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HOSPICE SOCIAL WORKERS BELIEFS, ETHICS, AND VALUES: HOW DO
THEY AFFECT TERMINAL CLIENTS REQUESTING PHYSICIAN ASSISTED
SUICIDE?

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Jazmine Camacho
Jessica Huver
June 2020

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ABSTRACT

Since the enactment of California's End of Life Option Act in 2016, physician assisted suicide (PAS) has become increasingly relevant within the field of medical social work. As a result, social workers will find themselves educating and assisting clients on EOLO. Research suggests that the amount of education and training received regarding PAS all had an impact on social workers' perceived preparedness to discuss PAS as and EOLO. Additionally, research indicates that social workers collectively support and have a positive attitude towards PAS; however, there is little research that explores the extent to which a social worker's personal values and ethics affect interaction with terminal clients who request PAS. This study explores whether a social workers' personal beliefs, ethics, and values affect the end of life options provided to terminal clients. The study implements qualitative research methods by using semi-structured one-one-one interviews. Fifteen Hospice social workers were recruited as participants. Interviews were transcribed into written form and coded into general themes. The study found that although social workers identified with a religion, it did not influence the end of life options offered to clients. Additionally, the findings emphasized a need to increase training, education and develop a standard of practice for social workers who are required to counsel clients on PAS. Further research should be conducted to have a better understanding of how personal ethics and beliefs may interact with professional beliefs of social workers when interacting with clients who are requesting PAS.

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Jessica Huver

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Jazmine Camacho

DEDICATION

I would like to dedicate this to my family, especially my parents, and all my friends who supported me throughout this time. There was nothing but a constant flow of support from my friends and family throughout grad school, and I could not do it without my consistent “cheering section”. Thank you all for being such a positive inspiration for me.

Jessica Huver

I would like to dedicate this to my son, Jassaiah Jasson Yanez, for inspiring me to achieve my goals, always aim higher and never give up. This dedication also goes to my fiancé, Jasson Yanez, who was nothing but supportive throughout my graduate studies. Having a baby while in graduate school was not easy, but Jasson’s continuous, encouragement, love and support always kept me going. Lastly, I dedicate this to the person who has been my personal cheerleader since the day I was born, my mother, Araceli Urzua. You have been my driving force in pursuing my professional career. Your self-less acts and sacrifice to provide me with a better future did not go unnoticed. This is for our future. Los amo!

Jazmine Camacho

TABLE OF CONTENTS

ABSTRACT	iii
ACKNOWLEDGEMENTS.....	iv
LIST OF TABLES	viii
LIST OF FIGURES	ix
CHAPTER ONE: INTRODUCTION	1
Problem Formulation.....	1
Purpose of the Study	3
Significance of the Project for Social Work Practice	4
CHAPTER TWO: LITERATURE REVIEW.....	6
Introduction	6
Physician Assisted Suicide and the Law	6
Conscious Clause	7
Legal End of Life Options.....	7
Palliative/Continuous Sedation.....	7
Voluntarily Stopping Eating and Drinking (VSED).....	8
Hospice and Palliative Care.....	8
Social Worker’s Role in End of Life Options	9
Social Workers Attitudes Towards Physician Assisted Suicide.....	9
Preparedness, Competence and Training.....	10
Theories Guiding Conceptualization	12
Summary.....	14
CHAPTER THREE: METHODS	15

Introduction	15
Study Design	15
Sampling.....	17
Data Collection and Instruments.....	17
Procedures	18
Protection of Human Subjects	19
Data Analysis.....	20
Summary	21
CHAPTER FOUR: RESULTS.....	22
Introduction	22
Analyses	22
Data Thematic Results.....	28
Summary	45
CHAPTER FIVE: CONCLUSIONS AND RECOMMENDATIONS.....	46
Introduction	46
Discussion	46
Physician Assisted Suicide Experience.....	47
Physician Assisted Suicide Law	48
Physician Assisted Suicide and Personal Beliefs.....	49
Physician Assisted Suicide and Professional Practice	51
Physician Assisted Suicide Education and Education Recommendations	51
Recommendations for Social Work Practice, Policy and Research	54
Social Work Practice	54

Policy	54
Research.....	56
Limitations.....	56
Conclusions	59
APPENDIX A: INFORMED CONSENT	61
APPENDIX B: INTERVIEW GUIDE.....	63
APPENDIX C: PARTICIPANT FLYER.....	66
APPENDIX D: DEMOGRAPHIC SURVEY	68
REFERENCES.....	71

LIST OF TABLES

Table 1. Sociodemographic Characteristics of the Sample: Gender.....	23
Table 2. Sociodemographic Characteristics of the Sample: Age.....	23
Table 3. Sociodemographic Characteristics of the Sample: Marital Status.....	24
Table 4. Sociodemographic Characteristics of the Sample: Religious Affiliation.....	24
Table 5. Sociodemographic Characteristics of the Sample: Race/ Ethnicity.....	25
Table 6. Sociodemographic Characteristics of the Sample: Education.....	26
Table 7. Sociodemographic Characteristics of the Sample: Years of Social Work Experience.....	26
Table 8. Sociodemographic Characteristics of the Sample: Years of Hospice Experience.....	27
Table 9. Sociodemographic Characteristics of the Sample: Employment Status.....	28

LIST OF FIGURES

Figure 1: Social workers' comfort level in explaining Physician Assisted Suicide to clients.....	29
Figure 2: Social workers' experience and encounters with clients requesting Physician Assisted Suicide.....	30
Figure 2a: Social workers' initial encounter with clients who requested Physician Assisted Suicide.....	31
Figure 3: Social workers' knowledge on how to handle clients requesting Physician Assisted Suicide.....	32
Figure 3a: How social workers would intervene with clients requesting Physician Assisted Suicide.....	32
Figure 4: Social workers' knowledge of Physician Assisted Suicide protocols/guidelines.....	33
Figure 5: Social workers' familiarity with Physician Assisted Suicide under CA law.....	34
Figure 6: Types of training that would allow social workers to be comfortable in talking to clients about Physician Assisted Suicide.....	35
Figure 7: Social workers' training/education in end of life care.....	36
Figure 8: Social workers' faith and how it interacts with client care and the NASW Code of Ethics.....	37
Figure 9: Social workers' personal beliefs about Physician Assisted Suicide.....	38
Figure 10: Social Workers' beliefs and how those beliefs facilitate client care...	39
Figure 11: Social workers' religious stance on Physician Assisted Suicide.....	40
Figure 12: How NASW translates to Physician Assisted Suicide.....	41
Figure 12a: NASW interpretation of Physician Assisted Suicide.....	41
Figure 13: Themes regarding social workers beliefs on NASW developing guideline for Physician Assisted Suicide.....	42

CHAPTER ONE: INTRODUCTION

Problem Formulation

In October of 2015 the California End of Life Options Act (EOLA) was signed into law by Governor Jerry Brown. When this law was enacted there were conflicting views due to religious beliefs, ethics, and values. The differing views regarding Physician Assisted Suicide (PAS) dealt with whether PAS is a question of morals and ethics, or whether PAS allows for self-determination from a person who is terminally ill. EOLA allows for physicians to write a prescription for medication that will induce death. According to the "NASW Standards for Palliative & End of Life Care" guide (NASW, 2004) social workers are expected to demonstrate an attitude of compassion and sensitivity to clients and respect clients' rights to self-determination and dignity. In addition, social workers should be aware of their own beliefs, values and feelings and how they may influence their practice. The concept of PAS is one that raises potential ethical dilemmas within the social work field as it relates to patients' rights to self-determination and dignity. Although part of a social workers' job is to advocate and educate clients on the resources and options available to their clients, little research exists in addressing how social workers' personal values and ethics affect terminal clients requesting physician assisted suicide.

Due to the change in California law, not all medical social workers may feel adequately prepared to take on difficult discussions about PAS (Brennan &

Kinney, 2017). Even though the NASW provides standards for end of life care, there are no specific protocols for how social workers should practice under PAS, which can ultimately cause practical conflicts with the law. The lack of education and training within this subject matter leaves social workers ill prepared to effectively manage a sensitive topic like that of PAS. Hence, the more education or training a social worker receives, and the more familiarity with the laws surrounding EOLA, the higher the perceived preparedness by a social worker to engage in conversations about EOLA as well as other available options at the end of life. Furthermore, there is a positive relationship between a social worker's religious beliefs and the acceptance or denial of PAS as a viable end of life option (Brennan & Kinney, 2017), but it is yet to be explored to what extent this relationship will affect social workers' roles in end of life care.

One aspect that has been explored is that the more a social worker believes that their professional values align with PAS, the more likely the social worker will feel that PAS is an acceptable intervention (Gaston, 2016). While more social workers reported that professional values were more influential in how prepared they were for talking with clients about PAS, it was also noted that personal values had an impact on levels of preparedness. Those who noted that their personal values were more influential on their preparedness to talk with clients about PAS were less likely to be prepared to discuss PAS with potential clients than those who cited professional values as influencing their level of preparedness to talk to clients about PAS (Gaston, 2016). Although personal

values were cited as being an important part of how prepared they are to talk to clients about end of life options and PAS, there is not sufficient research that explains to what extent a social workers' personal values would affect their interactions and care with clients who request PAS information.

