

2021

Literature review: Improving end-of-life care and creating a good death

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Recommended Citation

Smlatic, Erna, "Literature review: Improving end-of-life care and creating a good death" (2021). *Honors Program Theses*. 492.

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Running Head: END-OF-LIFE CARE

LITERATURE REVIEW: IMPROVING END-OF-LIFE CARE AND CREATING A
GOOD DEATH

A Thesis Submitted
in Partial Fulfillment
of the Requirements for the Designation
University Honors

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May 2021

This Study by: Erna Smlatic

Entitled: Literature Review: Improving end-of-life care and creating a good death

has been approved as meeting the thesis or project requirements for the Designation University

Honors

Date

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Abstract

The need for quality end-of-life care has increased drastically around the world in the last few centuries due to a surge in life expectancy. As people are living much longer, they are developing and succumbing to chronic progressive diseases which can significantly decrease quality of life. But what exactly does it mean to care for the aging population who are nearing death? Defining quality care at the end-of-life is important but also differs for individuals based on a variety of factors including age, culture, and life experiences. End-of-life care does not come as “one size fits all” and it challenges our healthcare system to design flexible treatment plans aimed to achieve a good death. When considering what is important to individuals during end-of-life, we must consider factors contributed by patients and their families but also by physicians and other care providers (nurses, chaplain, social workers). Therefore, the purpose of this literature analysis is to explore specific factors of treatment which need to be considered in order to improve end-of-life care as well as focus on the core elements necessary to provide individuals with a dignified death.

Introduction

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

-Dr. Cicely Saunders, founder of the modern hospice movement, 1959

End-of-life care has become one of the most challenging issues in healthcare. There is a significant need for improving end-of-life care due to a surge in life expectancy. Between 1959 and 2016, life expectancy in the United States has increased from 69.9 years to 78.9 (Woolf, 2019). The majority of the population is no longer dying due to acute infectious diseases, such as pneumonia or tuberculosis, but rather chronic diseases that bring about a prolonged dying process, such as cardiovascular disease or malignant neoplasms (Heron, 2017). Notably, life expectancy has been seen to decrease with each additional chronic condition. For example, A 67-year-old individual with no chronic conditions will live on average 22.6 additional years, but a 67-year-old individual with five chronic conditions and 10 or more chronic conditions will live 7.7 fewer years and 17.6 fewer years, respectively (DuGoff, 2014). Advancements in medicine have made treating these seriously ill patients possible in order to extend life but have brought up questions whether unnecessarily prolonging life is an appropriate goal of treatment. There is increasing acknowledgment that other goals that should instead guide end-of-life decision making. More patients have shown preference for treatment focused on relieving pain and discomfort whereas a small minority has shown preference for life-extending treatment (Mack, 2010). Defining quality care at the end-of-life is important but also differs for individuals based on a variety of factors including age, culture, and life experiences. End-of-life care does not come as “one size fits all” and it challenges our healthcare system to design flexible treatment plans aimed to achieve a good death. When considering what is important to individuals during

end-of-life, we must consider factors contributed by patients and their families but also by physicians and other care providers (nurses, chaplain, social workers). These goals of treatment are influenced by many parties, including patients themselves, their families, and care teams, but also encompass different aspects of social, psychological, and spiritual support.

Review of Literature

To begin this review, it is necessary to understand that Americans are very diverse and discussing end-of-life preferences can vary greatly from one person to the next. Particular factors which have been mentioned in previous research are not standards for end-of-life care but rather suggestions that policy and health care systems can be built on. The details of advanced care planning and treatments offered for patients near end-of-life and their families are their own preferences which they decide on. This review will aim to cover the most common and significant factors which have been previously studied, including factors of treatment, advanced care planning, costs of treatment, palliative and hospice care, and education, as well as explore the implications of the recent pandemic caused by SARS-CoV-2 on end-of-life care. Death is a complex subject and can be interpreted in different ways, but the common denominator in every story is that the terminally ill patient deserves to have options available in order to achieve the death they wish for.

Factors of Treatment

Practice of medicine is being challenged by the increasing number of Americans with varying combinations of frailty, functional limitations, physical and cognitive decline, and multiple chronic diseases. Many of these patients who are near end-of-life have expressed fear of experiencing great pain due to their complex disabilities. In 1986, the World Health Organization declared undertreatment of pain to be a public health crisis (WHO, 1986). Since then, numerous

guidelines and interventions have been released and tested. Pain is a common symptom of end-of-life and is reported to occur in approximately 50% of patients in the last month of life (Institute of Medicine, 2015). Pain experienced by terminally ill patients is often treated with medications which alleviate signs and symptoms of pain but are controversial when they hasten death. Specifically, there is concern that use of opioids can hasten death, and this may be the reason that pain is poorly managed in terminally ill patients. However, studies have shown that death in end-of-life patients is influenced by many factors and concern about hastening death or compromising respiratory status does not justify withholding opioid use (Portenoy, 2006). Opiates are the medication of choice for pain control and dyspnea, or difficulty breathing, which are common symptoms of active death (Albert, 2017).

