

A MODEL OF IMPLEMENTATION FOR END OF LIFE OPTION ACT IN
HOSPITALS

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A Thesis submitted to the faculty of
San Francisco State University
In partial fulfillment of
the requirements for
the Degree

Master of Social Work

Concentration in Individuals, Families, and Groups

by

Sarah Cathryn Peck

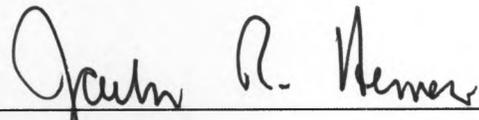
San Francisco, California

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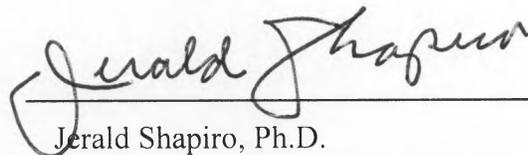
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CERTIFICATION OF APPROVAL

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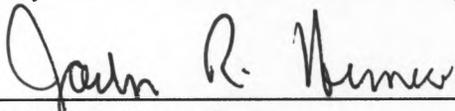
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A MODEL OF IMPLEMENTATION FOR END OF LIFE OPTION ACT IN
HOSPITALS

Sarah Cathryn Peck
San Francisco, California
2018

While California has been one of the states to take the lead in implementing policy around end of life options (End of Life Option Act), there remain a number of major issues and challenges directly involved in the implementation of the policy. In order for different hospitals within California to implement high quality/safe/ethical end-of-life options for patients, they must address the need for provider education, a streamlined process, and a clearly stated institutional policy. The resulting guidelines and procedures will serve as formative components in the framework for social work practice in the area of end of life options. This study works towards the development of a high quality/safe/ethical end of life options-oriented model of social work practice. It uses research on the many different areas related to patients at the end of life and takes a look at implementation plans of other healthcare institutions with similar patient populations. This model will help social workers (and other providers) fulfill ethical responsibilities to patients opting for quality end of life care and create a structure for social workers to lead implementation of such policies.

I certify that the Abstract is a correct representation of the content of this thesis.



Chair, Thesis Committee

14 May 2018
Date

PREFACE AND/OR ACKNOWLEDGEMENT

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Chapter 1

Problem Statement

While California has been one of the states to take the lead in implementing policy around end of life options (End of Life Option Act), there is a need for improvement with the implementation processes for this policy. As one author states, "The implementation of AB 15 would be improved by adjusting surveillance data-collection requirements and encouraging additional research investment, using the legalization of AID¹ to improve knowledge of and practices for end-of-life care generally, and creating ongoing educational opportunities for providers and the general public" (Cain, 2016, p.1).

In order for different hospitals within California to implement high quality/safe/ethical end-of-life options for patients, a model of practice will be developed to assist in implementation. This model will help social workers (and other providers) fulfill ethical responsibilities to patients opting for quality end-of-life care and create a structure for social workers to lead implementation of such policies. Qualitative research methods will be used to create a model of practice for implementation. The researcher will use case studies from other hospitals' implementation processes, interviews, and relevant research to assist in developing a quality implementation model. This model will try to address areas of improvement such as: relevant education and training for specific providers, an outlined process for patients and families, the development of an interdisciplinary team for consultation and support, and the collection of information around the efficacy of the process as a whole. As will be discussed later in detail, the model was created with challenges in mind such as the different ethical principles held by

all the individuals involved in the process and providing education that addresses the wide range of races and ethnicities of individuals that providers will interface with at healthcare institutions within California.

Chapter two of this thesis will look at and analyze relevant literature around the topic- this includes research about what patients at the end of life value from their providers, what procedures and education have been helpful to implementation at other California hospitals, and what data needs to be collected to assess the effectiveness of an implementation plan. Chapter three will capture what theoretical framework the researcher is using to structure the process of developing an implementation plan for end-of-life policies. Chapter four will define applicable variables and terms within the research and reiterate research questions to be addressed. Chapter five will cover a new model of implementation created with all relevant research and data in mind. Chapter six will discuss the potential effectiveness of the model of implementation in combination with the perspectives of the researcher. Chapter seven will delve into how this model of implementation is relevant to social work practice, policy, research and education.

Chapter 2

Introduction

The previous chapter outlined the problem statement that inspired this research project and what this project aims to accomplish. This chapter will provide literature and research studies that were used to inform the implementation model designed and outlined in later chapters. This literature review will outline many of the concepts and issues related to aid-in-dying prescriptions and end-of-life care for a wide range of providers.

Assembly Bill 15

There are now five states with some form of legalized AID process. These states include: Oregon, Washington, Vermont, California, Montana, and now Colorado. California has adopted its process and legislature mostly from Oregon's Death with Dignity Act.

Adults, defined as an individual over the age of 18, can initiate the process of requesting AID prescription from their medical team. The patient must be determined to have a terminal illness that will cause them to die within six months. This determination must be confirmed by the patient's attending physician. The patient must voluntarily request the prescription and be determined to be mentally competent to make such a decision. According to the legislation, this is defined as "In the opinion of an individual's attending physician, consulting physician, psychiatrist, or psychologist, pursuant to Section 4609 of the Probate Code, the individual has the ability to understand the nature

and consequences of a health care decision, the ability to understand its significant benefits, risks, and alternatives, and the ability to make and communicate an informed decision to health care providers” (Assembly Bill 15, 2015). The patient must be a resident of California and be able to prove residency through several outlined requirements. They must be mentally and physically capable to self-administer the prescription. Being able to self-administer is defined as “a qualified patient’s affirmative, conscious, and physical act of administering and ingesting aid-in-dying drug to bring about his or her death in the method prescribed by the physician” (Assembly Bill 15, 2015), No individual can make a request for AID on behalf of the patient- this includes people such as power of attorney, an advanced healthcare directive, or conservator.

A patient starts the process by making two oral requests, a minimum of 15 days apart, to their attending physician. In addition to this, they must make a written request to their physician. At any time, someone may rescind their request or be in possession of the AID prescription and not ingest it at any point (Assembly Bill 15, 2015).

The attending physician must follow specific procedures and requirements. The physician must be able to determine that the adult has the capacity to be making such decisions. If the physician finds any reason to believe the patient is suffering from significant emotional distress or other mental health concerns, they must refer the individual to a more intensive mental health assessment by a mental health specialist. If the mental health specialist determines that a patient’s judgement is impaired because of mental illness, they may not acquire an AID prescription. If the patient is cleared by a mental health specialist, the patient’s physician must inform the patient of all the

potential risks of ingesting such a prescription and outline specific rules for ingesting the medication.

Before the prescription can be given, a second consulting physician must confirm all of the attending physician's findings. All documentation must be completed with the correct documentation forms established within the legislation and outlined in the patient's medical chart. In addition, certain documentation of demographics and information that does not violate patient privacy must be sent the State Department of Health for data collection (Assembly Bill 15, 2015).

Palliative Care

It is difficult to discuss California's End of Life Options Act without defining and considering the role of Palliative Care in this legislation and possibly as a part of the implementation process. Palliative Care Consultative Services (PCCS) can be defined as an interdisciplinary team that is meant to improve quality of life for patients. The team may be composed of physicians, nurse practitioners, nurses, chaplains, and social workers. PCCS can be located within inpatient or outpatient settings. PCCS is "designed to improve symptom management, promote understanding of prognosis and treatment options, clarify goals of care, provide psychosocial and spiritual support, and assist in planning post-discharge care" (Pantilat, Kerr, Billings, Bruno, & O'Riordan, 2012, p. 7).

A common misconception of Palliative Care is that these teams are only consulted to "convince" patients to pursue end of life options instead of the continuation of life-sustaining treatment. However, the team is much more valuable than this. PCCS has been shown to improve the quality of life of patients and their families, reduce the amount of

time a patient may have to spend in an intensive care unit in a hospital, decrease a hospital's overall costs, and improve patient satisfaction (Pantilat et al, 2012). Teams like this are critical to high quality patient care and especially at times of end of life. Unfortunately, the majority of primary care providers have no training in Palliative Care. This includes specialists who might deal with end-of-life issues on a more regular basis such as oncologists, cardiologists, or nephrologists (Pantilat et al, 2012). Because of this, PCCS are often highly utilized in these areas when treatment options for patients are limited.

