terminal patients in comfort care.

Origination of Palliative Care

The principal foundations of palliative medical care are closely associated with the establishment of the modern hospice movement, spearheaded by founder Dame Cicely Saunders in 1967 (Merino 2018). For context, Saunders practiced Nursing at Archway Hospital in the United Kingdom at the height of the Second World War (Richmond 2005). It was during this time where Saunders developed a deep emotional connection to patients who were suffering immense pain, including a patient to whom Saunders would develop a deep connection with, David Tasma (Richmond 2005).

Specifically, this relationship served as the catalyst for the modern hospice movement when considering the minimal comfort care measures available during the death process that Saunders was able to provide. Therefore, the lack of available care interventions during this time period sparked an interest in Saunders to create an entire medical facility dedicated to aiding the needs of terminal patients. Considering there were no similar medical facilities present, this ambitious goal was supported by the inheritance to which Saunders bequeathed after Tasma’s passing (Richmond 2005). Even though the relationship was transient, Saudners bequeathed £500 which would soon be allocated towards the establishment of a medical facility that sought to alleviate mental, physical, and social dimensions of pain that are experienced by terminal patients (Richmond 2005).

By 1959, Saunders drafted a ten-page research proposal for the implementation of hospice treatment under the Church of England, however, multiple financial institutions refused to provide funding unless individuals of all faiths were permitted to receive care (Richmond 2005). Upon adopting additional clauses to essentially allow all applicable terminal individuals to receive this form of comfort care, Saunders proposal was accepted (Richmond 2005). Subsequently, construction for this new medical facility began in 1965, with the first hospice patient admitted in 1967 (Richmond 2005). Furthermore, Dame Cicely Saunders was accredited with being the founder of palliative medical care after establishing the first hospice institution in the world that specializes in patient comfort during the final stages of an individual's life.

Advancements made to Palliative Care in the 1970s

During the 1970s, significant progress was made in the reshaping of public attitudes towards morbidity within the United States. Notably, hospice or comfort care medical facilities were non-existent within the United States at this time (Richmond 2005). Soon thereafter, critical public attitudes soon influenced the medical interventions and available treatment options present within end-of-life care treatment options. In other words, society essentially recognized the need for this medical discipline and further called upon federal agencies and the generalized medical community for assistance in combating the inequities embedded within the dying process.

Florence Wald (1917-2008)

Florence Wald, the dean of Nursing at Yale School of Nursing, was a major pioneer to palliative medical care practices, essentially introducing the United States population to the domain of hospice care in addition to various comfort care interventions for terminal patients. After becoming incredibly frustrated over the medical profession's ignorance to terminal patient comfort, Wald essentially pursued a possible solution within the early workings of the hospice care movement (CWHF 1999). Further complicating this matter, previously published research was limited in assisting medical professionals in a search for possible care interventions (CWHF 1999).

After attending a lecture held by Dame Cicely Saunders at Yale University, Wald became inspired to cultivate her own ideas of comfort care to the United States healthcare system where in 1971, Wald opened the first hospice site in Branford, Connecticut (CWHF 1999). Finding similarities in the passion of care for vulnerable populations of individuals within the latent stages of the life course, Saunders soon became a mentor and ally for Wald’s ambitious ideas (CWHF 1999). Therefore, the formation of this crucial relationship would then inspire Wald to investigate further into palliative care medical practices. Subsequently, both Saunders and Wald formulated a systematic comfort care management framework for terminal patients with obstructive exacerbations from chronic conditions, thereby creating a new discipline of healthcare in the process (CWHF 1999). In turn, the importance of instituting hospice and palliative care medical centers would soon spread across the United States and the world (CWHF 1999).

Balfour Mount (1939-)

Another such pioneer to the field of palliative care is Doctor Balfour Mount, who is credited with coining the term palliative care as different from hospice care in 1974 (Williams 2001). Mount defined palliative care as supportive interventions that can be administered concurrently with other treatments measures from the time of diagnosis to death. Mount further defined that the traditional view of palliative care designates that symptomatic and supportive care interventions are generally withheld from patients until all attempts to treat the underlying disease and other medical problems are exhausted (Williams 2001). In other words, support and comfort measures generally are not prioritized by providers until all attempts to cure the patient from their diagnosis are exhausted. Furthermore, Mount was an influential contributor to the formation of palliative care in the United States from his conceptualized distinctions of the various psychosocial domains that must be recognized within this medical discipline. These classifications would bring further public recognition to this new medical discipline, influencing future public policy reforms that would grant additional services and resources for terminal patients and their loved ones.

Contemporary Advancements to Palliative Care

After the initial conception of palliative medical care, significant transformations to clinical practice would be reflected in various changes to legislation and public policy reforms. The subsequent alterations within this field of medicine are therefore driven by advancements to medical knowledge, evolving patient needs, implementation of research and evidence-based practice, government policies, in addition to public awareness and advocacy.