Dyspnea can be caused by many different mechanisms, including aspiration pneumonia, pulmonary edema, heart failure, pleural effusions, and deconditioning. It is often hard to assess dyspnea in end-of-life patients because it requires the patient to report specific signs and symptoms of difficulty breathing. Clinical assessments done by care teams can look for tachypnea, labored respirations, restlessness, and grunting as signs (Albert, 2017). Other symptoms frequently treated with medications in end-of-life include anxiety, delirium, increased oral secretions, nausea and vomiting. Benzodiazepines, such as lorazepam and midazolam, have potentially sedating effects but have also been effective at treating anxiety in the last hours to days of life (Henderson, 2006). As the ability to swallow is diminished and patients have difficulties with swallowing pills, medications are typically administered sublingually, transdermally, or via rectal suppository. Effective and proper management of symptoms at the end-of-life can be challenging but is often achieved with only a few medications. Clinicians are tasked with helping these patients and their families through the process of end-of-life by

appropriately dosing and administering these medications with the assurance that it will be safe and as comfortable as possible.

The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments (SUPPORT) documented that many patients receive unwanted, invasive, and expensive care and experience prolonged and painful deaths (Murphy, 2000). Avoiding unwanted pain may also include forgoing aggressive treatments which provide little hope for meaningful recovery. End-of-life conversations between patients and physicians are associated with fewer life-sustaining procedures and lower rate of intensive care unit admission (Wright, 2005). Some terminally ill patients decline resuscitation and intubation due to significant pain and unlikelihood of surviving these aggressive measures of sustaining life.

In contrast, studies have shown that African Americans are more likely than Whites to want aggressive care at the end-of-life, hold less favorable beliefs about hospice due to distrust in the healthcare system, and hold beliefs that conflict with the goals of palliative care (Johnson, 2008). Almost 50% of Caucasians who died in 2016 used hospice care compared to 31% to 37% of those with African American, Asian, or Native American descent (Bhatnagar, 2021). Ethnicity can be a sign of common cultural beliefs and values that can impact end-of-life decisions but is not a definite indication of one preference of treatment over another. Providing culturally sensitive end-of-life care becomes more important as the diversity of America grows.

Terminal illness can impact not only physical health but also mental and spiritual wellbeing. Meeting the spiritual and psychological needs near end-of-life are especially important when physical healing is no longer possible. Inclusion of chaplaincy services is significantly associated with lower rates of hospital deaths and higher rates of hospice enrollment (Flannelly, 2012). In this case, a chaplain can provide assistance to the patient and family

members in making decisions on end-of-life care and whether their values and wishes would align with possible treatment plans. The importance of psychological and social professionals in helping patients and their families through the aging and dying process is now more widely accepted. Medication side effects, physical impairments, dependency, bereavement, and family dysfunction frequently can occur, even simultaneously, during a terminal illness and can increase the risk of psychological and psychiatric difficulties. Although more health care professionals are aware of the impact of end-of-life and diagnosis of terminal illness on psychological being (Karel, 2012), it can be hard to assess psychological changes in a patient near end-of-life because it is sometimes assumed that increased dysphoric mood, anxiety, or suicidal ideation is normal for those who have accepted or come to terms with their death quickly approaching. Providing proper training and resources to care teams and family members can help with providing support to terminal patients who are undergoing psychological changes.

Considering the patient as an individual with specific preferences for care is important when determining end-of-life care. One person may want aggressive measures in order to have more time with family and friends while another individual may want to be freed immediately from their chronic and progressive diseases. Some patients will want spiritual, psychological, and/or social activities to be incorporated into their end-of-life care. As end-of-life approaches, healthcare and medical decisions should ideally include balanced medical, ethical, psychosocial, and societal considerations.

Advance Care Planning

Recognizing that end-of-life is near can be particularly difficult for patients and is often ignored even if recognized. Many people nearing the end-of-life are unable to cognitively or physically make their own decisions about the care they wish to receive and often rely on a

designated family member or close friend to make these decisions for them. Even when these family members or friends are confident in the dying person's wishes, it can still be emotionally difficult for them to move forward with these decisions. Studies have shown that the treatments patients would prefer at the end-of-life are often different from the treatments they actually receive (Fried, 2002). Advance care planning ensures that a patient's wishes can be respected when their physical or cognitive decline begins.