Sixty-one to eighty percent of California hospitals have access to Palliative Care services (Pantilat et al, 2012). Unfortunately, most for-profit hospitals, small hospitals, and community hospitals do not have access to PCCS because they are the only healthcare providers for their area. "Outpatient and home-based palliative care programs in California have the capacity to serve only 24–37 % of patients in need, and 22 of 58 counties have no such services" (Pantilat et al, 2012, p.9). The majority of patients request access to AID in outpatient settings. Right now, outpatient PCCS are less easily accessible than that of those in inpatient settings. Palliative Care plays a role in how low the actual usage of AID prescriptions is and has been in other places like Oregon. When patients have access to PCSS, there is an opportunity for symptom management and for patients to have control over decision making. This means that they can be comfortable at the time of death while also wanting to access AID less often. If PCSS can address physical, psychological, and spiritual suffering then AID options would only truly be used as a last resort in the most appropriate cases (Pantilat et al, 2012).

Public Opinion

The debate over any AID practices has a lengthy history previous to the effective date of EOLOA in California on June 9, 2016. The development of current and past policies related to end of life issues has demonstrated the growth and change in public opinion surrounding these issues and services. The Hospice and Palliative Care movement gained momentum in the 1970's. In 1973, the development of the Advance Healthcare Directive occurred. The National Association of Social Worker's stance at this point was around the belief that competent people should state their choices for medical treatment or designate who should make health care decisions for them if they are unable to make them at any point (Luptak, 2004). Next came the Patient Self Determination Act in 1990. This was the first federal legislation to reinforce the right of competent adults to refuse life-sustaining treatment. This act also required that health care facilities that receive funding from Medicare and Medicaid inform patients, staff and the public about Advance Directives. Still, presently only 15-20% of Americans have Advance Directives, again demonstrating the need for quality implementation plans for institutions (Luptak, 2004). After this legislation, in 1994, the NASW made a statement related to client self-determination and end-of-life decisions. These decisions are based on the principle of patient autonomy and states that social workers should support individual choice of the client in all aspects of life and death (Luptak, 2004). This statement clearly leaves room for interpretation and has caused some of the debate over how to proceed with this ethical principle in actual practice with patients.

Many physicians face ethical issues that are currently not addressed by the law or implementation plans. The ethical discussions over physicians playing a role in a patient hastening death continue within the context of this legislation. Much of the ethical challenges exist within the medical practitioner context. Some believe that any role a physician plays with providing a patient with means to possibly end their life go against a medical practitioner's duties. Their ethical duties are framed from the perspective of "healers" and not from the perspective that Palliative Care of Hospice advocates take with end-of-life decisions. Other physicians believe that providing AID consultation or medication will destroy a patient's trust that the physician is or has been trying to find that patient a "cure" (Shaner, 2016).

Those who ethically support AID prescriptions think that if there is no way to "heal" the patient, then it should be up to the patient to decide how to proceed- many of these individuals take on a humanism perspective that aims to relieve suffering. This may be the only way to give patients a sense of control during the course of an uncontrollable illness. There are resources such as PCSS and Hospice care. Experts state that "Although many concerns of the dying can be adequately addressed by palliative or hospice care, these have limits with regard to the ability to restore lost autonomy, to promote personal dignity, to make life sufficiently enjoyable, and to lessen a patient's sense of burden on loved ones" (Shaner, 2016, p.5). This is the attitude of many physicians who have opted in to providing AID prescriptions. Some patients may be able to benefit from palliation of symptoms, but others may hold their independence and autonomy at a higher priority and opt for AID prescriptions from doctors whose ethics align with their individual beliefs (Shaner, 2016). This belief can be supported by a study done in 2008 that revealed that

end-of-life discussions are associated with less aggressive medical care when death is near and earlier referrals to resources such as hospice care. If a patient receives more aggressive care, this has been shown to have a poorer quality of life for the patient and more difficulty adjusting to loss. When good end-of-life care is implemented it results in less unnecessary treatment and therefore less costs for the hospital (Bomba, Morrissey, & Leven, 2011).

Part of public opinion includes those that will eventually be implementing care for individuals at the end of life. A study done in the *Journal of Social Work in End-of-Life and Palliative Care* looked at Social Work students' attitudes about end-of-life planning and their willingness to participate in work in this area (Kwon, Kolomer, & Alper, 2014). These studies demonstrated overall that students in health care settings had limited knowledge of end-of-life services. Their attitudes about end-of-life decision making were connected to their knowledge of these services and what they perceived to be their role in assisting with items such as Advance Directives. Factors that also influenced their attitudes were their personal and individual attitudes about death and comfort with conversations around death. Perceptions about end-of-life decisions were also associated with an individual's attitude about curative treatments, gender, level of education, socioeconomic status, race, and ethnicity (Kwon et al, 2014).

Multi-Ethnic Attitudes

Attitudes towards AID and EOLOA also vary within different areas such ethnic groups, ages, and spiritual beliefs. California is the first state to legalize such practices where the majority of the state is made up of individuals of different races and ethnicities.

Tracking the ethnic background of patients that request/utilize AID prescriptions will be important in order to find how faith, religion, culture, ethnicity, or spirituality can influence these requests. In addition, many worry that since California has such a large racially and ethnically diverse population that this could make certain populations more vulnerable to AID care for many reasons that will be discussed in later chapters. As of now, data reflects that age and spirituality are found to be the most determining factors of opting for requesting AID prescriptions (Periyakoil, Kraemer, & Neri, 2016). In addition, it has been found in other states that African American patients are more likely than white patients to opt for aggressive treatment rather than opting for hospice or EOLOA (Petrillo, Dzeng, & Smith, 2016). According to data gathered to this point, this appears to be due to years of unequal treatment from the healthcare system and the resulting in mistrust and lack of credibility among this population (Petrillo, Dzeng, & Smith, 2016).

Kaiser Permanente Hospital Organization has conducted one of the few research studies since the enactment of AB-15 legislation. The study used a year's worth of patient data collection. Their key implementation steps with the EOLOA process included: "surveying physicians about their willingness to participate after viewing an educational video; staff training regarding how to manage EOLOA requests, additional training was provided for volunteer physicians; volunteer pharmacists were identified to dispense and provide education on proper use of the medications; and training was provided for dedicated EOLOA-licensed clinical social work coordinators" (Nguyen, Gelman, Bush, Lee, & Kanter, 2017).

Within the year that data was collected, 379 patients made an inquiry into EOLOA. One hundred and seventy-six of these patients were determined eligible to proceed with AID process. Almost 130 of the patients that received the AID prescription ingested them and died within nine days after the prescription was written. According to patient data collected, the socio-demographics and end of life characteristics of patients were overall similar. Most were over the age of 55 years. There was a slightly greater number of males requesting the drug than females. The population was largely white with an education level of high school level or higher and an income of \$150,000 or greater. The two most common reasons that patients indicated for opting for EOLOA were that they not able to pursue activities that contributed to quality of life, they did not want to suffer any longer, and they had lost the ability to be autonomous. (Nguyen, et al, 2017).

Provider Participation

Much of the success and effectiveness of implementation of EOLOA revolves around the support given for the range of medical providers involved in the process. At the basis of the legislation, the laws are built to protect the right of healthcare providers to choose whether or not they want to participate in AID practices. This includes all disciplines found within medical settings and not just physicians. This aspect provides freedom for providers to participate or not depending on what may align with their ethical beliefs. This is a strength of the legislation and implementation process. However, this also may cause providers with ethical or moral distress. They may both want to respect their patient's autonomy but feel an obligation to "do no harm." Providers have also

voiced that there is a general lack of knowledge around the AID prescription and EOLOA process (Petrillo, Dzeng, Forbes, Scribne, Koenig, & Harrison, 2017).

So far, education has proven to be the best tool to reduce provider distress. There are different areas of education to be provided to different practitioners and settings. For all providers, education around the law and local policy is important to reduce distress and improve consistency in providing quality care for patients. Specific training for different clinical roles may include areas such as education for emergency providers to respond to failed AID attempts, how to approach difficult end-of life conversations for, cultural sensitivity, and when physicians should involve Palliative Care Services (Petrillo et al, 2017). Specific education for social workers and social work students is a necessary component of this and will be discussed in detail in later chapters.