Purpose of the Study

The purpose of the study is to determine how a social workers' personal beliefs coincide with professional standards in the way that a social worker conducts an intervention with the client who is terminally ill. Currently, the NASW does not have a standard of practice for when a client is asking for PAS which can potentially raise ethical dilemmas for social workers who work with this population. Due to the lack of clarity as to how social workers should deal with clients requesting PAS, social workers are left uncertain and ill prepared to address PAS as a viable end of life option. Thus, there is a need to further explore how social workers currently deal with this topic and whether their personal beliefs and values affect the end of life options provided to clients.

Additionally, this study explores the social workers' competency regarding PAS legislation and how their approach to PAS align with their personal values and ethics. It is important that social workers are informed and knowledgeable about laws in order to navigate through complicated and conflicting legislation and give clients all options for end of life. Being knowledgeable about law is important for PAS since PAS is only legal in a few states, but legislation for PAS has been introduced in more than 25 states.

The research method that was utilized in this research study was an exploratory design due to limited research regarding PAS as an end of life option. The study consisted of fifteen semi-structured open-ended questions to explore the topic in depth and detail. In addition, this type of research design allowed the participants to provide detailed personal anecdotes and experiences that were essential for this study. Furthermore, the design selected gathered relevant yet unanticipated data.

Significance of the Project for Social Work Practice

The need to conduct this study ascended from the lack of research on how social workers' values and ethics affect terminal clients who request PAS. Additionally, the lack of clarity and guidance on how social workers should address and provide services to clients requesting PAS suggests a need for a professional framework that social workers can abide by. Although it is important that social workers understand the law and ethical implications behind PAS, it is equally important to explore and examine how knowledgeable and prepared social workers feel in addressing PAS as an EOLO. By exploring whether personal beliefs, ethics, and values decrease the chances of a social worker giving a client information on PAS, a platform or protocol can be developed to assist social workers to feel more competent and confident in providing clients with PAS information. Furthermore, an educational framework on the most appropriate and effective methods of educating clients about this EOLO can be beneficial to ease feelings of incompetence among social workers dealing with

terminally ill clients. Lastly, the potential development of such protocol can also help decrease ethical dilemmas among social workers as it relates to PAS. The question addressed in this study is: How do hospice social workers' values and ethics align with EOLA of California, and how do those values and ethics affect client care?

CHAPTER TWO: LITERATURE REVIEW

Introduction

The purpose of this chapter is to analyze the current law regarding PAS along with other end of life options available to those who are terminally ill and explore how social workers feel about those options. While most medical social workers encounter clients at the end of life, not all social workers have the education, competence, or training to handle discussions with the client about all end of life options. Personal beliefs may coincide with professional beliefs and change how a social worker would interact with a client at the end of life, resulting in social workers not giving all EOLOs to a terminally ill client.

Physician Assisted Suicide and the Law

Currently eight states allow PAS as a legal EOLO. California considers PAS to be legal pending a decision from the California Supreme Court on whether PAS is unconstitutional or not (CNN, 2018). California Legislative Information (2015-a) states that EOLA is authorized to stay in place until January 1, 2026.

SB 128 explains that a person who would like to request PAS must be 18 years old, have the capacity to make their own decisions, be free and clear of any mental disorders, be terminally ill with 6 months left to live, and be a resident of California (California Legislative Information, 2015-b). A person requesting

PAS must make two separate verbal requests along with one written request which must be done more than 15 days apart (California Legislative Information, 2015-a).

Conscious Clause

According to Sung (2017), medical staff do not have to give patients information about PAS if that person objects to the intervention based on religious and/or personal beliefs. Yet, another law states that medical staff who interact with terminally ill patients must give all plausible EOLOs, which would include PAS (Sung, 2017). Therefore, social workers' personal beliefs could affect the information given to clients who are terminally ill, and PAS could be left out of the choices given to a client for EOLO.

Legal End of Life Options

Social workers should be able to help any client despite religious or personal beliefs (Sweifach, 2011), but not all social workers believe that PAS is a viable EOLO (Brennan and Kinney, 2017). Social workers may not be prepared to talk to patients about PAS, which shows that it is important to be educated on all EOLOs for terminally ill clients.

Palliative/Continuous Sedation

Palliative or continuous sedation (CS) is where a terminally ill client in the last few weeks of life is sedated until death using medication and is not ever awoken. The difference between PAS and CS is that in PAS a client is over

medicated with the intention to cause death, whereas with CS a client is given just enough medication to keep them comfortable until death (Broeckaert and Leuven, 2011). CS is legally accepted throughout the U.S., but it is considered an ethical dilemma when it is used to expedite death (Quill, Ganzini, Truog, and Pope, 2018).

Voluntarily Stopping Eating and Drinking (VSED)

VSED is used with terminally ill clients and is a readily accepted EOLO due to VSED being seen as a client's right to refuse treatment (Jansen, 2015). VSED allows time for the family to say goodbye and get closure for the death of a loved one. In VSED clients stop eating and drinking, and medications are given to manage pain. VSED can be seen as ethically wrong since VSED can be considered a type of suicide (Quill et al., 2018).

Hospice and Palliative Care

Hospice care (HC) and Palliative care (PC) are both ethically sound EOLOs that help clients manage symptoms related to illness (National Hospice and Palliative Care Organization, 2006). PC begins once a person is diagnosed with an illness and can be used concurrently with treatments that may cure the illness, whereas HC begins when the client is expected to die and treatments are stopped, but symptoms such as pain are managed with medications (U.S. National Library of Medicine, 2018). Both EOLOs are accepted by society since both provide comfort care that will not directly result in death.

Social Worker's Role in End of Life Options

Social workers are responsible for helping clients and their family through the end of life process. Clients should be given all legal EOLO and the right to choose which option is best for their circumstance. When clients are allowed to make their own choice, then social workers are fulfilling the client's right to self-determination (National Association of Social Workers, 2018). Snow, Warner, and Zilberfein (2008), state that although social worker interventions are helpful in improving the quality of life of clients, the training for these interventions are often learned on the job. Typically, end of life care is not learned in social work programs, and evidence-based practices for end of life are not taught to student social workers (Snow, Warner, and Zilberfein, 2008). With little training, it is not clear how the Code of Ethics should guide practice for EOLO.

Social Worker Attitudes towards Physician Assisted Suicide

PAS has become increasingly relevant within medical social work since PAS is considered a viable EOLO. As a result, social workers have expressed certain attitudes towards PAS as it relates to their professional ethics and values. Oregon has been a focal point of research regarding attitudes and experiences with PAS since it was the first state to enact PAS in 1997. Miller, Harvath, Ganzini, Goy, Delorit & Jackson (2004) assessed social worker and nurses' attitudes towards PAS and it was suggested that $\frac{3}{4}$ of hospice social workers were in favor of PAS as an option compared to nurses. However, 22% also

reported not being comfortable having conversations regarding PAS with clients. Social workers reported it would be more comfortable for a client to initiate the conversation about PAS. Ganzini et al. (2002) shows that less than half of social workers and hospice nurses have cared for someone requesting PAS. Pomeroy et al. (1997) shows that 7% of participants stated there was never a client who wanted to discuss PAS, but 57% of the participants had experienced a client who wanted to discuss PAS. Ogden & Young, (2003) concluded that social workers favored PAS because of the belief that clients should have the right to self-determination and unnecessary suffering. In addition, social workers believed that they should be active participants with clients who were considering PAS to ensure that those clients' rights were being protected and not infringed upon by others.

The legalization of PAS affects several aspects of social work, particularly in the hospice sector as social workers deal directly with terminally ill patients that are near the end of life. As a result, social workers are expected to engage in such conversations to ensure that they are providing adequate EOLOs and respecting clients' right to self-determination. Overall, data illustrates that social workers collectively supported and had a positive attitude towards PAS.

Preparedness, Competence and Training

Social workers' level of preparedness is crucial in addressing EOLOs with clients. There are competencies and skills that an end of life social worker must

possess in order to provide adequate services for this population. Such traits include knowledge, values and attitudes (Gwyther et. al, 2005). Prior to moving forward in this area of work, the values and attitudes of the social worker should be analyzed and continually self-assessed. Self-analysis is considered a crucial first step because the fear of death and personal experiences with terminally ill diagnosis can directly impact a social worker's preparedness and willingness to effectively address PAS as an EOLO with clients (Black, 2005). Furthermore, with an increasing geriatric population, one can conclude that death and EOLOs will increase as a topic of interest, and social workers must be able to address such issues without hesitation. In 2017 the majority of persons that used PAS in California were white and educated (California Department of Public Health, 2018). With better training and willingness to address PAS, social workers can increase awareness of PAS within other cultural communities so that it is a viable option for all that qualify for PAS.

While there have been several studies that previously highlighted social work attitudes towards PAS in several states, there is limited research in addressing social workers perception of preparedness, training and competency as it relates to PAS. Kramer (1998) evaluated the perception of preparedness in assisting dying patients and their grieving families among second year Master of Social Work Students, and results found that social workers were slightly prepared to assist this population. Following this study, Csikai and Bass (2001) asked participants questions regarding how much education and training that

was received regarding end of life care, including PAS. The study showed that 18% of participants received social work program education and 21% reported that they received continued education on biomedical ethics (Csikai & Bass, 2000). While training in end of life care is embedded in most BSW and MSW programs as part of the academic curriculum, it is superficial. Kane, Hamlin, & Hawkins (2005) examined how prepared social workers were in assisting the elderly with EOLOs. The study concluded that participants felt prepared enough to provide support to clients during the end of life process. (Kane, Hamlin, and Hawkins, 2005). Respondents also regarded themselves as highly knowledgeable in the resources that were available to elders. Such responses suggest that there is a positive correlation between being knowledgeable about current resources and feeling prepared with assisting elderly clients with EOLOs (Kane, Hamlin, & Hawkins, 2005).