Advancement made to Palliative Care in the 1980s & 1990s

Notably, the hospice movement held a prominent consciousness throughout the mid-1970s, influencing voluntary initiatives to institute comfort care measures across communities nationwide (Buck 2011). The various nationwide programs that began as a result were all committed to the foundations of the hospice program, albeit uniquely interpreting the standards of applicable care in different delivery methods (Buck 2011). For further clarity, three major hospice organizational structures appeared, hospital-based programs, home-hospice programs, and independent hospice facilities that all predicated alleviation for terminal patient needs (Buck 2011). Hospital-based programs encompassed trained administrative medical staff, primarily doctors and nurses, social workers, and chaplains (Buck 2011). Home hospice programs appeared in suburban settings, almost entirely staffed by visiting nurses and aides providing a majority of the care to their patients (Buck 2011). Lastly, independent hospices derived mostly from community-based volunteer efforts to influence legislative changes for the dying (Buck 2011). Independent hospices further requested additional funding and resources to provide these interventions to the public (Buck 2011). Independent hospices often relied on charitable donations and funding from other foundations to hire program coordinators, as an additional means to influence public policy reforms (Buck 2011).

The various programs associated with the hospice movement thereby lobbied for legislative policy reform to absolve basic hospice care cost-coverages from insurance companies and the federal government alike (Buck 2011). Collectively, this goal was met in 1980 following bipartisan support, Title XVIII of the Social Security Act was amended to define hospice as an individualized care method for the terminally ill (Buck 2011) Therefore, this amendment allowed patients to choose hospice as a particular form of care over other Medicare benefits throughout a terminal disease progression (Buck 2011).

The need for palliative and hospice care soon spread nationwide, resulting in communities calling for more equitable payment options for receiving end of life comfort-care services. Following the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985, reimbursement for hospice services under Medicaid programs were instituted (Buck 2011). Then in 1991, the same services were extended to service men and women enrolled in the Military (Buck 2011). These provisions would then historically be perceived as the most efficient template for reimbursement for hospice and palliative care services under Medicare (Buck 2011). Finally, near the mid-1990s, commercialized health-insurance agencies covered comprehensive hospice and palliative care services nationwide (Buck 2011).

Modern Advancements to Palliative Care

The financial expansion of comfort care services within the United States fostered a global shift to perceptions of death and the dying process (Massachusetts Medical Society 2024). In turn, global communities sought similar advancements to medical practices, when in 1990 the World Health Organization recognized palliative care as a distinct specialty aiming to relieve the suffering from painful exacerbations (Massachusetts Medical Society 2024). Within this process, the World Health Organization outlines guidelines for improving quality of life standards for patients with terminal conditions (Massachusetts Medical Society 2024).

Following this momentous accomplishment, not all individuals were included into eligible care, resulting in additional publicity behind the hospice movement in order to expand universal coverage (Massachusetts Medical Society 2024). These concerns were highlighted within the Institute of Medicines report entitled “Approaching Death: Improving Care at the End of Life”, where notable discrepancies between the needs of the American public for end-of-life care and their actual experiences differed (Massachusetts Medical Society 2024). In turn, multiple philanthropic foundations propelled efforts to promote universal palliative care research and care practice for terminal patients (Massachusetts Medical Society 2024).

These efforts lead to the recognition of a separate medical specialty designated by The World Health Organization in 1991 (Sheikh et al., 2022). This distinction would soon impact westernized healthcare settings where in 2006, both the American Board of Medical Specialties (ABMS) and the Accreditation Council for Graduate Medical Education (ACGME) approved Hospice and palliative care as distinctive specialties.

Dimensions of Palliative Care

Intrinsically, palliative and hospice care both encompass end-of-life medical care interventions that may provide support and comfort to terminal patients and families alike (Sheikh et al., 2022) Specifically, palliative care encompasses an interdisciplinary collaboration of caring for patients and their caregivers to best manage chronic illness (Sheikh et al., 2022). The management of such conditions aims to alleviate discomfort surrounding physical, emotional, spiritual, and psychosocial requirements (Sheikh et al., 2022). In addition, both hospice and palliative care are often used interchangeably, even though palliative care is the broader term of latent comfort care, with hospice simply being a part of it (Sheikh et al., 2022).