Social workers are often the providers that are pulled into the team when an end-of-life decision is being made. This happens despite the fact that many Social Work curriculums do not have specific training that result on competence in this area (Luptak, 2004). This, again, emphasizes the importance in education for all providers. A study done of social workers in South Carolina who work with patients initiating the aid-in-dying process indicated that they had no specific practice guidelines for working with patients that initiate this process. They felt that it was the duty of any clinician to refer to a provider who is an “expert” in this area, however, it is not clear what criteria makes a practitioner an expert in this area. In addition, the NASW does not provide guidance related to when a social worker should be involved in these cases or for how long they should intervene. The results of this study demonstrate the need for education and

discussion around end-of-life participation for providers and outlined guidelines from each profession's ethical body (Manetta & Wells, 2001).

Implementation Problems and Suggestions

For California healthcare organizations, there was limited time between when EOLOA was signed into law and when it was implemented into action. Because of this, there was little time for organizations to prepare plans that would provide their patients and providers with a safe and streamlined process for accessing AID prescriptions. Many responses to the enactment of this law were to develop local policies or processes and start to implement provider education (Petrillo et al, 2017).

Research has shown that developing policy is important when implementing such a policy within healthcare organizations. Throughout the process of developing policy, an organization can decide their values and a common plan for responding to AID requests. Every healthcare organization that has seriously ill patients should have a plan for dealing with issues related to AID whether or not they opt in to allowing physicians to prescribe. Several issues can arise regardless of if the organization as a whole has opted in to EOLOA. An example of an issue that may arise is the existence of "destination patients" who travel to a specific healthcare organization just for the purpose of obtaining AID prescriptions. The dilemma of the organization then becomes if the healthcare institution constitutes the patient's home, how will they handle the patient ingesting the prescription there? This is just one of the many complex issues that can arise around this legislation and process (Petrillo et al., 2017). Policy changes also must ensure that providers get ongoing training to manage the needs- physically, mentally, emotionally, socially- of

growing numbers of seriously ill patients (Periyakoil et al, 2016). New policies may also add further safeguards to the existing legislation. This might mean aspects such as: requiring providers to receive certain credentialing to prescribe medications under EOLOA or mandating that patients are referred to Palliative Care before receiving AID prescriptions (Petrillo et al, 2017).

California itself has special considerations for implementation and policy creation. The state has a diverse economic status, race, and language population. In addition, California has the largest number of adults living with disabilities. The concern here is that certain groups that are at a disadvantage might disproportionately request AID prescriptions to save financial resources. Others think that these more vulnerable populations may resort to AID prescriptions instead of symptom management because they have limited access to quality healthcare. This makes it especially important for organizations within California to implement policies that ensure patients receive education around all options for end of life treatment and access to things such as interpretation services if necessary. Because of the cultural variation of possible patients, some fear that AID practices will devalue patients' lives and providers and patients will have much different ideas of what makes life worth living. Components of the California law pose challenges to approaching AID processes in a culturally competent way. The requirement that providers and patients have private conversations in order to prevent coercion may not be appropriate for patients from cultures that are group-based instead of individual decision makers. Limited access to the law also exists for poorer patients who cannot afford the prescription or limited education about the law itself (Petrillo et al, 2017). Healthcare institutions must be able to balance providing support to providers,

whether they opt in or out, and be able to provide quality care to patients who request AID prescriptions. In addition, California has a shortage of Palliative Care workers and limited budgeting for this specific area (Petrillo et al., 2017). This will need to be addressed to be able to implement the most effective processes (Petrillo et al, 2017).

Hospital implementation

Specific hospital organizations within California have taken their own implementation approaches in addition to what is already outlined within the legislation. For example, University of California at San Francisco's policy states that any attending physician who opts in to prescribing AID must have a credential that certifies he/she/they has had adequate training to explain all end of life options to patients. They also mandate that ALL patients asking for AID prescriptions undergo an evaluation by a mental health specialist, which differs from mandates set forth by the legislation. UCSF has opted in to providing care to patients around the EOLOA (UCSF Medical Center, 2016). Data about other hospitals' implementation plans are still forthcoming as this legislation is still relatively new to institutions.

Implications for Social Work

The position of social workers in the EOLOA process and implementation presents a complex scenario. Social workers, at times, are at the center of AID consultations. For example, outlined in the UCSF policy is the first step in initiating the process is to contact the social worker within that specific service. There is an intersection of social workers' code of ethics and individual perspectives. "NASW's position suggests that, for terminally ill people who are capable of making decisions, the

ethical responsibility to promote self-determination outweighs social workers' responsibilities to avoid doing harm, even if people choose to withdraw or refuse life-sustaining treatments" (NASW, 2003a; "End-of-Life Practice," 2003, p.57). The role of a social worker is also to ensure that any end of life policies and implementation practices are driven by patient choice, while considering the other ethical guidelines that social workers are professionally bound by.

Social workers should work to ensure that practices do not discriminate against vulnerable groups such as people of color, women, people with disabilities, and those within the LGBTQ community. They should constantly consider whether a patient's end-of-life decision is motivated by self-determination and not because that patient may suffer from a lack of resources. Social workers should continue to examine the influence of mental status on EOL actions. This means considering questions such as: should these services be extended to patients who may have dementia with an advanced directive and have previously expressed an interest in EOLOA? Within the day to day work, social workers can provide education to patients about all the options for their EOL care. "We can help people make informed decisions by attending not only to disease processes, but to the totality of health and illness, including biosocial, psychosocial, and cultural implications" (Mackelprang, Romel, Mackelprang, & Romel, 2005, p. 2).

Research and studies of social work students and providers illuminates that there is a great deal of need for education in this area for practitioners. In addition, this research reveals that education and experience translate to better patient care and more positive attitudes of end-of-life practices in general. In 1994, the NASW made their official

statement about care in this setting stating “End of life decisions are the choices made by a person with a terminal condition regarding his or her continuing care or treatment options. These options may include aggressive treatment of the medical condition, life-sustaining treatment, palliative care, passive euthanasia, voluntary active euthanasia, or physician-assisted suicide” (NASW 1994a, p. 58).

However, author Carol Wesley, points out that social workers must consider self-determination at the end of life within the social environment that the patient exists. Social workers must remember that the decisions at the end of life do not only involve the patient but the good of others in the environment (1996). This research also states that it is the duty of social workers to make “every effort to foster self-determination on the part of the clients” (Wesley, 1996, p.1). This duty translates to multidisciplinary settings, such as a hospital. Social workers can advocate for self-determination at the end of life in many different ways that do not necessarily result in the aid in dying process. Social workers can advocate for pain management, hospice care, education about the disease process, assessment for depression and competency, assistance with Advance Directives, and promoting the biopsychosociospiritual models to their institutions (Wesley, 1996). The goal is to promote quality of life for all aspects of the cycle including death (Wesley, 1996). This contributes to compassionate healthcare and aims to eliminate the idea that practitioners are supporting the hastening of death.

Looking Ahead

Research and assessment are a great area of need regarding implementation processes and policies related to EOLOA. Research should focus on unequal access for

patients who may qualify but cannot afford medication or lack resources to comply with the guidelines. Further ethical and moral examination is needed pertaining to the perspective that AID policies represent health care organizations and providers devaluing patients' lives. Studies about attitudes about death and dying and AID legalization will be useful. Further work toward the balance between protecting providers and providing access to patients should be developed. The influence, presence, and effectiveness of PCSS should continue to be tracked and assessed within the context of EOLOA (Petrillo, et al, 2017). Education for providers (and therefore patients) is one of the largest components that should be improved upon moving forward. Specific education improvements will be discussed in later chapters.

Conclusion

Care related to the end-of-life is complex and important. The legalization of California's End Of Life Act illustrates our society's progress toward the normalization of conversations and care around death. However, it also illustrates the complexity in implementing legislation that includes many ethical aspects and considerations for different providers. This literature aimed to provide an overview of the EOLOA process and how this legalization has impacted the many providers involved in the process. The next chapter will focus on the specific theoretical framework and subjectivity that this project has been designed within.

Chapter 3

Introduction

This chapter will outline the theoretical framework of my research project. Using the content and research from the previous chapter's literature review, I have formed a framework to structure my study and views as a researcher. This chapter will give insight to my personal positioning as a researcher on the topic of End of Life decisions and ultimately what would make an effective and thoughtful implementation plan for inpatient medical settings.