In conclusion, research shows that social workers have the necessary skills to address PAS, but there is a need for more in-depth training regarding PAS to ensure that social workers feel adequately prepared to address EOLOs with clients. Also, an increase in academic courses in universities can help ease the anxiety of addressing such topics in the future.

Theories Guiding Conceptualization

Due to the lack of research on how ethics of social workers affects care of clients, it is necessary to find a framework in which social workers can guide practice for working with terminally ill patients. Research has proven that care for

a terminally ill client goes beyond the client, and care must involve the entire family (Christakis and Iwashyna, 2003). Traylor, Hayslip, Kaminski, and York (2003) suggest that end of life decisions of one family member will affect another family member. Also, communication between families determines the grief process. Therefore, social workers must address the family unit when determining EOLO, especially regarding PAS.

McBride and Simms (2001) explain that the first step of the therapeutic process in talking about death and dying is for the therapist to be self-aware. The therapist must be aware of the many facets of the individual and family, including race, lifestyle, and community. Within those contexts a therapist can help a client to communicate needs and wishes to the family, and the family can start to cope with the clients' decisions. By including family in the decision-making process, therapists can eliminate abuse of PAS due to emotional or financial strain on the family (King, Kim, and Conwell, 2000). When looking at PAS from a family systems theory it is concluded that having family involved can help eliminate negative consequences or illnesses of family members due to the client's decision to do PAS. (King, Kim, & Conwell, 2000). Therefore, in this paper, researchers will use Family Systems Theory to determine how ethics and values of a social worker will affect their care of terminally ill patients.

Summary

Under the California End of Life Options Act, there are several EOLOs available to terminally ill clients including PAS. Although PAS has been a long-standing EOLO in California, research suggests that PAS is not typically provided or discussed by social workers to terminally ill clients. Data illustrated that while social workers collectively support PAS and had a positive attitude towards it, social workers reported only having some level of preparedness to discuss PAS. Additionally, the literature review indicated that the amount of education and training received regarding PAS all had an impact on social workers' perceived preparedness and willingness to discuss PAS as an end of life option. A family systems theory was applied and discussed as the most appropriate theory as it relates to PAS and the ethics and values that social workers will encounter as they provide end of life options to terminally ill clients. Overall, this study seeks to explore the extent to which social workers values and ethics affect terminal clients requesting PAS.

CHAPTER THREE:

METHODS

Introduction

This study explored the personal and professional beliefs and values of Hospice Social Workers and how these values and beliefs affected client care when explaining end of life options. This chapter will include details on how this study was conducted. The sections within this chapter will be the study design, sampling, data collection and instruments, procedure, protection of human subjects, data analysis, and summary.

Study Design

The overall purpose of this study was to explore hospice social workers' personal and professional beliefs, ethics, and values to see how they coincide when interacting with clients who are seeking options for end of life care. This project was an exploratory design since there was not much information regarding the End of Life Options Act as it was recently enacted into law in 2016 and PAS has only been recently included as a possible option for end of life care. This study was qualitative in nature since there can be a wide range of beliefs, values, and ethics seen amongst social workers in hospice care. This study included a semi-structured interview with open-ended questions for data collection that allowed Hospice Social Workers to answer according to personal and professional values, beliefs, and ethics.

One reason for using one-on-one interviews was to allow each social worker who was interviewed to respond openly and honestly without worry that responses were judged by others. Also, in allowing open-ended questions, personal and professional experiences could be given, and responses were not limited to a specific set of answers. With open-ended questions, different themes could emerge regarding beliefs about end of life care that previous research does not include. Because end of life care is a very sensitive subject, one-to-one interviews allowed each participant to add personal details to their experiences as well as explanations to beliefs, values, or ethics. Also, in interviewing each participant one-on-one the researchers were able to analyze non-verbal cues throughout the interview process.

While the researchers believed that a qualitative approach using interviews was the best approach, there were still some limitations to using this method. First, the process of doing individual interviews will be very time intensive. Each interview had to be transcribed and coded by the researchers, which could also be considered a limitation due to recording devices not always being clear enough to transcribe every detail of the interview. Another limitation to using interviews was that there was only a small number of participants due to the time it took with interviewing, transcribing, and coding each interview. With less participants, there were not as many viewpoints to look at. Lastly, with interviews there was the possibility of social desirability bias in which a

participant may have responded to a question the way that the participant felt the researcher would want them to answer.

Sampling

In this study, researchers used a non-probability sample that was not randomly selected due to the type of participants needed to be interviewed for the research. The researchers interviewed 15 Hospice Social Workers from multiple agencies in the Southern California area. In order to be recruited for this research project, social workers must have earned at least a bachelor's degree, but could also have earned a master's degree or PhD in social work. Approval for each agency where hospice social workers were interviewed was obtained by an agency administrator prior to the interviews. Some social workers were recruited using networking outside of the social workers' primary agency. Only hospice social workers were interviewed since this particular population has experience with clients who are terminally ill and searching for end of life care options.

Data Collection and Instruments

For this study, qualitative data was collected using live audio-recorded one-on-one interviews taking place between March 2019 and March 2020. For each interview, participants were given the purpose of the study, a description of the study, and an informed consent page. Prior to the start of each interview, demographic information for each participant was collected. The demographic information included: age, gender identification, marital status, religion or spiritual

belief, ethnicity, education, number of years as a social worker, number of years working in hospice, and employment status of the social worker.

The researchers conducted interviews that consisted of 13 questions with each participant using semi-structured open-ended questions. The questions asked were created by the researchers due to the topic being relatively new with the legalization of PAS. The questions that were asked consisted of questions regarding education and training in end of life care, experience in end of life care, personal beliefs, professional beliefs, how the NASW Code of Ethics guides practice, how comfortable clients typically were in asking about end of life options, and how comfortable the social worker was with talking about death and PAS. While this was a new instrument for collecting data, it helped to expand knowledge regarding how beliefs, values, and ethics guide practice with terminally ill clients who are asking about end of life options.

Procedures

To get the research project started, researchers contacted multiple hospice agencies to solicit voluntary participation with the social workers on staff. Prior to soliciting hospice social workers to participate in this project, agency administrator approval was given by each agency. Next, the researchers created a flier stating the goals and purpose of the study and asking for participation in the project. Fliers were given to the social workers on staff at each agency for the option to participate in the study, and the social workers were asked to contact the researchers if they were willing to volunteer. Other social workers who were

known by the researchers via professional networking were also asked to participate outside of their agency. Those social workers were also given a flier with how to contact researchers if the hospice social worker wanted to participate. Researchers then set up a time for each of the participants to meet at a neutral, private, and quiet location in order to conduct the interview. Each interview lasted between 5-20 minutes, giving participants enough time to answer each question thoroughly. Each interview was audio recorded by the researcher.

Participants were given a short information sheet asking about demographic information prior to the interview starting. Then, confidentiality was explained to the participant to ensure them that the information would remain private. Also, participants were given an informed consent form in order for participation in the study as well as to allow researchers to audio record the interviews, and participants signed these consents prior to the interview.

Participants were thanked for contributing to the research and the study was introduced and explained. The audio recording device was then turned on, and the interview began. At the end of the interview participants were reminded that at any point in time they can withdraw the answers they provided for the research project.

Protection of Human Subjects

Identifying information from each participant was not collected in order to protect the identity of each participant. In order to keep the information obtained in the study confidential, interviews took place in a neutral and quiet location.

Participants read and signed an informed consent prior to starting the interview. The audio recordings from the interviews were kept on a password encrypted USB drive and stored in a lock box. Upon transcription, pseudonyms were used instead of participant's names in order to keep information confidential. Immediately after transcription the audio recordings were deleted. All other documentation was erased from the USB drive one year after the completion of the study.

Data Analysis

In this research project, researchers gathered data via one-to-one interviews. After collecting the data, researchers prepared each interview into a transcript in written form. For this study, content analysis was used as the form of data analysis. Hsieh and Shannon (2005) explain that content analysis has been used often in studies regarding end of life care. Also, there are a few different types of content analysis that can be used based on the type of qualitative research being done and the amount of information already known on the subject. The method of content analysis that was used was conventional content analysis. In the present study researchers wanted key themes to emerge on their own. While there are some themes that researchers believed may develop, there were not any themes that were set in stone.

With conventional content analysis, researchers first transcribed the interview. Each researcher then transcribed every interview with nonverbal cues in mind. Next, the researcher read the transcript in its entirety. After the transcript

was read once, then the researcher reread the transcript word by word in order to start adding codes for each question with different concepts that emerged per question. After the researcher coded the transcript, then the codes were sorted into categories based on the relation to each other. After the codes were separated into categories, then the codes were sorted into a larger cluster of between 5-10 main ideas or themes that emerged with each question. Once clusters were formed, then the clusters were ordered from themes that emerged the most to those themes that were seen the least. Lastly, each cluster, code, and category were given a definition as to how it related to the question that it fell under. Then, relationships between categories were identified for the purpose of the study.

Summary

This study explored the beliefs, values, and ethics of Social Workers involved in end of life care of terminal patients and how those beliefs, values, and ethics affect client care. Interviewing Social workers one-on-one allowed for opinions to be expressed more freely without being judged. Also, interviews allowed for more or differing views to be expressed. Therefore, qualitative methods were the most efficient and effective way to perform this research study.