An advance directive is a legal document used to appoint these medical decisions. However, only one in three Americans completes any type of advance directive for end-of-life care (Yadav, 2017). Many individuals who do participate in advance care planning prioritize their independence and quality of life over quantity of life (Institute of Medicine, 2015). Having a set plan in place also reduces the deep regret and guilt family members or friends may develop while trying to make complex end-of-life decisions for someone. While there is no current standard procedure in medicine which outlines exactly when, how, or who should initiate advance care planning, these are conversations which should be encouraged and documented by both patients and professional caregivers.

There has been substantial evidence which shows that advanced care planning positively impacts quality of end-of-life, decreases use of life-sustaining treatment, and increases use of hospice and palliative care while preventing unnecessary hospitalizations (Brinkman-Stoppelenburg, 2014). Legally binding documents, such as advanced directives and advance care planning, are tools which are to be used in order to give patients the death they have shown preference for. Without these discussions and documents in place, there is no definitive answer to what the patient's preferences are when they are incapacitated and can no longer speak or make decisions for themselves. Patients are more likely to receive end-of-life care that is

consistent with their preferences when they have had the opportunity to discuss their wishes with a physician (Mack, 2010). Care inconsistent with patient preferences can be associated with numerous negative outcomes, including higher healthcare costs. Patients who have shown preference for comfort care but believed that their care was inconsistent with their wishes had higher medical care costs than those who believed that their care was consistent with their wishes (Teno, 2002). Patients who receive care inconsistent with their wishes are not only experiencing decreased quality of life at the end-of-life, but are also paying a high price for it.

Cost of Treatment

Patient-physician discussions about end-of-life allow for patients to set their boundaries on which types of care they do and do not wish to receive. Patients who have these conversations with physicians have been shown to have significantly lower health care costs as well as less physical distress in their final week of life (Zhang, 2009). Patients at end-of-life represent a disproportionate share of Medicare's costs, and this number will continue to increase as the number of Medicare beneficiaries increases with the aging population. Most notably, Medicare expenditures increase sharply in the last few days of life, particularly for patients who die in the hospital (Duncan, 2019). Palliative care services may help to ensure that care at the end-of-life is consistent with patient and family goals while still reducing the cost of care. Increasing value of care while minimizing costs in the care of seriously ill individuals is one of the major public health challenges in America.

Higher costs of healthcare treatment are also associated with worse quality of death (Zhang, 2009). The cost of aggressive measures at the end-of-life is not only monetary but is also physically and psychologically taxing to the patient. Many individuals who pursue aggressive measures at the end-of-life do so in hopes that it will extend their life, but studies have shown

that patients who received life-extending treatment did not live longer than those who did not (Mack, 2010). Interestingly, this same study noted that poorer quality of life and increased distress has been associated with life-extending treatments.

Palliative and Hospice Care

One in five Americans die using intensive care unit services (Agnus, 2005 & Dartmouth Atlas of Healthcare, 2017). As the aging population continues to rise, is expected that this number should only increase with time. In order to accommodate for a rapidly growing elderly population, our health care system will be forced to expand intensive care units and staff or find alternative ways to embrace and treat dying Americans. The highly technological critical care environment of emergency rooms and intensive care units may press for more aggressive treatments which could potentially prolong suffering of end-of-life patients.

Palliative care offers an approach which gives the highest possible quality of life while still aiming for the longest possible life. Patients undergoing palliative care can still receive treatments which could potentially cure their disease. Patients are able to participate in shared decision making with their physicians and care team while still focusing on the qualities of life which are important to them. Palliative care teams are multidisciplinary and often include doctors, nurses, social workers, therapists, and chaplains who collectively come together to provide medical, social, emotional, and practical support to the patient and their family. If the care team no longer believes the patient is benefiting from continued treatment, they can be transferred to hospice care.

Some of the shortcomings in the care of near-death patients and their families include limited communication in regard to care plans, prognosis, and transfer to hospice care (Bradley, 2002). There is substantial evidence of increased patient and family satisfaction with hospice

services, either at home or inpatient. Hospice care is an important approach to addressing palliative care needs in those patients with a limited life expectancy. Admission requirements to hospice care require a physician's diagnosis of a terminal illness in which the patient has only six months or less to live.