Theoretical Framework and Subjectivity

Becoming a part of the social work community is a privilege granted to me by the idea that the knowledge I am obtaining is viewed as legitimate by society. Individuals are socialized by means of some sort of education. Certain types of knowledge and education are viewed in a light that affords them privilege and power, such as the researcher in graduate school and eventually as a social worker (D'Cruz, 2004). This automatically puts me in a position of power when working with clients, and especially with patients within the healthcare system. Patients may have received differing levels of education from different places, but since those are not seen in the same light as my education, I am viewed as an "expert" in my work. It will remain important to always keep this in mind as a reminder that each individual is the expert in their own lives, their own experiences, and their own wishes when it comes to end of life decisions. In addition, all patients deserve the proper and full education about what all of their options are for healthcare if they are suffering from a terminal illness. This is a

value that has the most influence on my positioning of exploring the ways to best implement a policy that implements aid-in-dying options for patients.

In addition, I have been committed to those that may need an advocate or someone to help them obtain knowledge. This value guided the decision to pursue social work and research the ways to best implement a policy that deals with the lives of humans from a wide variety of backgrounds. While reading D'Cruz, I discovered that my idea of who may need an advocate or need knowledge is a perspective of mine only. Clients may not view themselves in this way, and I must be careful with this assumption.

The idea of varying levels of education making certain individuals more powerful than others is very apparent in a hospital setting. Medical providers are seen as the experts on patients' (clients') lives. They are imparting their knowledge and views onto patients and their families- even to the extent of feeling they know what is best for a patient and when to determine if the patient should or should not stop treatment and move towards end of life care. They do not often realize or take on the view that each patient is an expert on their experience and hold individual values that influence their decisions. D'Cruz's statement brings this issue to light when he says "Practitioners have a professional responsibility to be alert to the ways in which power operates through the ways of knowing. To be in a position to understand and name the needs and problems that others experience is to be powerful. To be in a position where others accord you the right to know and give credibility to your understandings is also powerful. And it is especially powerful to be able to secure, through legal requirement of voluntarily the

engagement of others in a range of mechanisms and approaches, treatments and care plans, and on the basis of these understandings.” (D.Cruz, 2004).

Social workers have a duty to bring this to the attention of others within the healthcare system. In the hospital setting, it will be important to bring this to the attention of all providers with the use of education. Providing education about how to have end-of-life conversations with patients from different cultures will contribute to an aim towards taking away from the power dynamic that already exists. Patient autonomy should also be a priority when thinking about implementation of this policy and the position of the researcher. Being an observer to this phenomenon has helped form my position as a constructivist within a large system.

Each patient has their own reality and state of being. They hold their own experiences. As a constructivist researcher in this setting, I believe that this extends to patients possessing the right to end their own life in a safe way if that is their wish. Holding my personal beliefs and values around this topic in mind will be important when designing an implementation process because I will need to be able to support those that opt in to providing aid-in-dying measures and those that opt out.

Patients in a hospital setting come from a wide range of backgrounds, races, ethnicities, cities, and experiences. This setting would lend itself to the opportunity to work alongside many different populations. Some are viewed as having less knowledge than others and therefore providers impose their “expertise” more strongly on those patients. It will be important to consider how patients and their families come to make decisions while in the hospital- were they able to stay true to their individual values and

beliefs, or were they persuaded by those viewed as the “experts?” Also, how do the experiences of those viewed as “more knowledgeable” because they may speak English or make more money differ from those that are put into a separate category for whatever reason? It will be important to keep data that informs whether certain populations received different messaging or access to aid-in-dying options in order to ensure that disadvantaged populations are not more vulnerable to this option.

The desired outcome is to design an implementation process that is patient-centered. The process of implementing a policy centered around accessing end-of-life options should consider the patient and their family first. The process should ensure a safe and reliable process for patients to be able access this kind of care or receive well-rounded education about where they can access this kind of care. Since this policy comes up in a healthcare setting, it will be important that strategies consider the large systems impact that must be factored in. The hospital setting includes many levels of power related to its existence as a bureaucracy. At the most basic level, strategies must include meeting providers at every level, providing appropriate education to the varying providers, and emphasizing the importance of this process for the system as a whole.

The idea of creating or improving implementation processes around the End of Life Options Act comes from experience the I have had in working with patients who suffer from terminal illnesses. I have witnessed first-hand several dynamics that contribute to a desire to want to streamline this process for hospitals. Several providers have demonstrated a fear around this policy mostly due to a lack of education given before the policy was implemented. There did not appear to be one source of support for

providers or way to access support if patients expressed interest in this option. In addition, there was a general lack of conversation happening between patients and providers around what options are available to patients when they are in a position of suffering at the end of life. When the topic is not readily discussed, patients and families seem to become afraid to initiate the conversation even though it may be what they truly desire.

At the most basic level, the I have found that bearing witness to human suffering was enough to put more thought into the process of accessing treatment that may give a patient a sense of control and end to their suffering. On differing levels, I became interested in the power dynamic in a hospital setting and how this may be contributing to who is able to access knowledge about all of the treatment options available.

Conclusion

This chapter established my viewpoint as a constructivist in the large systems-based setting of a hospital. This framework will structure my perspective in the following chapters throughout my research project. The next chapter will define certain medical and legal terms that will be used throughout my implementation plan and the rest of this thesis.

Chapter 4

Introduction

The previous chapter outlined the framework and perspective from which this thesis and implementation plan were born. The rest of the thesis and implementation plan will include terms specific to the medical setting or to the EOLOA legislation specifically. This chapter aims to define those terms for the reader for a more thorough understanding of the research project.

Research Questions

How can hospitals in California alter their implementation practices in accordance with the End of Life Options Act?

How will a more effective implementation plan of AB 15 improve patient care?

What have other hospitals in California succeeded in incorporating within their implementation processes with this policy?

What social work implications exist around End of Life Policy implementation?

Variable Definitions

Assembly Bill No. 15- "End of Life Options Act" (EOLOA)

"The End of Life Option Act (AB 15 or EOLOA) was put into law June of 2016 in California. This policy allows a resident of California with a terminal illness to request a prescription for medication that will end their life. California is the fifth state in the

country to pass this type of legislation- modeling the policy mostly after Oregon's Death with Dignity Act. AB 15 outlines procedures and documentation required for the process of requesting, receiving, and using lethal dosages of medication (Cain, 2016)." These procedures are meant to make sure that this prescription is only given to those who are fully informed and can make the decision themselves without outside influence. The following are patient protocol for obtaining such prescription. (This does not include protocol for other providers.)

1. "The adult (as defined by an individual over 18 years of age) must be diagnosed with a terminal illness that has been determined to be fatal within 6 months by their attending physician.
2. The patient must make two oral requests to their physician.
3. These oral requests must be made 15 days apart.
4. The patient must also provide a written request (the legislation details how this request should look) and must be signed by witnesses.
5. The physician must assess the patient's mental capacity to make sure they are choosing this option without the influence of others.
6. The physician must inform the patient of other options.
7. A consulting physician is required to certify the diagnosis and prognosis and the patient's mental competency. (if there are mental health concerns- either physician can request a mental health evaluation by other qualified providers)" (Cain, 2016)

Attending Physician

“The physician who has primary responsibility for the health care of an individual and treatment of the individual’s terminal disease” (AB-15).

Terminal Illness

“An incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, result in death within six months” (AB-15).

Palliative Care

Palliative care is medical care, provided across inpatient and outpatient settings, that focuses on relieving suffering of, providing comfort to, and supporting the best possible quality of life for patients and their loved ones, without respect to disease, prognosis, or other goals of care. Can occur alongside curative care.

Hospice Care

Hospice provides the relief of suffering to patients who are expected to die within six months, and who have decided to forgo further attempts at treatment with curative intent. It is most often provided within the home, but can also be offered in extended care facilities, acute care hospitals, or inpatient hospices.

Aid in Dying Drug

“A drug determined and prescribed by a physician for a qualified individual, which the qualified individual may choose to self-administer to bring about his or her death due to a terminal disease” (AB-15).

Capacity to make medical decisions

“In the opinion of an individual’s attending physician, consulting physician, psychiatrist, or psychologist, pursuant to Section 4609 of the Probate Code, the individual has the ability to understand the nature and consequences of a health care decision, the ability to understand its significant benefits, risks, and alternatives, and the ability to make and communicate an informed decision to health care providers” (AB-15).