CHAPTER FOUR:

RESULTS

Introduction

For the purpose of this research, medical hospice social workers were used as the sole data source. While most of the medical social workers who participated in this research were obtained via directly contacting an agency for approval to interview, some participants were obtained via word of mouth and snowball sampling. Themes from each question participants were asked were grouped together based on how often similar responses were given to the same question. To understand the background of the participants, data were collected on participants that helped the researchers to understand how experience, religion, education, and other factors that can shape the responses to the questions that were asked.

Analyses

Tables 1 through 9 report the sociodemographic characteristics of the sample data collected from all participants in this research study via the demographics survey. Table 1 describes the gender demographics of participants. Eighty-seven percent of the participants were female, while only thirteen percent of participants were male.

Table 1

Sociodemographic Characteristics of the Sample: Gender

	N	%
Female	13	87
Male	2	13

Table 2 shows age demographics of participants. While the age range of participants is 25 to 65 and older, the most common age group for participants is 45-54 years old, with 33% of participants falling in this age group.

Table 2

Sociodemographic Characteristics of the Sample: Age

	N	%
18-24	0	0
25-34	2	13
35-44	3	20
45-54	5	33
55-64	4	27
65 and older	1	7

Table 3 describes the demographic data based on marital status. The most common marital status of participants was married, which comprised 47% of participants.

Table 3

Sociodemographic Characteristics of the Sample: Marital Status

	N	%
Single, Not Married	3	20
Married	7	47
Living w/ Partner	1	7
Separated	1	7
Divorced	3	20
Widowed	0	0

Table 4

Sociodemographic Characteristics of the Sample: Religious Affiliation

	n	%
Christian	3	20
Catholic	6	40
Protestant	0	0
Jewish	2	13
Muslim	0	0
Hindu	0	0
Buddhist	0	0
Atheist	2	13
Other	2	13

Table 4 reports demographic data that was collected based on religion. There was a wide range of different religions that were represented in this research, including Christian, Catholic, Protestant, Jewish, Muslim, Sikh, Hindu, Buddhist, Atheist and other. The most popular religion was Catholic, which comprised 40% of participants, followed by 20% of the participants who practice Christian faith.

In table 5, demographic data based on race/ethnicity is reported. Participants consisted of three different races: White/Caucasian, Hispanic/Latino, and Black/African American. The most common race of participants was Hispanic/Latino which consisted of 53% of the participants. Forty percent of participants were White/Caucasian, and seven percent of the participants were Black/African American.

Table 5

Sociodemographic Characteristics of the Sample: Race/Ethnicity

	N	%
White/Caucasian	6	40
Hispanic/Latino/Spanish	8	53
Black/African American	1	7
Asian/Pacific Islander	0	0
Native American	0	0
American Indian/Alaskan Native	0	0
Other	0	0
Mixed Race	0	0
Middle Eastern	0	0

Table 6

Sociodemographic Characteristics of the Sample: Education

	N	%
Less than High School	0	0
High School Diploma/GED	0	0
Some College	0	0
College	2	13
Master's	13	87
PhD/Other Advanced	0	0
Professional Degree		
Other	0	0

Table 6 shows data based on participants' education. Only two of the participants, or 13% of participants, earned a bachelor's degree, whereas thirteen participants, or 87% of the participants, earned a master's degree.

Table 7

Sociodemographic Characteristics of the Sample: Years of Social Work Experience

	n	%
Under 1 Year	1	7
1-2 Years	1	7
3-5 Years	2	13
6-9 Years	1	7
10-15 Years	3	20
15+ Years	7	47

Table 7 explains the demographic data based on participants' social work experience. The most common amount of social work experience among participants was 15+ years, which equated to 47% of participants, and twenty percent of the participants had 10-15 years of social work experience.

Table 8 reports demographic data on participants' experience as a hospice social worker. Most participants had between 3-5 years of hospice experience, which equated to 33% of the participants, and 27% of the participants had 10-15 years of hospice social work experience.

Table 8

Sociodemographic Characteristics of the Sample: Years of Hospice Experience

	N	%
Under a Year	2	13
1-2 Years	2	13
3-5 Years	5	33
6-9 Years	0	0
10-15 Years	4	27
15+ Years	2	13

Lastly Table 9 shows the demographic data based on participants' current employment status within a hospice agency. The data shows that 73% of the participants work full-time in hospice, whereas 20% of participants worked part-time and 7% of participants worked free-lance or contract.

Table 9
Sociodemographic Characteristics of the Sample: Employment Status

	n	%
Full-Time	11	73
Part-Time	3	20
Freelance/Contractor	1	7
Student Intern	0	0
Other	0	0

Figures 1 to 13 contain the themes that were discovered from the participant interviews based on the question that was asked. The themes were broken up per question to see how each theme relates to the type of question asked. The transcripts were coded after all interviews were conducted, then the themes were taken via the most used words and phrases given within each question.

Data Thematic Results

This research specifically studied the question: How do hospice social workers' values and ethics align with EOLA of California, and how do those values and ethics affect client care? This study was qualitative in nature and was used to explore differing opinions based on ethics, values, and beliefs within professional settings as well as personal settings. The data collected from medical hospice social workers helped to gain insight into how the participants ethics, values, and beliefs in professional and personal settings help to guide

medical hospice social work practice. Each question generated at least three main themes, and the themes varied based on the question that was asked by the researchers. The following section will highlight the themes generated from each question.

In Figure 1: Social workers' comfort level in explaining Physician Assisted Suicide to clients, the question asked was, "When clients have come to you seeking options to end of life care, how comfortable have you been at explaining Physician Assisted Suicide?"

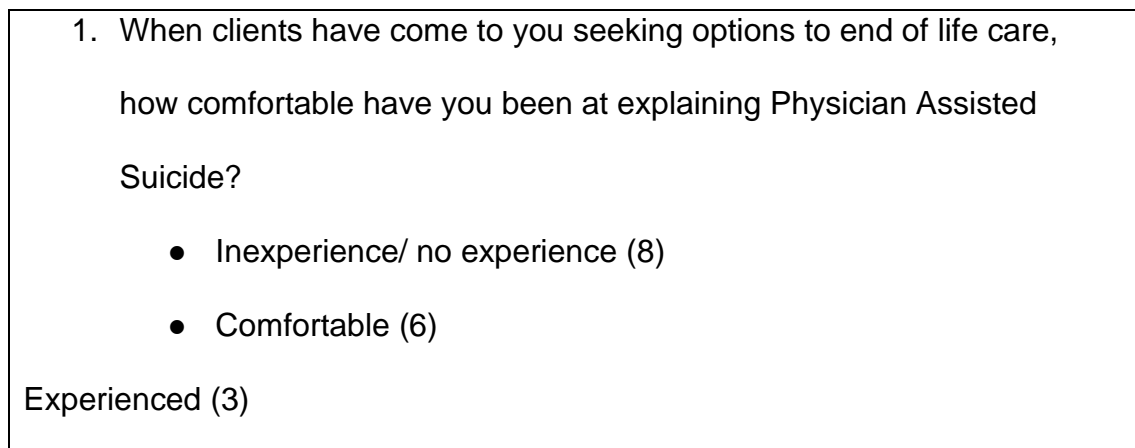


Figure 1: Social workers' comfort level in explaining Physician Assisted Suicide to clients

Based on that question the themes uncovered were inexperience/no experience, comfortable, and experienced. One participant noted "I've never had a client, or a patient come to me requesting information about physician assisted suicide" which is a prime example of what majority of the participants expressed

in the interview. One participant had an opposite experience and stated “I’m very comfortable discussing it with my patients and with their family members... It’s something we... have the privilege of offering here. Not every agency does, but we do.”

In Figure 2: Social workers’ experience and encounters with clients requesting Physician Assisted Suicide, researchers asked “Based on your experience, how many encounters have you had with clients requesting PAS as an end of life option?”

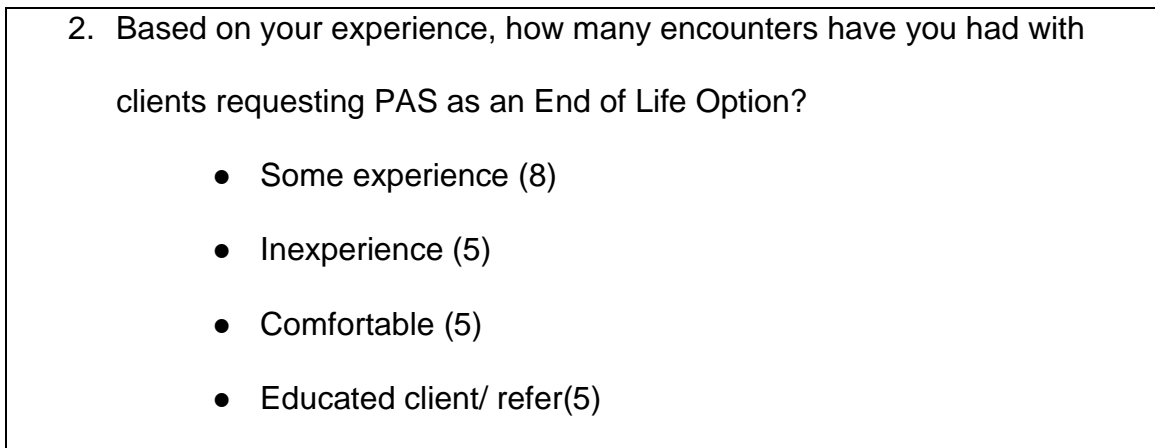


Figure 2: Social workers’ experience and encounters with clients requesting Physician Assisted Suicide

The themes that emerged from the question were: some experience, inexperience, comfortable, and educate client or refer client. A participant mentioned “ I have not had anybody ask, I’ve not had anyone mention or be curious about it” which was a sentiment of many of the participants, but there

were a few participants who had an opposing answer to this question. When asked "...how many encounters have you had with clients requesting PAS," one participant stated, "at least 10, probably more," which was an exception to most of the answers.