The hospice movement began with the work of Dr. Cicely Saunders, who opened St. Christopher's Hospice in London in 1967. As a nurse, social worker, and physician, she was devoted to the dying and aimed to advance the modern hospice movement to focus on patient-centered care and pain management. Prior to her work, medicine was focused on curing disease and those who could not be cured were a sign of failure. The first hospice program established in the US was in 1974 and was based on the practice of St. Christopher's Hospice. Since 1983, hospice services have become widely available through Medicare, Medicaid, and almost all US insurance plans. In 2016, there were 4,382 Medicare-certified hospices operating in the US (Bhatnagar, 2021). As the access to palliative and hospice services continues to increase, the opportunities to improve value in health care and quality of life at the end-of-life will continue to increase.

Providing a good death would suggest patients would feel more comfortable with dying at home. Initially as life expectancy increased a few decades ago, patients and families expressed feeling overwhelmed about managing symptoms or a dead body in their home and showed preference for skilled facilities (Steinhauser, 2000). However, more recent evidence shows people prefer to die at home, even as their illness progresses (Gomes, 2018). Focusing on home-based care is important but also requires policy in place to support those who do not feel quality of care and their quality of life is met with dying at home. Hospice benefits under Medicare fall into four different categories: routine home care, continuous home care, general inpatient care,

and respite care. Patients with more advanced disease who require a higher level of care can be admitted into hospice homes, units at the hospital, or nursing homes where they receive 24/7 care. Patients can also decide to receive hospice cares at home and have regular daily to weekly visits from nurses and other aids but also have 24/7 access to a nurse over the phone. When the patient dies at home, the family is instructed to call a hospice nurse instead of 911.

Diagnosis of a fatal disease can be devastating but being able to provide these patients and their families with comfort care tailored to their specific needs and wishes can potentially improve the amount of suffering they endure. Hospice care is not focused around trying to cure or fight their disease but rather on how an individual's last moments of life can be enhanced by the activities they enjoy, last wishes, being surrounded by family, and alleviating symptoms of pain. Hospice care centers around social support and comfort measures which allows the patient to live out the remainder of their life with close support but while still relieving pain and managing symptoms of active death. Palliative and hospice care have become a growing field of medicine but will likely require more public education in order for society to properly utilize their services as the definition of a good death continues to evolve.

Education & Initiatives

In 1994, the Open Society of Institute (OSI) initiated a new program called the Project on Death in America (PDIA) in hopes to improve the experience of dying in the United States. By the end of 2003, PDIA had distributed \$45 million in grant awards to various organizations and individuals rooted in professional and public education, public policy, research, and clinical care, all of which are strongly dedicated to improving end-of-life care for dying patients and their families. The work of this organization did not stop because there was a lack of need but rather there simply was not enough funding to keep up with their efforts to challenge end-of-life care.

As the PDIA finished its movement in 2003, the International Observatory on End of Life Care (IOELC) at Lancaster University, UK, was founded. This organization was the first ever to provide clear and accessible research-based information about palliative and hospice care at the international level (Clark, 2007). Since its establishment, the IOELC has conducted research on the impact of various care settings, models of hospice and palliative care, populations receiving hospice and palliative care, clinical research, and research methods related to improving end-of-life care.

It is also important to focus on the education of professionals in the medical field regarding aging populations, palliative care, and hospice care. By properly educating and influencing the attitudes of physicians, they can in turn influence the care of end-of-life patients in order to guide them on deciding what a good death means to the individual and making these preferences known. Proper physician education on advance care planning allows them to feel comfortable to discuss these issues with patients and subsequently increases the number of end-of-life decisions patients make. It is important to incorporate end-of-life care into medical schools, residency programs, and continuing education for physicians that better cover the complexity of caring for the dying population. Physicians who have more knowledge about terminal care and hospice care have more discussions with their patients about hospice care and refer their patients more often for such care. Greater knowledge about end-of-life care has also been associated with a more positive attitude about terminal care and hospice care (Bradley, 2002). Major initiatives, such as Robert Wood Johnson Foundation's Last Rites Campaign and American Medical Association's Education for Physicians on End-of-Life Care project, are striving to improve the quality of end-of-life care by providing education for professionals and the public. Many dying individuals have demonstrated desire to alleviate burden, which includes

financial, on their family members and have expressed worry about the potential high costs of aggressive care near end-of-life. Proper education of end-of-life care and options of quality treatment could reduce unnecessary prolonged suffering and extortionate price.