Health care provider or provider of health care

“Any person licensed or certified pursuant to Division 2 (commencing with Section 500) of the Business and Professions Code; any person licensed pursuant to the Osteopathic Initiative Act or the Chiropractic Initiative Act; any person certified pursuant to Division 2.5 (commencing with Section 1797) of this code; and any clinic, health dispensary, or health facility licensed pursuant to Division 2 (commencing with Section 1200) of this code” (AB-15).

Informed decision

“A decision by an individual with a terminal disease to request and obtain a prescription for a drug that the individual may self-administer to end the individual’s life, that is based on an understanding and acknowledgment of the relevant facts, and that is made after being fully informed by the attending physician” (AB-15).

Hippocratic Oath

An oath embodying a code of medical ethics usually taken by those about to begin medical practice.

NASW Ethics

Professional ethics are at the core of social work. The profession has an obligation to articulate its basic values, ethical principles, and ethical standards. The NASW Code of Ethics sets forth these values, principles, and standards to guide social workers’ conduct. The Code is relevant to all social workers and social work students, regardless of their professional functions, the settings in which they work, or the populations they serve.

Opting In/Out Of EOLOA

“The bill would make participation in activities authorized pursuant to its provisions voluntary, and would make health care providers immune from liability for refusing to engage in activities authorized pursuant to its provisions.

The bill would also authorize a health care provider to prohibit its employees, independent contractors, or other persons or entities, including other health care providers, from participating in activities under the act while on the premises owned or under the management or direct control of that prohibiting health care provider, or while acting within the course and scope of any employment by, or contract with, the prohibiting health care provider.

A health care provider or professional organization or association shall not subject an individual to censure, discipline, suspension, loss of license, loss of privileges, loss of membership, or other penalty for participating in good faith compliance with this part or for refusing to participate in accordance with subdivision (e).

If a health care provider is unable or unwilling to carry out a qualified individual's request under this part and the qualified individual transfers care to a new health care provider, the individual may request a copy of his or her medical records pursuant to law" (AB-15).

Chaplain

A clergy member ordained to assist in spiritual care of patients in the hospital setting.

Mental health specialist assessment

"One or more consultations between an individual and a mental health specialist for the purpose of determining that the individual has the capacity to make medical

decisions and is not suffering from impaired judgment due to a mental disorder” (AB-15).

Mental health specialist

“A psychiatrist or a licensed psychologist” (AB-15).

Physician

“A doctor of medicine or osteopathy currently licensed to practice medicine in this state” (AB-15).

Conclusion

This chapter defined important terms that will be used throughout the implementation plan for inpatient medical settings and the discussion throughout this research about issues surrounding End of Life legislation. The next chapter will discuss the methodology behind the implementation plan and provide a logic model for components and desired outcomes of the plan.

Chapter 5

Introduction

Serving as a social work intern within the inpatient medical setting has exposed me to the many complex issues that providers face when providing quality care for patients. My experience specifically pertained to patients with rare hematological cancer diagnoses and treatments. Patients in this setting face aggressive treatment and are often facing end-of-life decisions. I was able to witness the suffering of patients and the desire for patients to be in control of the end of their own suffering. This emphasized to me the importance of options for patients such as California's EOLOA. At the same time, I was able to hear from practitioners first-hand about the lack of preparation for implementing EOLOA and the ethical distress this has caused. These factors contributed to my desire to design an implementation plan for an inpatient medical setting that may provide the structure and support providers and patients need for safe and quality care. This chapter will use the terms defined in chapter four to outline an implementation process that can be utilized by inpatient medical centers opting in to EOLOA. This chapter will outline the major components of an implementation model that will be later explained in detail in chapter six.

Table 5.1 Theory of Change Logic Model for End of Life Option Act

Research, Practice, Theory	Assumptions	Strategies	Results
<p>-Trauma-Informed Medical Care</p> <p>-Coordination of Care Model</p> <p>-Systems Theory</p> <p>-Empowerment/Advocacy Theory</p> <p>-Anti-Discriminatory Sensitivity Theory</p> <p>-Constructivism</p> <p>-Humanism</p> <p>-Cultural Humility</p> <p>-Intersectionality</p> <p>-AB 15 Policy</p>	<p>-Death and dying decisions should be patient-centered</p> <p>-Hospital staff should have a comprehensive implementation plan in place for responding to/implementing Aid in Dying requests</p> <p>-Unexpected issues may arise with vulnerable populations</p> <p>-Aid in Dying measures devalues patient's lives and hasten death</p> <p>-Unequal access exists for patients from more vulnerable populations</p> <p><u>Reasons for Providers "Opting Out" of Providing Aid in Dying Prescriptions:</u></p> <p>-Belief that this is a violation of the Hippocratic Oath</p>	<p>-Develop healthcare system policy that states values and practices of that system in relation to providing aid-in-dying prescriptions</p> <p>-Develop an Evidence-Based Implementation Plan for hospitals to use when/if "opting-in" to providing Aid in Dying prescriptions to patients within their healthcare system</p> <p>-Develop an Interdisciplinary Team as a resource for providers and consulting team for patients; using Palliative Care team or designated social workers for this team</p> <p>-Provider Survey</p> <p>-Provider Education</p> <p>"Clinician openness to discussion, regardless of personal ethical position, improves the therapeutic alliance and alleviates distress. Providers may need training to develop</p>	<p>-Specific healthcare system's policy about access to aid-in-dying measures is clear to patients</p> <p>-Clear communication and understanding of the system's process once aid-in-dying requests have been initiated (for its providers)</p> <p>-Streamlined process for patients with prepared providers to support patients</p> <p>-Comprehensive education for hospital providers</p> <p>-Increased communication between all providers and patients about the end of life</p> <p>-High-quality patient/family care at the end of life</p>

	<ul style="list-style-type: none">-Belief that this is a violation of personal ethics -Lack of education around the policies and procedures accompanied with legislation -Conflict between patient autonomy and do no harm -Moral/emotional distress	<p>these skills.” (Petrillo, 2017)</p> <p>-Data Collection measures</p>	
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To effectively and safely implement the End of Life Options Act (EOLOA) in hospitals within California, hospitals must develop and/or adjust comprehensive implementation plans. A critical component to the implementation process is the education of staff within the hospital about: the policy itself, additional procedures put into place at individual hospitals, end-of-life conversations, and moral/ethical obligations of providers versus providing patient-centered care. According to the National Institute of Health in 2017, “Education is an important tool that health care organizations and clinics can use to prepare staff and reduce distress; providers should be taught about basic aspects of the law and local policy. Providers in each clinical role in the health care system will have specific educational needs, such as training emergency providers to respond to unsuccessful PAD attempts. Undergraduate medical training and continuing medical education should teach health care providers about broad issues that are relevant to the care of all dying patients, such as cultural sensitivity, and how to approach difficult end-of-life conversations” (p.2). The training of providers is central to the implementation plan. This will accompany longer term objectives such as forming a multidisciplinary consulting team that will work on cases throughout the hospital when requested.

5.2 Program Logic Model for End of Life Option Act

Resources	Activities	Outputs	Short-term Outcomes	Intermediate term outcomes	Long-term outcomes	Impact
<p>-Recent and relevant research about end of life policies</p> <p>-Education Materials for both providers and patients/families</p> <p>-Interdisciplinary Representatives from many roles within hospital</p> <p>-Education/Training Time</p> <p>-Education/Training Space</p> <p>-Consulting trainers from other hospitals or institutions- draw on representatives from health care organizations across the state</p> <p>-Funds</p> <p>-Administrative Support</p>	<p>-Meet with implementing body of hospital (risk department) to discuss implementation plan</p> <p>-Work with administration to develop system policy (if one does not already exist)</p> <p>-Survey providers to find out what providers will opt in</p> <p>-Selection of Interdisciplinary Consulting Team (specific social workers and/or use of palliative care team)</p> <p>-Schedule of Training Times/Days</p> <p>-Creation of education material- research, presentations,</p>	<p>-Consult with other hospitals on their implementation plans</p> <p>-Provider participation in education opportunities</p> <p>-Created interdisciplinary consulting team for EOLOA cases</p> <p>-Increased provider and patient awareness and education of EOLOA process</p> <p>-Growing numbers of participants in training days</p> <p>-Feedback about level of education training gained</p>	<p>-Gained understanding of research and rationale behind EOLOA.</p> <p>- State-Wide conferences for providers to compare strategies and outcomes of process</p>	<p>-Growing number of medical providers "opt in" to EOLOA process</p> <p>-More open communication within the hospital about policies, procedures and ethics behind policy</p>	<p>-Providers consider care to be more patient centered (social factors become just as important as medical factors)</p>	<p>-Greater or more well-rounded patient care</p> <p>-More access for community members for this type of care</p> <p>-More states across the country pass similar legislation to AB 15.</p>

-Key Informants	information packets to leave with -Conduct education trainings -Finalize consulting team within the hospital for EOLOA cases -Survey providers about level of confidence and knowledge after receiving trainings					
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To begin designing a comprehensive and applicable implementation plan, I hope to speak with a key informant from a California hospital about their implementation plan and any challenges or successes they faced when EOLOA came into practice. This information will help me develop an achievable and applicable implementation plan. As previously mentioned, education of hospital staff will be critical to the plan. This will include staff trainings on items such as policy, protocols for the specific hospital, how to have conversations with patients, and concerns around ethical/moral obligations. I hope to be able to have consulting staff from other hospitals assist with the training. In addition, part of the process will be to create education materials that providers can continue to refer to after their training experience.