Figure 2a: Social workers' initial encounter with clients who requested Physician Assisted Suicide, researchers asked a follow up question from Figure 2 for participants who have experienced clients who wanted to know about PAS. The question asked in Figure 2a was "What was your initial encounter like? (Did you feel prepared, nervous, overwhelmed?)."

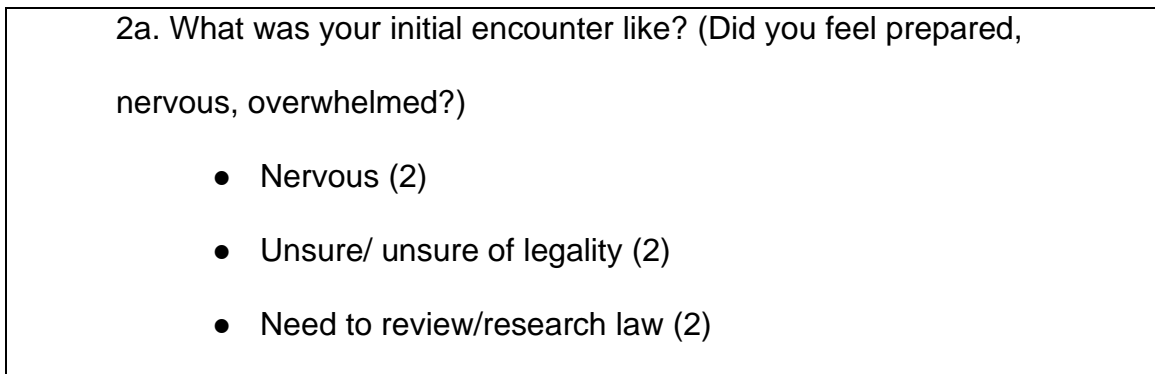


Figure 2a: Social workers' initial encounter with clients who requested Physician Assisted Suicide

Based on the follow-up question these themes emerged: nervous, unsure/ unsure of legality, and need to review/research law. One participant stated, "I haven't had any patients come to me, so I can't speak to the experience," which

is what most participants expressed. Another participant explained the steps to take when a client or patient requested PAS and when asked how she felt during times when clients or patients were requesting information on PAS, the participant stated “[I] just [felt] prepared” which shows how the themes contrasted.

For Figure 3: Social workers’ knowledge on how to handle clients requesting Physician Assisted Suicide the question “Do you know what to do if a client requests Physician Assisted Suicide as an End of Life Option?” was asked. Link to Resources and Experience/ well-informed were the themes that emerged from this question. Researchers found that linking clients to resources was the main theme for most participants, and one participant expressed this by stating “I think I would be comfortable in asking the questions and kind of giving them the information [they were requesting].”

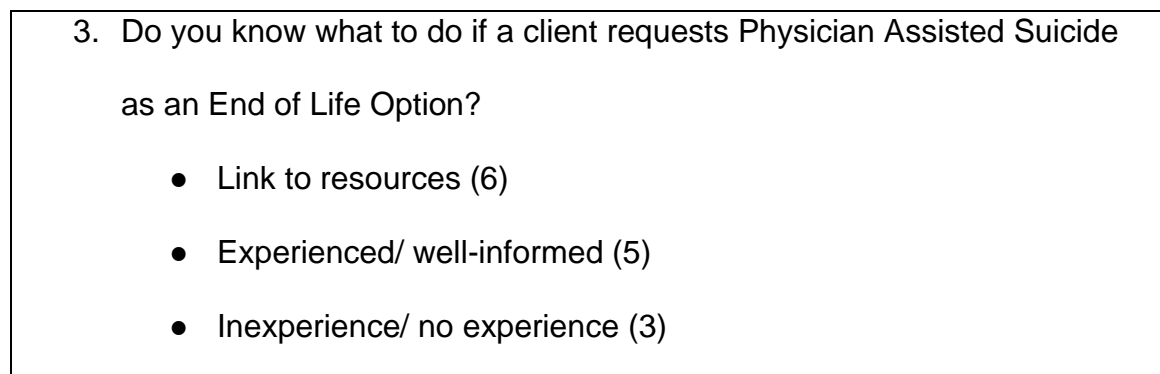


Figure 3: Social workers’ knowledge on how to handle clients requesting Physician Assisted Suicide

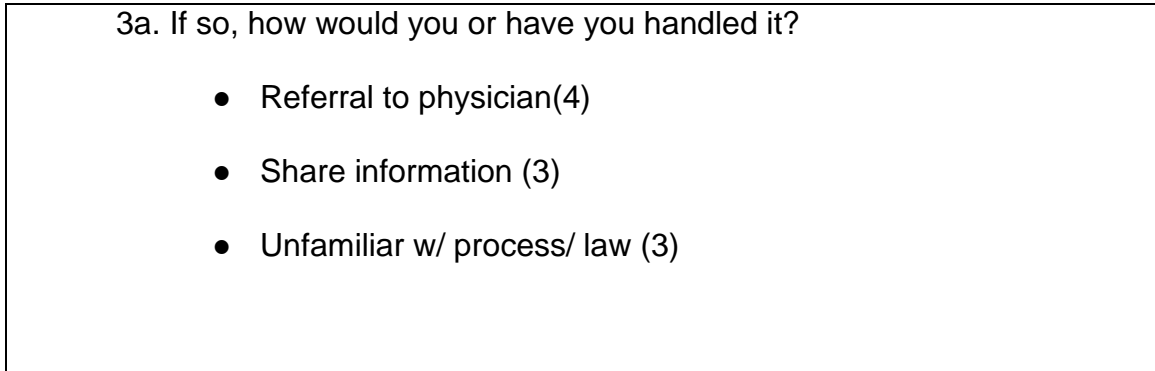


Figure 3a: How social workers would intervene with clients requesting Physician Assisted Suicide

Figure 3a: How social workers would intervene with clients requesting Physician Assisted Suicide was a follow-up question to Figure 3 where researchers asked, “If so, how would you or have you handled it?” The themes from this question were referral to physician, share information, and unfamiliar with process/law. More participants explained that the participant would refer to a physician and an example of this was one participant who explained “They have several websites and I can let [the patient] know that [the patient] can look on the website or [call] 1-800 number ... so they can have more information...[the patient] can get a referral for a physician that would be able to do the assessment for the patient because it requires two assessments.”

Figure 4: Social workers’ knowledge of Physician Assisted Suicide protocols/guidelines, the question that was asked was “Are there any protocols or

guidelines for social work practice regarding end of life care specifically PAS that you abide by or refer to?”

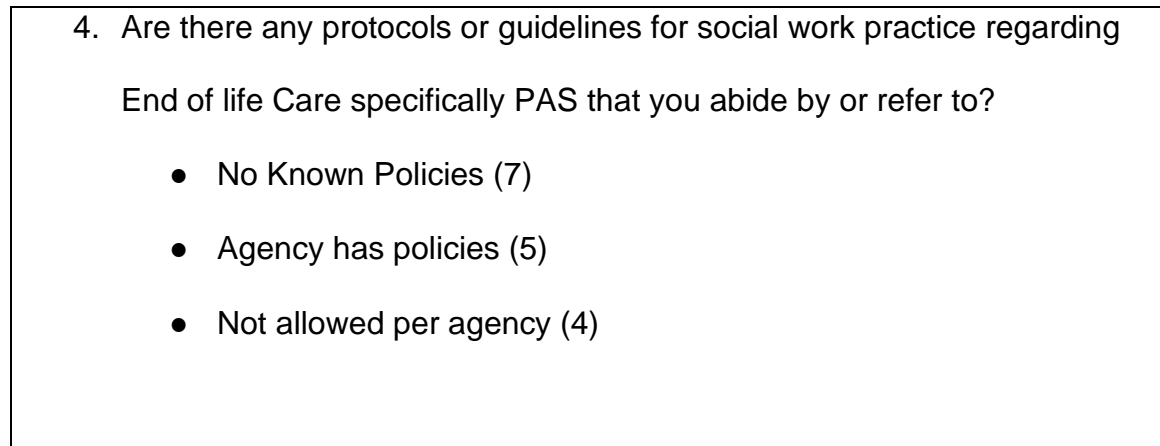


Figure 4: Social workers' knowledge of Physician Assisted Suicide protocols/guidelines

Based on the question asked in Figure 4, three main themes emerged: no known policies, agency has policies, and not allowed per agency. A participant expressed “Not here, because we were told that we don’t... do that here. That was kind of our administration’s response. So, we don’t have a policy per se” which is an example of how some of the participants responded to this question, whereas other participants responded differently like the participant who stated “We have our own agency policies that we follow. That we actually, we created. The social

workers [created]