Pandemic Considerations

The recent coronavirus (COVID-19) pandemic has shed an entirely different light on end-of-care discussions between physicians, patients, and their family members. The quick spread of disease has led to overrun critical care units with limited staff, beds, and equipment (Pattison, 2020), which has raised important ethical questions, specifically regarding the potential need to ration cares provided based on likelihood of survival. Data has shown that coronavirus disproportionately affects those who are elderly, frail, or with chronic health conditions because they are at higher risk of both contracting COVID-19 and suffering a more severe disease course (Yang, 2020). As infections continued to climb rapidly, many people became worried that a healthier individual may receive a ventilator over them because their chances of survival or high quality of life after aggressive care was small. Clinicians are given the duty to ensure that patients receive the care that aligns with their goals and values, but the pandemic posed a challenge because many individuals became very ill before they could complete advanced care planning. This pandemic has highlighted the importance of advance care planning prior to serious acute illness and clear discussions about goals of care at the onset of serious acute illness. Clinicians should encourage these conversations in order to avoid intensive life-sustaining treatments which could be unwanted by patients and can put other patients, family members, and health care workers at higher risk of transmission of COVID-19 (Curtis, 2020). For patients hospitalized with COVID-19, the focus for goals of treatment is typically establishing a code

status, or the use of cardiopulmonary resuscitation (CPR) and advanced cardiac life support (ACLS).

The pandemic has also caused a substantial restriction in visitors in the hospitals and nursing homes. Due to physical distancing guidelines and travel restrictions, it may not be possible to provide physical comfort to patients at the end-of-life. At the beginning of the pandemic, elective surgeries were canceled for several months, medical appointments were switched to phone and zoom calls, and patients who needed medical attention often deterred seeking care in fear of contracting COVID-19. Those hospitalized with COVID-19 were not allowed any visitors and those hospitalized for other reasons were often only allowed one visitor which had to be the same person throughout the entire hospitalization. Many patients took their last breaths alone in their hospital or nursing home rooms and most families did not have the opportunity to say their goodbyes in person. Funeral homes and crematories have been overwhelmed with a soaring demand for their services and traditional in-person funeral services were mostly stopped with only the option to watch from home with live-streaming services. All of these sudden changes have placed an enormous emotional and psychological burden on individuals, care teams, and their families. Families bereaved as a result of their loved one dying while under critical care have been shown to have worse outcomes (Lundorff, 2017), but we can expect higher numbers of complicated grief to arise given the unusual circumstances of the COVID-19 pandemic.

Conclusion

End-of-life care has evolved in the last several decades as people are living much longer than they used to. As a result of longer life, individuals are developing chronic and progressive diseases which have a remarkable impact on quality of life. Individuals with conditions such as

chronic kidney disease, congestive heart failure, dementia, or various cancers are physically unable to live the same life as individuals without these diseases, which can also have a profound impact on their mental state. Although the field of medicine, specifically emergency medicine and critical care medicine, have advanced significantly to be able to provide lifesaving treatments in order to extend life but have brought up numerous ethical questions about unnecessarily prolonging life. Once these patients are no longer able to physically heal, aggressive and life prolonging measures become futile and focusing on comfort care and improving quality of life in the final days is a more appropriate goal of treatment. Common hopes of end-of-life care include avoiding suffering and having wishes respected as well as followed.

Personal preferences for care are especially important when providing end-of-life care in order to provide the best possible death. Each individual's story is different at the end-of-life; death can come suddenly, or a person can linger and gradually fade away. Some individuals remain physically strong while cognition becomes impaired, and vice versa. Defining quality care at the end-of-life is important but also differs for individuals based on a variety of factors including age, culture, and life experiences. These factors can vary greatly when looking at the diversity of individuals living in the United States. The healthcare system in the United States has been challenged by these expectations from patients and their families and subsequently will force the healthcare industry to further expand palliative and hospice services in order to provide individuals with the death they deserve and support their families as they experience often overwhelming grief.

Palliative and hospice care serve as options for individuals with chronic and progressive or terminal diseases. The multidisciplinary teams of palliative care aim to offer the highest possible

quality of life while still aiming for the longest possible life. Patients are able to participate in shared decision making with their care team while still focusing on the qualities of life which are important to them. If the patient is no longer benefiting from treatment, the transition to hospice care is initiated. Hospice care focuses on emotional support and comfort measures which allows the patient to live out the remainder of their life while relieving pain and managing symptoms of active death.

The recent coronavirus (COVID-19) pandemic has brought to light how important end-of-life discussions and advanced care planning truly is. Many individuals with chronic conditions at baseline who were infected with SARS-CoV-2 became very ill quickly and were unable to express their wishes for treatment and establish a code status. This pandemic has showed the importance of advance care planning prior to serious acute illness as well as clear discussions about goals of care at the onset of serious acute illness. Facing terminal illness and death is tough for both patients and their families but creating adaptable treatment plans is necessary in order to provide them with appropriate end-of-life care and a good death.

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