Further into the process, part of the plan will be to develop a multidisciplinary team that would be available for consults with patients who are initiating the process of AID medication. This will be a resource for providers to have a team to assist with such complex decisions such as this one. Another long-term goal would be that more providers feel confident in their education about the policy and process that they will opt in to be a physician of record who is willing to write an AID prescription. Ultimately, the goal is more well-rounded and high-quality patient care. In addition to this, creating more access points across the state and country for patients to receive the care they decide to have at the end of their life.

Outcome & Impact Evaluation

Criteria	Evaluation Questions	Data Collection	Who will be involved?	Data Analysis
<p>-Training participants' feedback</p> <p>-Feedback from patients and families who have gone through the process within the hospital</p> <p>-Administrative feedback</p>	<ul style="list-style-type: none"> • “Do I feel comfortable discussing all of the options available to patients at the end of life and initiating palliative measures to address patient needs? If not, do I know where to refer?” • “Do I know who among my colleagues is willing to serve as a consulting physician, and where to refer patients for mental health evaluations and hospice?” - “What education is necessary to prepare all providers (physicians, nurses, social workers, chaplains, administrative staff) to respond to requests, whether the facility opts to participate or not?” • “If the overall system chooses 	<p>-“Conduct interviews with patients, family members and health care providers in an effort to create case studies that will further inform how organizations adapt to the new law”(Schwartz, 2017).</p> <p>California department of health</p> <p>Town Hall</p> <p>Conference Participants' Input</p>	<p>-Hospital administration</p> <p>-Providers from wide variety of disciplines within the hospital setting</p> <p>-Patients and their families</p> <p>-Providers from different hospitals state-wide</p>	<p>-Qualitative analysis of feedback from different stakeholders</p> <p>-Quantitative Analysis (Increasing rates of request in AID, Cal Dept. of Health)</p>

	<p>to participate, how should it allow conscientious objection for individual providers and personnel while still ensuring continuity of care and access for patients?"</p> <p>-“Will there be a credentialing process for physicians who choose to participate?”</p> <p>-“Will the clinic or facility require any additional steps beyond the recommendations of the law (e.g., psychosocial evaluation, palliative care consult, advance care planning, hospice referral)?”</p> <p>• “What new resources need to be put into place to handle patient requests and comply with law requirements and any additional institutional requirements (e.g., patient</p>			
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	<p>navigators, educational materials for patients, checklists for staff, phone lines)?”</p> <ul style="list-style-type: none">• “Should the clinic or facility formalize a process for one-on-one conversations with patients as required by law, and for how to deal with patients that prefer family decision-making?”• “Who will be responsible for the collection and submission of forms, including the final attestation form?”-“How should the clinic or facility make all employees aware of the institutional policy?”• “Can inpatients begin the process of making a			
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	<p>request while hospitalized?"</p> <ul style="list-style-type: none">• "Can patients ingest an aid-in-dying drug at the hospital?" <p>(Perillo, 2017)</p> <p>-How would I rate the quality of care I/my family member received throughout the EOL process? (1-10, 1 being zero quality in care and 10 being the best quality care I could imagine receiving during this time).</p>			
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The evaluation process will incorporate different stakeholders- hospital staff who participate in trainings (physicians, social workers, nurses, mental health professionals, pharmacologists, administrators, etc.), patients and their families who complete the AID process, and providers from other hospitals state-wide. Different stakeholders will answer questions geared specifically toward their perspectives and relevant issues that may have come up for them. In addition to this, participants from the trainings will provide feedback before and after completing the education training. This will assess if they feel more equipped to participate in the AID process after completion of the training. Qualitative data analysis will be used to look at this feedback.

Quantitative data analysis will be performed on data already gathered by the California Department of Health. In addition, an analysis of how many more patients request the initiation of the AID process will be completed. This will indicate if patients are receiving the proper education and communication from providers.

Conclusion

This plan was created with patients suffering at the end of their life in mind. The aim was to design a plan that provided structure and support to both patients and providers in the inpatient medical setting. This implementation plan was developed with the use of research and data relating to implementation processes that are already in use in the state of California and research about the attitudes/knowledge of providers in these settings. In the following chapter, components of the process, values, assumptions, possible shortcomings, and efficiency will be analyzed in detail.

Chapter 6

Introduction

In chapter five, the skeleton for a model of implementation for EOLOA in inpatient medical settings was outlined. The plan generally states the components of the implementation plan and the outcomes that will result from the process. This chapter will provide detail to all of those components and the ethics and values behind the implementation plan.

Implementation Components for Stakeholders

Inpatient Providers

This implementation model rests heavily on the basis that it will provide support to all stakeholders within the EOLOA process. The legislation itself does not outline how institutions must structure their referral or education process for providers or patients in relation to accessing AID prescriptions. The legal requirements are put forth; however, this leaves institutions with the responsibility of designing a plan that properly supports their employees and healthcare consumers. The goal of this plan is to address that gap between legislation and implementation.

Providing education and training to inpatient providers is a critical component of the plan and one that has been missing based on research developed about implementation in other settings since the passing of the legislation. Each institution must determine who of their providers “opt-in” to providing EOLOA consultation within their specified role. This can be done with an institution-wide survey and by giving the

institution specifics about what providers need in terms of specific education. All providers within the inpatient setting should receive education about what the institution's official policy and process is for patients receiving AID prescriptions. Even if providers opt out, they will still need this information in order to properly refer their patient to the right next step. Providers who opt-in to provide AID consultation should receive specific EOL training. This will include components such as knowing all the options available for a patient- hospice care, palliative care consultation, AID prescriptions. They will need to know the components/procedures of the legislation and how to communicate these to patients in a comprehensive way. Each provider should have the knowledge of where specific roles fit into the process- from physicians to nurses to social workers to pharmacists.

In previous chapters, the concept of Palliative Consultative Services was discussed as a way to provide support from experts in a specific area. This implementation process includes moving toward that model for the AID process. An interdisciplinary team would be built that would then serve as consults when patients initiate the AID process. This team would receive specific training and credential for EOLOA and how to work with patients and families around these decisions. This would serve as an extra layer of support for providers and a "point-team" for questions, concerns, and needed modifications to the process as they arise.

Patients and Families

Once providers receive comprehensive education through training, they will be better able to educate the patient and their family on all EOL options. Patients should be

able to access information about all EOL options in a clear and comprehensive manner. Education and messaging for all patients and families should be delivered in a consistent way with a streamlined process. Education material such as packets or pamphlets will be developed to leave with the patient after an in-person consultation is made for patient and family reference throughout the process. Patients and families will have access to surveys that will allow them to give feedback about the quality of care received during this process.

Social Workers

Social workers will engage in further education and training, especially if a part of the interdisciplinary team. Whether or not social workers opt-in to providing consultation for AID processes they must receive specific training about the process to be able support their patients and other providers. In addition, training around how to notice and ensure all patients are receiving the same access and education will be important for social workers. Often social workers are the first to be consulted when other providers have ethical or moral challenges with practices or requests within the medical setting, so education/training will assist in social workers preparedness to handle these situations in a professional and ethical manner. Specific social worker education and training should be based on what research and research studies reveal about what practitioners report they need to provide the best care.

A study done in New York after a pilot program related to implementing end-of-life treatment trainings and ethics revealed aspects of education that should be provided to social workers in order to provide the best care with patients who are at the end of life.