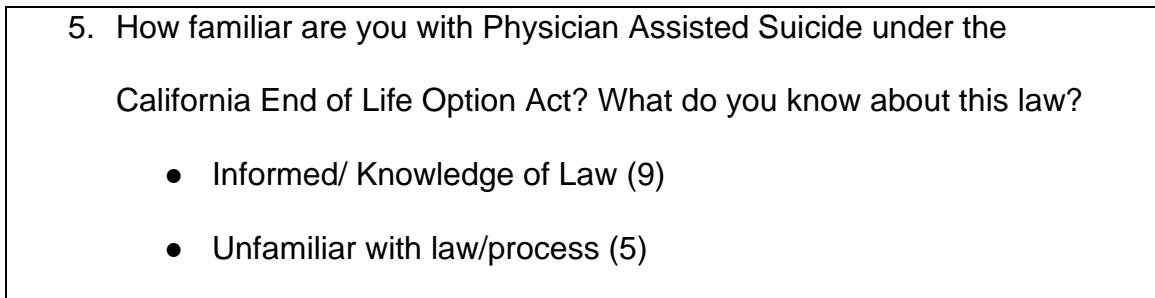


Figure 5: Social workers' familiarity with Physician Assisted Suicide under CA law

Figure 5: Social workers' familiarity with Physician Assisted Suicide under CA law asks "How familiar are you with Physician Assisted Suicide under the California End of Life Option Act? What do you know about this law?" After asking this question, researchers found that the following contrasting themes emerged: informed/knowledge of law and unfamiliar with law/process. One participant stated, "I'm not too familiar" which shows just one example of how some of participants responded, whereas another participant stated "[I'm] very familiar" which is an example of the contrasting responses that were given to this question. One participant went into more depth and explained "I know that you have to be a resident of California. You have to be able to make your own decisions. Nobody can do it for you. You can't have a health care agent do it and you have to be able to administer the medication yourself. ... you have to have a physician come and examine you to make sure that you're cognitively capable

and physically capable. And then, you have a second physician who, um, verifies that you have a terminal diagnosis. And then in our case, the first physician is the one who then will see you for a second time and provide prescriptions.” This participant was one of only a few of the participants that were able to demonstrate full knowledge of the PAS process.

Figure 6: Types of training that would allow social workers to be comfortable in talking to clients about Physician Assisted Suicide asked participants “What type of training or education would make you feel comfortable talking to a client about Physician Assisted Suicide?”

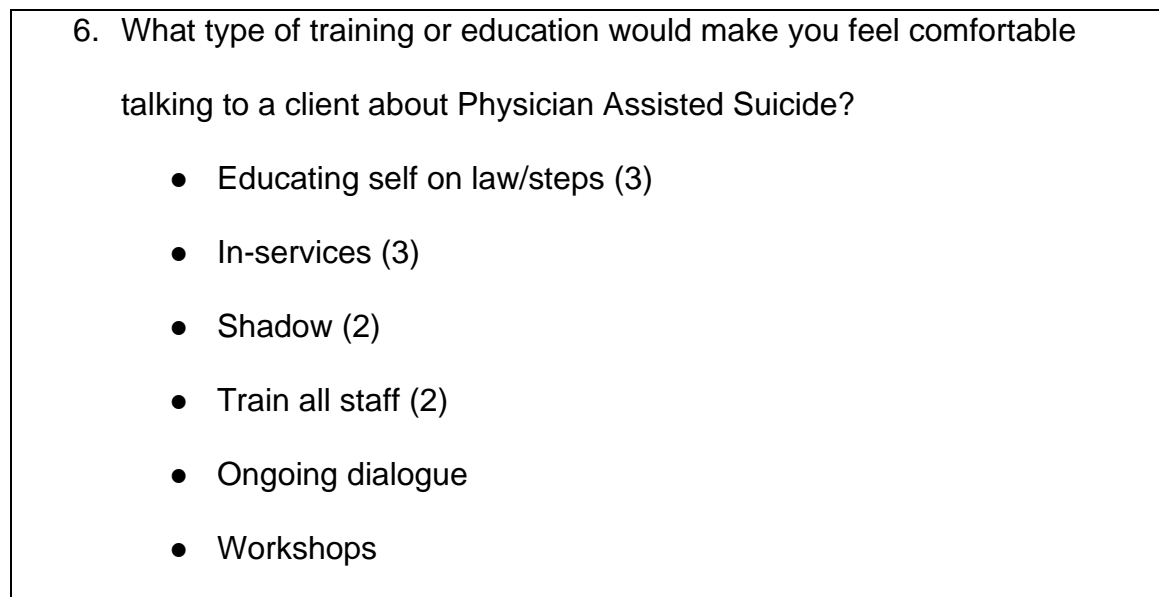


Figure 6: Types of training that would allow social workers to be comfortable in talking to clients about Physician Assisted Suicide

The themes that emerged from Figure 6 are as follows: shadow staff, train all staff, educating self on law/steps, in-services, ongoing dialogue, and workshops. One participant stated "... it's always been self-taught. So obviously I looked online and researched it" which is just one example of what participants responded to this particular question. Ultimately there were many answers that explain various ways that respondents felt would best educate them on the California End of Life Options Act.

7. Have you had any training or education in end of life care? If so, what did it consist of and how has it prepared you for interacting with terminal clients?

- Agency education (4)
- Self-education (4)
- Online training (3)
- Little training (3)
- Shadowing (3)
- Life/ work experiences (3)

Figure 7: Social workers' training/education in end of life care

Figure 7: Social workers' training/education in end of life care shows the question "Have you had any training or education in end of life care? If so, what

did it consist of and how has it prepared you for interacting with terminal clients?” From this question multiple themes emerged: agency education, self-education, online training, little training, shadowing, and life/work experiences. One example of a responses to this question was “I have had little training. Okay. So that’s all I can say on that.” Another participant explained “I have had some training and it’s been online... we’ve had some online education as a group,” and a similar response from another participant was “So, I haven’t had any formal training... it’s been based on being out in the field and experiencing it.” Many of the participants answered in a similar way to this question, stating the types of training and/or education that has been given to the participant within the participants’ career.

Figure 8: Social workers’ faith and how it interacts with client care and the NASW Code of Ethics the question asked was “How has your faith and/or spirituality interacted with what the NASW code of ethics states when considering end of life care options for your clients?” Based on that question the following themes emerged: self-determination, professional opinion doesn't matter, and faith has not interacted with end of life options. One participant noted “My faith has not restricted me in any way. I really think that that's up to our patients to decide and really it's our ethical responsibility to make sure that they're informed regardless of what our personal, religious orientation may be” which is a prime example of what the majority of the participants expressed in the interview. One participant on the other hand did not share the same feelings and stated “I am of

Christian faith and I don't, um, really agree with the end of life option. As you see I am having a hard time talking about it right now.”

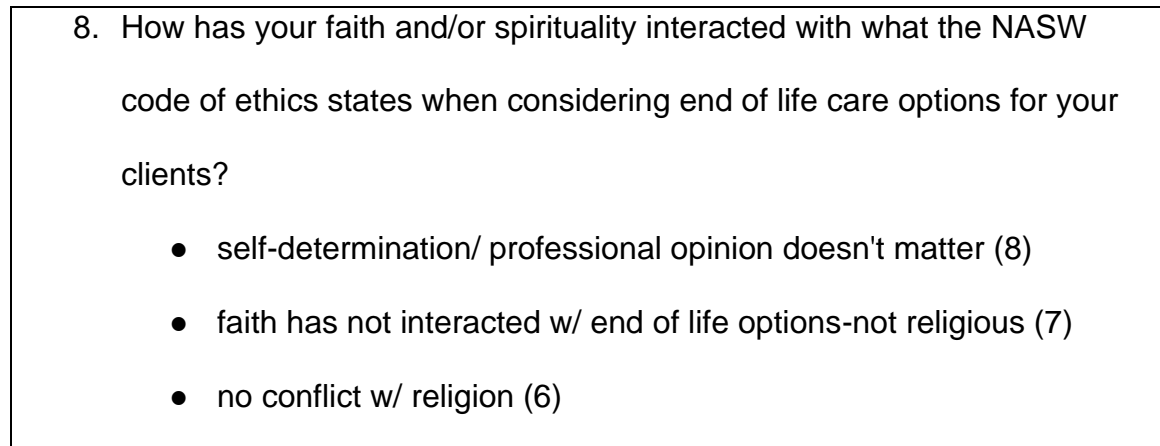


Figure 8: Social workers' faith and how it interacts with client care and the NASW Code of Ethics

Figure 9: Social workers' personal beliefs about Physician Assisted Suicide poses the question, "What are your personal beliefs about Physician Assisted Suicide?" Based on the question in Figure 9, three main themes emerged: dignity of self-worth, self-determination and wonderful option for terminal. One participant reported "You know, I think it's, I think it is a wonderful thing for people who have really horrible, you know, terminal illnesses that they're really not going to get better. Um, I think it's a, you know, a good option." Such a quote illustrates the most common theme that participants expressed. However, one participant did not share the same beliefs and feelings and stated "Yeah. I

just feel that it's wrong because I feel that you, um, have a day you are born or they, when you die and uh, you know, doing that physician assisted suicide is, is it's, um, against what I believe.”