Within the scope of palliative care, the primary goal is to facilitate the needs of terminal patients and their families admits distinct periods of disease progression. (Harris et al. 2014) Individuals who are eligible to revive non-hospice interventions, or the form of palliative care administered directly before hospice, must conform to set of strict guidelines of qualification (Harris et al. 2014) These standards include the initial diagnosis of a unfavorable illness that unfavorably impacts the daily functioning's of the patients, in addition to possessing significant disease symptoms that require supportive measures for the curative condition (Harris et al. 2014). Patients who experience decreased mobility, an overall deterioration disease status, oxygen dependency, progressive weight loss, or experience any other aggravating stressors that may impact their treatment further qualify for available palliative care interventions (Harris et al. 2014). Subsequently, within this process of care, healthcare providers analyze the various psychosocial patient domains that influence over treatment outcomes, including the patient's means of support and their current mental status (Harris et al., 2014). The structure of this field of medicine often involves human interventions, human resources and management, physical space, medical and nonmedical equipment, and various research activities (Dokmai 2021). On the other hand, the process of palliative care encompasses the response to physical and psychosocial needs, the provision of effective communication strategies, and respect for patient autonomy (Dokmai 2021). These interventions may further be administered concurrently during other treatment regiments, in order to best maximize the patient's quality of life and comfort standards (Harris et al., 2014)

In contrast, patients become eligible for receiving hospice care referrals when their life expectancy decreases to less than six months. Such conditions that may influence this timeline include diagnosis of cancer, cardiac and circulatory abnormalities, dementia, and respiratory disease (Dokmai 2021). To receive this treatment, physicians may employ the Palliative Performance Index (PPS) that determines patient ambulation, consciousness level, complete intake and output, self-care and activity levels, and the extent of disease progression when determining treatment options (Sheikh et al., 2022).

Contemporary Catalyst to Care

The Russian invasion of Ukraine drastically altered the landscape of palliative care interventions throughout the world, triggering a cascade of daunting challenges that reverberated throughout the healthcare system. Admitting the chaos and conflict of war, access to essential medical supplies became severely compromised, exacerbating the effects of an already fragile state of palliative care infrastructure (Military Medicine 2024). The critical absence of comfort interventions for individuals suffering from combat-related injuries, in addition to those who are suffering from illness that were undiagnosed prior, reaffirms the need for such medical interventions (Military Medicine 2024).

Sequentially, the effects of overall poor healthcare outcomes from war can be traced to the Russian tactical strategy of destroying essential infrastructure. In turn, facilities such as "...warehouses, and transport systems distracted supply chains and humanitarian aid routes, restricted mobility, and caused mass displacement which encumber access to potable water, sanitation, hygiene, food security, shelter and security, all of which complicated the evacuation of civilian and crowded shelters which bred infection and COVID" (Military Medicine 2024). As war perpetuates a separation from means of comfort extreme detrimental consequences ensue that ultimately will influence future healthcare practices. As such, the displacement of civilians, the destruction of healthcare facilities, and the strain on healthcare professionals further compounded the difficulties in providing adequate palliative care interventions.

Moreover, the psychological wage to which conflict on both patient and caregivers brings, poses unique dimensions of suffering and discomfort, demanding innovative approaches to total care. As Ukraine navigated the complexities of war, the realm of palliative care emerged as a poignant microcosm of the broader humanitarian crisis, underscoring the imperative for resilience in times of crisis, adaptation, and international support in safeguarding the dignity and wellbeing of vulnerable populations. Throughout a concerted effort to address the intersecting challenges posed by conflict, displacement, and healthcare provision, society must strike towards ensuring that even during period of adversity, the fundamental principles of palliative care, including passion, dignity, and adversity, to remain steadfast pillars of support for those facing terminal conditions.

Conclusion

The intricate relationship between the evolution of palliative care over time and the changes to societal attitudes towards death underscores the dynamic interplay between healthcare related practices and cultural norms. Further, this notion posits the influence to which public health crises and global periods of armed conflict often bring additional awareness and critical funding for future research methods in order to advance current medical practices. Across various different historical epochs, the concept of death has been imbued with diverse meanings and interpretations, thereby shaping the confound of available end of life care. Prior to the mid-20th century, individualistic and reserved forms of bereavement from macro-agencies were propagated by western cultures as a means of effective and standard grief management.

The hospice movement would further bring about a paradigm shift to cultural perceptions of death and dying, essentially advocating for a return to compassionate, patient-centered care rooted in dignity, comfort, and agency. This movement, catalyzed by prominent figures such as Dame Cicely Suanders, laid the foundations for contemporary hospice and palliative care practices.

Over time, as societies have grappled with existential questions surrounding mortality, attitudes towards death have undergone extreme transformations. Essentially, generalized fears and anxieties of morbidity mutated into emotions of acceptance and empowerment. This cultural shift has been reflected in the broader integration of palliative care systems worldwide, alongside a growing recognition for the need of compassionate terminal care services that honors the unique and diverse preferences of every individual. Undeniably, these historical trajectories must be further introduced into the public sphere in order to serve as a constant reminder for the ongoing imperative to prioritize human dignity, compassion, and holistic support in end-of-life decisions.

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