Many of the practitioners indicated that they felt they did not have comprehensive education or training in ethics of other areas of end-of-life in order to provide well-informed care to terminally ill patients. Because of the lack of training and education, they reported more hesitancy in engaging in these discussions with patients, which then contributes to preventing patients getting the care they should receive (Bomba et al, 2011). Their responses in the study indicated that more knowledge and training were needed in the following areas: cultural/religious/spiritual differences, research on practices, psychosocial interventions, and state/federal legislation associated with end-of-life care ((Bomba et al, 2011). These areas were kept in mind during the design of the implementation plan and will hopefully be improved upon by the components outlined in the implementation plan. Many of these topics can also be addressed within social work curriculum for students. Curricular aspects will be addressed in the next chapter of this project.

Implementation Process Values

The structure and components of this implementation plan are based on my values as a person and the values set forth by National Association of Social Workers. This plan does not assume that each provider must possess the same values, but that all providers are committed to providing safe, efficient, and human-focused patient care. With this in mind, there are some values that hold more weight than others. However, it is important to note that ethical bodies, such as the NASW, do not state specific guidelines to follow in order to make ethical decisions, as previously discussed in the literature review. It is

important that social workers hold the values that contribute to patient autonomy but also the duty to the greater good (Wesley, 1996).

Cultural Humility

The healthcare system, and in this case, inpatient settings see people from all different races, ethnicities, religions, genders, areas of the country, and more. A hospital setting must prepare its employees to work with and appreciate individuals that may hold different values and beliefs than they may hold themselves. This becomes even more difficult to hold when concepts such as providing AID prescriptions or even discussing the idea of being a part of someone's process that will ultimately result in the end of their life. This is why the education/training given to providers must be from a cultural humility lens. No one person can ever be completely competent in every culture, however, we can work with strategies that may better our communication or techniques. All providers should have basic training around how to approach EOL conversations in a safe and sensitive way. It would be beneficial during the education/training to have providers think about the ways that different cultures may make decisions and how that might affect EOL decisions. For example, the law only allows for an individual to have a private conversation with their provider without their family present. This may cause distress for the patient if they come from a group-oriented culture, so it would be helpful for the provider to simply have this in mind when approaching conversations with the patient. This may come into play when gauging a patient's comfortability in talking about death as some cultures view speaking about death in a specific way. A provider must have opportunities to learn how to best listen and learn about their patient as a whole

person in order to provide the best care, especially when discussing possible AID interests. A provider's own culture may also factor in to providing care around this process which is why it is important that providers who opt in and opt out to being a provider for consults receive education. This creates a safety for the provider to know how to proceed if they feel their own culture and beliefs may stop them from providing care to the patient.

Institutional Accountability

Another value present in this plan is that of institutional accountability. How will an institution, such as a hospital, be held accountable for the type of care they are giving patients and families when consulting about EOLOA? One of the first steps for this stated in the research done by other institutions is that each institution must have a policy that states their position on the EOLOA. Are they opting-in institution wide? And if so, are there only specific providers that are willing consult for AID prescriptions? These clearly stated beliefs hold the institution accountable when patients come to receive care that the policy states are accessible at a particular institution. A part of the implementation process is also carefully designing surveys to give to both providers and patients/families. These should indicate how helpful education was for providers, their confidence in their abilities, areas of need, etc. For patients and their families, the surveys should be designed to indicate how families felt about the care they received and the experience of navigating the AID process. This holds both the providers and the institution as a whole responsible.

Developing and communicating the process for accessing AID prescriptions also holds the institution accountable. Without a clearly outlined process that is available to the patients, an institution could make decisions at the last minute or make different decisions in different situations which could lead to unequal treatment to particular types of patients. Outlining the process and designing materials to hand to patients that explain this process is an important portion of the implementation plan for this reason.

Power

Finally, the power dynamic in a setting such as a hospital was kept in mind when designing this implementation model. The legislation itself already grants a certain amount of power of the provider over the patient. The patient must “prove” and complete a large number of requirements throughout the process to be granted access to AID prescriptions. They are working to “prove” their need to the provider. This automatically gives providers power over a patient, their decision-making, and ultimately how they will choose to die. There is a certain amount of this that cannot be avoided based on the structure of our healthcare system and how this law has been outlined. However, there are measures that can be taken throughout this process that can contribute to a less extreme power dynamic.

Designing an interdisciplinary team that is available for consults can contribute to more fair treatment to patients. This means that several providers will be involved in the process and that one single provider’s beliefs are not influencing their treatment and communication to the patient. The development of a clear process and consistent communication to all patients is another way to take away from the power providers may

hold over patients. This comes with the education given to providers. All providers should know what options should be presented to patients, what messaging should be given to patients about the institution's policies, and how the process works. There is no "guarantee" that all providers will deliver on all of these aspects due to confidence or comfortability. However, the hope is that more and more providers will build confidence and communicate effectively to put the power back in the patient's hands. The surveys discussed previously may also reveal the power dynamics that exist in the institution that need to be addressed.

Outcomes

The short-term outcomes of this implementation plan are, firstly, an institution's gained understanding of the research and rationale behind EOLOA. This gained understanding will then contribute to the development of an institution's specific policy around EOLOA access for patients. The hope will also be that state-wide conferences will continue to happen that allow providers from different institutions to compare strategies of their process and learned outcomes.

As a result of provider education and training, intermediate outcomes will follow. These include more open communication about the AID process as a whole related to procedures, policies, and ethics behind the policies to providers, patients seeking care, family, social workers, and other providers working with a patient. As a result of clear communication and education, another outcome to work toward is gaining more and more providers who feel comfortable enough to opt-in to providing consultation around EOLOA. More providers who opt-in means more access for more patients in need. In

addition, this will contribute to normalizing the process so that it does not become a topic that people avoid or are afraid of. All of this will contribute to a long-term outcome of providers becoming overall more patient-centered and their views expanding to the idea of social-emotional, philosophical, and existential questions about the quality of life and the quality of death becoming as important as physical/medical factors that contribute to a patient's treatment and care at the end of life.

Challenges

In American culture, end of life and the issues/ethics that surround it are already challenging for many individuals to engage in conversations about or process actions related to this idea. Many individuals are divided ethically on the issue of physicians assisting patients in any way to reach the end of their life. This is one of the anticipated challenges of this plan, or any plan, that deals with such a controversial topic. A challenge will be to be able to provide a space where providers and patients can learn and discuss this option with comfort and safety.

There are also implementation limitations that arise when the type of medical setting changes. For example, the law states that an individual may not ingest the AID prescription in a public place. This includes the inpatient medical setting within a hospital. The implementation process then must be different for inpatient versus outpatient settings. This is a challenge that will require navigating around the legislation and clear communication with patients. Clear communication must also exist between an institution's different settings in order to act in a way that honors the institution's stated policy around EOLOA, but also follows the legislation's guidelines appropriately.

Pieces of the legislation also may contribute to challenges with the implementation process and provider confidence. One major area of difficulty is the portion about the role of a patient's mental health in determining if they can proceed with the AID process. If a patient has a current or past mental health diagnosis, a provider has concerns about depression/suicidality, etc. this can ultimately stop the patient from accessing care that may end their suffering. For providers who work with patients with terminal illness, it can be difficult to determine what patient may need additional mental health assessment to continue in the AID process or who may just be depressed due to the nature of their difficult disease status. It can cause emotional distress for providers and a gray area for institution on more complicated cases. This is an area that will need more development as the process continues, same as the other challenge areas discussed.

Implementation Model Appraisal

Appraisal of this model will need to link the policy with what is actually being done at the hospital setting. Does this implementation model satisfy all the guidelines of the legislation while taking into consideration patient autonomy, patient-centered care, and ethical decision making?

Data collection is one area not outlined by the legislation and one area greatly needed, based on the research about those hospitals already implementing EOLOA. Data collection is made more difficult because of guidelines that protect patient privacy; however, there is data to be collected that can assess the model and an institution's implementation of AID processes. Data around patient demographics can inform the process- are certain populations accessing this process more than others? Does this mean

communication is not fair and consistent when it comes to all populations? The number of patients accessing the process can also inform the efficacy of the model- if more patients are initiating the process, this may indicate to institutions that there is efficiency within the process.