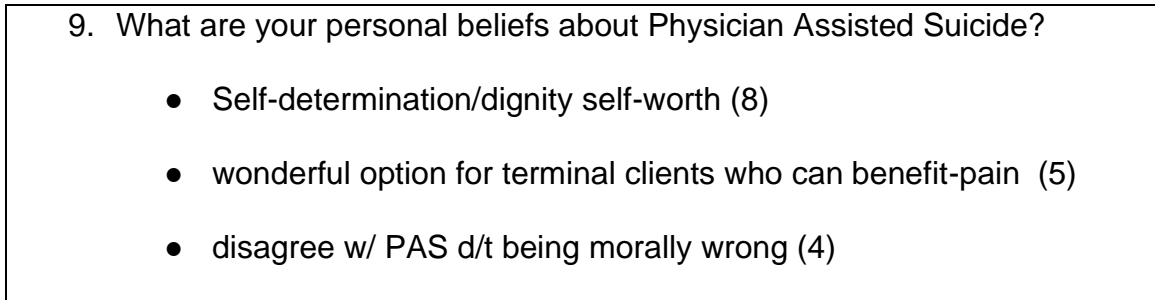


Figure 9: Social workers' personal beliefs about Physician Assisted Suicide

In Figure 10: Social Workers' beliefs and how those beliefs facilitate client care researchers asked, “Do your personal beliefs about Physician Assisted Suicide help facilitate your interactions and discussion with patients who request PAS as an End of Life Option?”

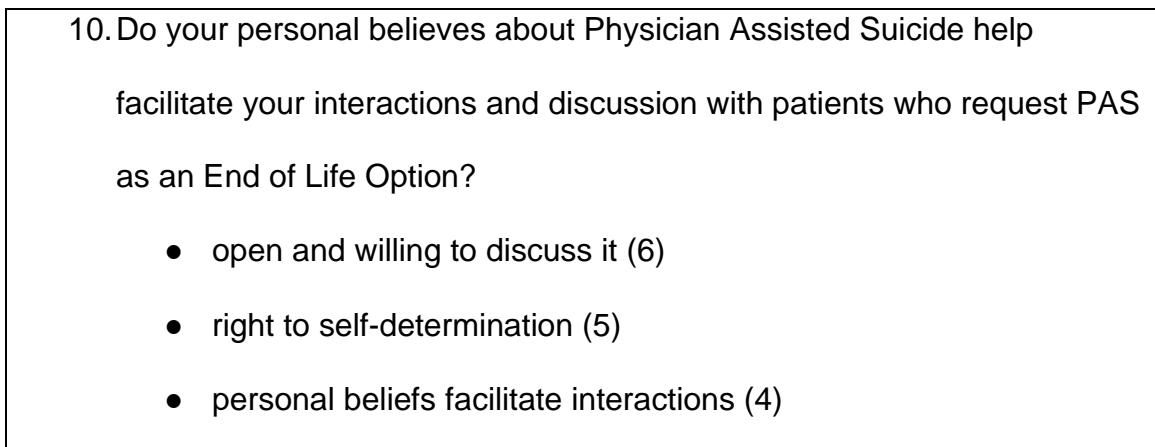


Figure 10: Social Workers' beliefs and how those beliefs facilitate client care

The themes that emerged from the question in Figure 10 were: open and willing to discuss, personal beliefs do not interfere with PAS interactions and right to self-determination. A participant expressed “I would say in a positive way because I'm open and willing to discuss it. Some people get really kind of squirrely about it and don't want to have a discussion and say, well, you need to talk to your doctor. Whereas I will openly discuss any subject with my patient whether or not I am in agreement or not” which is an example of how some of the participants responded to this question, whereas, another participant stated “The thing that's considered if you will murder. Assisted self-suicide is not something that we talk about. As you can see, I'm having a difficult time speaking about it” which is an example how some participants responded as well.

Figure 11: Social workers' religious stance on Physician Assisted Suicide inquires the following “What does your religion and/or spirituality state about Physician Assisted Suicide?” Based on the question asked, researchers found that the following themes emerged: religion states PAS is morally wrong, religion plays no part and unsure. One participant noted “I'm not sure what the Catholic states, cause I'm not practicing. I'm not, honestly, I'm not sure. Um, now I just consider myself more of a spiritual person. I'm not actively attending church, so I'm not sure what the catholic church stance is” which is just one example of what participants responded to this question. Ultimately, there were varied responses to what participants believed their religion and/ or spirituality stated about PAS.

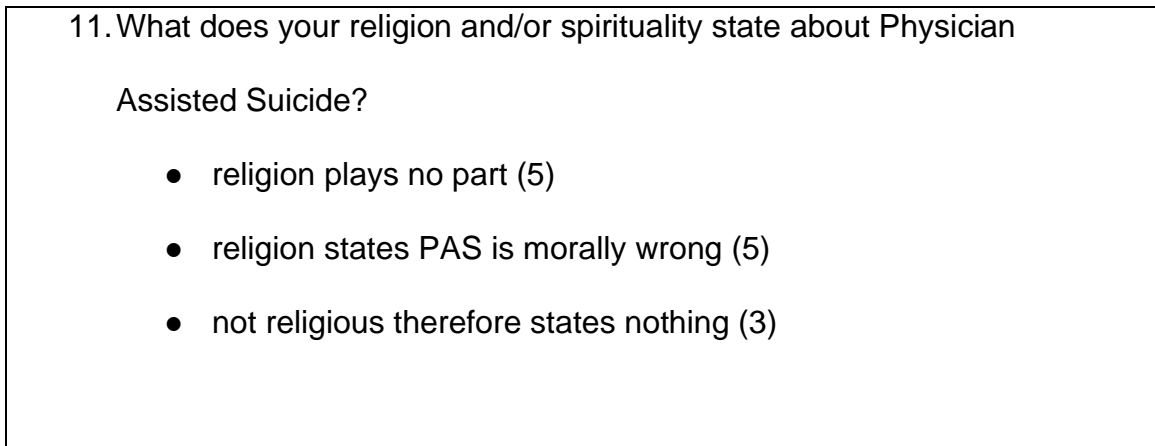


Figure 11: Social workers' religious stance on Physician Assisted Suicide

Figure 12: How NASW translates to Physician Assisted Suicide asked "How would you say the NASW Code of Ethics translates to Physician Assisted Suicide?" The themes that emerged from the question were: unsure how PAS relates to NASW, self-determination and dignity in death. One participant noted "All about the patient self-determination and dignity. You know, when you, when you watch people die there, a lot of their dignity is gone and the physician's assistant suicide or you know, aid in dying is what it is. Its technically not physician assisted suicide because you have to do it yourself. Um, but it's all about dignity and self-determination" which illustrates just one example of how most participants responded.

Figure 12a: NASW interpretation of Physician Assisted Suicide there was a follow up question to item 12 where researchers asked, "Would you say that the NASW Code of Ethics consider Physician Assisted Suicide to be ethical?" The themes that emerged from this question were considered ethical,

empowerment and acceptable. Most participants agreed that the NASW Code of Ethics considered PAS to be ethical and one respondent noted “I think that the NASW as it stands now, um, focuses on making sure that you provide, um, services that are again, being aware of your ethics, your biases, making sure that you are presenting the information, um, in a fair, um, and unprejudiced manner. I think that's extremely important. And the ethics, um, I think fall in line in general, but they tend to, I don't know, I should say this, but I think they, um, I think they are in line with that.”

12. How would you say the NASW Code of Ethics translates to Physician

Assisted Suicide?

- unsure how PAS relates to NASW (7)
- participate in decisions/self-determination (4)
- dignity in death (3)

Figure 12: How NASW translates to Physician Assisted Suicide

12a. Would you say that the NASW Code of Ethics consider

Physician Assisted Suicide to be ethical?

- considered ethical (4)
- empowerment (2)

Figure 12a: NASW interpretation of Physician Assisted Suicide

Figure 13: Themes regarding social workers beliefs on NASW developing guideline for Physician Assisted Suicide asked participants “Do you believe the NASW should consider developing a guideline or protocol for social workers dealing with clients requesting PAS? If so, why?”

13. Do you believe the NASW should consider developing a guideline or protocol for social workers dealing with clients requesting PAS? If so, why?

- guidelines needed to feel comfortable (7)
- national and statewide training needed (3)
- formalize/ provide direction (3)
- education needed nationwide (2)

Figure 13: Themes regarding social workers beliefs on NASW developing guideline for Physician Assisted Suicide

Due to the question posed, multiple themes emerged which were as follows: guidelines needed to feel comfortable, national and statewide training needed and formalize/ provide direction. A participant expressed “Yeah, well, I, I don't think a guideline can hurt. I think a guideline would be helpful. Um, just maybe formalizing it a bit more, providing, um, more support for the law itself and, um, giving social workers a little more direction. So, yeah, I definitely want to

think that's something to look toward the future.” Many of the participants answered similarly to this question and agreed that developing a guideline would be beneficial to social workers dealing with clients requesting PAS

Summary

For this research, key themes were found based on participants' answers to each question. Each question was transcribed, coded, and themed separately due to the nature and content of the questions. While some questions were situational, others were based on experience and/or personal beliefs. After coding themes for each question, several main themes emerged per question. Those questions and theme are reflected in the figures above. The research data that were collected helped researchers to understand that most participants were inexperienced and unknowledgeable about PAS and the law surrounding it. Although many participants were inexperienced and had minimal knowledge, the participants still felt comfortable in talking with clients regarding PAS and despite any personal beliefs surrounding PAS. Analysis regarding the results will be explained in the next chapter.

CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS

Introduction

In this chapter there will be a further analysis of the results found from this research study. Within the analysis there will be a discussion regarding experience with PAS, knowledge of PAS law, personal beliefs surrounding PAS, professional practice with PAS, and current education and education recommendations on PAS. Along with a discussion regarding the results of this study, there will also be information regarding the limitations to the study and what researchers recommend for future studies. This section will also speak to the implications of this research and how it can help to inform social work practice.