Since much of this process and topic are connected with individual, institutional, and professional ethics, it is fair to assume that there are some ethical shortcomings within this implementation process. There are a variety of providers in the inpatient that may follow differing codes of professional ethics. Physicians must hold in mind their ethical code to “do no harm” while also making ethical decisions about whether a patient should continue with harsh medical treatment. Social workers must hold in mind the NASW code of ethics that respects the dignity and worth of a person and human autonomy while struggling with their individual ethics around the topic of EOLOA. This implementation plan aims to hold many aspects of ethical decision making by basing the plan on current research and what has worked/not worked in other institutions so far. Despite this, there will be flaws that must be improved throughout the process of implementation. In addition, since this legislation is new, the research and data on its efficacy is limited. As more data is collected, this plan and others can be altered to meet the needs of the variety of providers and patients.

Conclusion

This chapter’s aim was to give detail to the largest and most important components of an implementation for End of Life Options Act for an inpatient medical setting. The aim was to hold in mind the variety of stakeholders within this process,

values and ethics behind the process, and possible shortcomings of the proposed plan.

The following chapter will conclude with further implications for data collection, where to go from here, social workers, and the social work community as a whole.

Chapter 7

Introduction

The previous chapter presented an in-depth analysis of a proposed implementation plan for the EOLOA in inpatient medical settings. This chapter will serve as a conclusion for this thesis that will look at state policy implications, further research needed, what is needed in social work education, limitations of the plan, and where to go from here.

Policy Implications

The End of Life Options Act in California is the first attempt for this state to address additional options for patients who are suffering from terminal illness at the end of their life. Since this policy was recently enacted in June of 2016, there is much room for policy guideline and enactment changes. After 10 years, this legislation will expire if the state does not do anything further. In that time, there is room for development in certain areas such as the mental health component and decision-making/ingestion capacity. The mental health component could be amplified by including a specific assessment that should be used by practitioners and who should perform the assessment. In addition, it would be beneficial to tease out what mental health disorders automatically disqualify an individual. For example, many patients facing terminal illness endorse feeling depressed, but should this person be held in the same view as another who has a diagnosed depressive disorder? Right now, decision making can only be held by the patient. In the coming years, it would be worth considering how health care agents or surrogates could be a part of this process. If they are designated in a patient's Advance Directive to make health care decisions, then should this include when a patient wants to

end their life in a medically safe way? These ideas required a great deal of research and data to ensure measures can be taken with safety, however, I believe they are worth considering in the frame of providing patient-centered care.

Further Research

Because of the newness of this legislation, there is a great need for research and data collection. The department of health for the state of California is already collecting data through the forms that are required be filled out by physicians for patients that complete the EOLOA process. In addition to this, specific data collection can help inform the implementation process and possible changes that may be needed to be made to the legislation. There is a need for data and research about the process of obtaining AID prescriptions and populations of individuals are accessing these prescriptions most often. So far, research has shown that many patients that obtain the prescription find relief in just possessing the medication but do not actually ingest it. Because of this, specific case studies about those who do ingest the prescription could offer valuable information to research and providers. Ongoing studies and the patient and family experience of this process are also an area of research need.

Social Work Education

As a culture, we have not yet normalized conversations around death and dying. This extends into social work and social work education. Before social workers can provide quality care and counseling to clients, they must possess their own comfortability with the topic of end of life and all associated challenges that come along with this topic. Death and dying topics and ethics should be a component of any basic Master of Social

Work curriculum. Further than this, students should have the option to take courses geared toward terminal illness and what patients, families, and caregivers may experience and what options are available for care at the end of life. This should also include information about advanced care planning and how to discuss the tools that can be used for advanced care planning with any client whether at the end of life or not.

Based on my experience in the inpatient setting this year, there are specific areas that would be important for students to learn if they know they want to go into work that is specifically geared toward working with individuals who are at the end of life or who have a terminal illness. Students must learn the tools to assess their own values and feelings about death and dying before they can provide support to patients and/or caregivers. Education around current policies and resources for clients is also needed within the curriculum. Much of what is needed for students who want to go into this field is the experience of being in the presence of someone who is at the end of life and being able to assess what the needs are of that person or their family/caregiver. This cannot necessarily be taught in the classroom but can be provided in the form of more internships in settings that would provide this specific experience for students.

The study of social work students' attitudes towards end-of-life care previously discussed in the literature review also offered suggestions for specific curricular additions that may be beneficial. Their attitudes about providing end-of-life care were related to how they perceived their clinical role to be in these situations and that education/training may increase their competency, knowledge, clinical skills, and sense of preparedness. Specifically, students cited that the following should be incorporated into their social

work curriculum: end-of-life specific objectives and practice behaviors that link to core social work competencies, completing Advance Directives in class, discussions related to death/dying, a course specifically on death/dying, more opportunities in health care settings (Kwon et al, 2014).

Working with other professionals and holding their values and ethics is another aspect of teaching that would benefit social work students. Examining the NASW code of ethics more closely and really learning about ethical decision making could contribute to strengthening the skill of working with other professionals. In addition, creating courses and field experiences on ethical decision-making related to biomedical ethics situations at the end of life could provide rich learning experiences for social work students. Many times, the counseling requests may come from providers in another discipline about making difficult, ethical decisions and not necessarily just from the patient or client. Learning how to balance others' beliefs and your own is a skill that would benefit students in a medical setting or a setting with end of life exposure.

Social Work Practice Implications

The Journal of Social Work in End-of-Life and Palliative Care puts into perspective the undertaking that medical social workers take on when engaging in this type of professional work. The journal states in one of their articles, "The social worker has the skills to work with individuals in diverse environments, understand their social ecological contexts, and help them make meaning of their medical decision-making experiences. The social worker can perform an assessment of the patient and family situation and probe the psychosocial, emotional, and multidimensional aspects of what is

at stake for the patient. Assessment should include evaluation of pain and suffering. The charge of social work to initiate, facilitate, and support end-of-life discussions with patients, families, and surrogates, and coordinate discussions with other members of the health care team is a dynamic process role that positions the social worker as a central health care professional in the health systems. Social workers can be helpful in educating patients and families about the goals of palliative care at the end of life” (Bomba et al, 2011, p.21). The medical social worker is assumed to have all these competencies in addition to the ethical-decision making capacity that they may or may not have received education/training on. A study that looked at ethical issues within hospice care revealed that about only half of social workers received education/training related to ethics and bioethics (Csikai, 2004). What this means for practice is that more institutions must implement opportunities for social workers to build competency and that social workers hold a great deal of ethical responsibility.

Medical social workers must also hold the values discussed in previous chapters when trying to make ethical decisions. They must keep in mind their aspects of power and privilege that apply to working with patients in an inpatient setting. Many times, they are entering a patient’s space and initiating a conversation about a topic that could trigger different reactions depending on the culture of the patient (death). This automatically gives the power to the social worker. They also have the privilege to move in and out of the patient’s life as a healthy individual, whereas the patient may be bound to the hospital setting because of their disease or treatment.

In addition to keeping in mind the rights of the client to self-determination, a medical social worker must also advocate for public policy that can contribute to the good of society. Social workers should keep in mind the views of death of a patient's community while helping that patient make end-of-life decisions. The patient's individual decisions ultimately affect the community in which they live. Social workers should also advocate for the conversations about death and dying to be spread to the wider community instead of in individual cases only. Social workers can engage in advocacy by being a part of interdisciplinary ethics committees or community-based committees (Wesley, 1996).

Limitations

As previously stated, one of the largest limitations of this implementation plan and thesis is the lack of research and data available due to the newness of the legislation. There are only a handful of states in the country that have implemented this type of legislation and most recently is California. I was able to draw on plans and research already done by institutions; however, these implementation plans themselves have yet to be assessed for ethics and efficacy of the process. The design of my model will need assessment as well. This is a current limitation because assessment cannot be offered before it is proposed to an institution as a theory of practice. The lack of different perspectives is also a limitation of this design. My perspective is unique and heavily focused on ethics, values, and the social-emotional needs of a person. The perspective of a physician or administration, for example, would offer invaluable ideas about what the obstacles of this plan might be or other areas of need that I have not considered because

of my unique perspective as a social worker. This model will help social workers (and other providers) fulfill ethical responsibilities to patients opting for quality end-of-life care and create a structure for social workers to lead implementation of such policies.

Conclusion

Where does this implementation model go from here? Input from providers of different disciplines would be a good next step for this proposed implementation model. As previously stated, their perspectives would add valuable input to several areas of this plan. After that, this plan will be disseminated to the appropriate supervisors at my internship site- an inpatient medical setting in the city of San Francisco.

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