Discussion

This study highlights multiple elements that reflect how a social worker's personal beliefs, values, and ethics interact with professional standards set by the NASW in how social workers should interact with clients. While the NASW has not provided professional standards as to how a social worker should handle a client who is at the end of life and is requesting PAS, the research explores practices that social workers would feel more comfortable in exploring the PAS

option with a client. Some of the topics that are broached during the qualitative interviews in this research which will be explored further in this section include experience with PAS, knowledge of PAS law, how PAS relates to the social workers' personal beliefs, how professional practice relates to PAS, and education and education recommendations on PAS, with an emphasis on social worker recommendations for educating clinicians on PAS to further the knowledge and understanding of the law and be able to incorporate the law into professional practice.

Physician Assisted Suicide Experience

Miller et al. (2004) explains that while most hospice social workers in their study felt that PAS was a viable option, only 22% of them were comfortable with having conversations with clients about PAS. In the current study, 53% of participants stated that they had little to no experience in working with clients who have requested PAS. Of the 15 participants in this research, only 6, or 40%, stated that they would be comfortable in explaining the PAS option to a client when and if a client had asked about PAS. In a similar study, less than half of social workers who were interviewed had actually cared for a patient who had requested PAS (Ganzini et al., 2002). Although most social workers who were interviewed in this study had no experience with PAS and had not had a client who requested PAS, 40% of participants did mention that if a client had contacted the participant regarding PAS, that the participant would know how to link the client to the proper resources, but 20% of participants had little to no

experience regarding how to go about working with a client who wanted more information regarding PAS.

The lack of experience or knowledge of PAS can be very detrimental to patient care and the patient's right to self-determination which is embedded within the NASW's Code of Ethics (2018). Social workers should be able to provide the highest standard of care to their clients, and clients have the right to know all the options available regarding their care. Pomeroy et al. (1997) shows that 57% of the social workers who participated in their study had a client who had wanted to discuss PAS at some point in time. If patients are asking for information, yet social workers are unable to provide the answers or relevant information, then the social worker is doing a disservice to the client. Therefore, the results of this study support previous studies indicating that social workers feel uncomfortable and inexperienced in caring for a client who is interested in PAS, and there should be more education and training opportunities on PAS law and end of life care for social workers.

Physician Assisted Suicide Law

Social workers should know the current law and the agency policy regarding PAS in order to have client conversations surrounding PAS as an end of life option. In this study, 46% of participants stated that there were no policies that they could refer to in order to help guide their practice. Thirty-three percent of participants stated that the agency had policies that the social worker must follow, but 26% stated that the agency did not even allow social workers to talk

about PAS. Among the 15 participants, only 60% were actually informed of the current law surrounding PAS, whereas 33% were completely unfamiliar with the law or the process surrounding PAS. First and foremost, knowing the law is an important part of social work practice. Previous research showed that social workers should be informed on the current law that may affect their patients so that social workers can ensure that the clients' rights are not being infringed upon by any other persons, and the social worker can advocate for the clients' rights to be protected (Ogden & Young, 2003). Gwyther et al. (2005) state that hospice social workers must possess specific knowledge, values and attitudes in order to successfully provide hospice clients with adequate services. Therefore, it becomes an issue when hospice social workers are unknowledgeable about the law surrounding possible options for end of life care in terminally ill clients.

Physician Assisted Suicide and Personal Beliefs

The "NASW Standards for Palliative and End of Life Care" guide (NASW, 2004) states that social workers are expected to demonstrate an attitude of compassion and sensitivity to clients while recognizing their beliefs, values and feelings and how it may influence their practice. Brennan and Kinney (2017) found that there was a positive relationship between a social worker's religious belief and the acceptance or denial of PAS as a viable end of life option. However, the previous study did not explore the extent to which this relationship affects the social workers' role in end of life care. The current study was, however, able to further explore the relationship between a social worker's

religious and personal beliefs as they relate to PAS and revealed that although 40% of participants identified as Catholic and 20% as Christian, most of the participants stated that their religious background did not influence or interfere with the delivery of services. Additionally, the participants shared that their personal beliefs towards PAS did not affect their interaction with patients who requested PAS as an end of life option. While this study illustrated that most social workers had personal and religious beliefs about PAS as an end of life option for clients, they ultimately reported that it was the clients right to self-determination to choose their end of life option.

In a similar study, Ogden and Young (2003) concluded that social workers favored PAS due to the belief that clients should have the right to self-determination and unnecessary suffering. Based on the responses provided by participants in the current study, it was evident that although some participants may identify as religious or have personal feelings about PAS, the participants ultimately adhere to the NASW Code of Ethics and respect their clients right to self-determination. Social workers should be aware of their religious and personal beliefs and ensure that they don't try to influence clients' end of life decisions due to the social workers' own personal beliefs. Furthermore, social workers should be engaged with clients considering PAS to ensure that those client's rights are being protected and all possible options are known to the client for end of life care.

Physician Assisted Suicide and Professional Practice

The concept of PAS as an end of life option can be controversial and is one that may raise potential ethical dilemmas within the field of social work as it relates to patients' rights to self-determination and dignity. Because Social workers are expected to be adept at navigating potential ethical concerns that may arise in practice, such a task can become complex when there are no specific protocols for PAS in place to help guide them. Currently, the NASW provides standards for end of life care; however, it fails to address PAS as an EOLO. Gaston (2016) found that the more a social worker believes that their professional values align with PAS, the more likely the social worker will accept PAS as an acceptable EOLO. The current study found that most participants were unsure of how the NASW Code of Ethics views PAS and were completely uncertain if the NASW Code of Ethics even considered PAS to be ethical. The lack of guidance as to how social workers should address and provide services to clients requesting PAS suggests a need to develop professional guidelines to which social workers can refer to. Such professional guideline can help social workers feel more confident in their professional practice and, minimize ethical concerns for end of life care options.

Physician Assisted Suicide Education and Education Recommendations

Education is the cornerstone of social work practice. Social workers must be educated in order to be considered competent in their practice (NASW, 2018). Students spend two years learning micro and macro social work but are barely

exposed to the death and dying process or options for treatment or non-treatment at the end of life. Csikai and Bass(2000) surveyed social workers to get an understanding of how much education each social worker received on end of life care and/or PAS. The study showed that only 18% of social workers were given education regarding end of life care during their master of social work program. While a small portion received some education in college, only 21% of participants received continuing education after college to gain a better understanding of end of life options (Csikai & Bass, 2000).One study showed that second year Master of Social Work students were only marginally prepared to assist an aging population facing death and dying (Kramer, 1998).

In the current study, participants were asked if the participant had received education or training on end of life options, and if so what type of education and/or trainings has the participant received. While there was a wide array of answers that came from the question regarding education and trainings, 26% of participants stated that the agency provided education and another 26% of participants reported educating themselves on topics of PAS and end of life care. Other answers regarding education included participants received online training, shadowed experienced employees, had life and work experiences that taught the participant about PAS and end of life care, and had very little training in end of life care. While experience is always helpful, it is important that social workers are educated on all options in end of life care. Kane, Hamlin, and Hawkins' (2005) research shows that although social workers may not be educated fully on

end of life care, simply knowing resources for the elderly population helped the social worker to feel more confident in working with a client at the end of life. While being confident is great, the NASW (2018) also states that social workers should be competent in their field of practice, including understanding the law that surrounds the social workers' practice. NASW (2018) also reports in the ethical standards portion of the Code of Ethics that social workers should educate themselves, do research, consult others and much more when a standard does not exist in an area of practice that is emerging. PAS is considered an emerging area due to the recent legality of the law. If student social workers are not getting the necessary education and training, then the social worker cannot be competent in their work with clients requesting information regarding PAS and must seek other ways to further educate themselves on the process and law.

Within the current study participants were also interviewed regarding what type of education and/or trainings would be beneficial in order to feel confident and comfortable in interacting with clients regarding PAS. Thirteen percent of the participants stated that they would feel more comfortable with talking to clients about PAS if they were to shadow a social worker who is knowledgeable in the PAS process. Further responses that participants identified as helpful in feeling more comfortable addressing PAS as an EOLO included staff training, ongoing dialogue and workshops.

Recommendations for Social Work Practice, Policy and Research

Social Work Practice

A recommendation based on this research would be for all agencies that handle end of life care including hospitals, hospices, palliative care, and dialysis centers to put out agency specific policies in order for the social workers within each agency to understand how to handle the conversations with patients who would like more information on PAS. Another recommendation for social worker practice would be for every social worker to self-educate on any laws that surround the social workers' scope of practice. It is important to be able to understand the laws in order to better educate clients. Also, since the persons who would be seeking PAS are a vulnerable population, it is important that social workers understand the law in order to advocate for the client and to make sure the client's rights are not being violated or infringed upon.

Policy

Currently, when looking at end of life care, social work policy is lacking in a sense. While the NASW (2004) has put out a guideline for social work practice when faced with palliative or hospice care, there is only a very small mention of PAS within that guideline. Due to the responses from participants within this research, one recommendation within policy practice would be for the NASW to develop formal guidelines for social workers who interact with clients who are interested in PAS. A formal guideline from the NASW can help social workers

ensure that their practice is following the Code of Ethics and is abiding by social work ethical guidelines.

Based on the limited available research regarding PAS and the results of this current study, it is evident that social workers are not provided with enough training and education regarding all end of life options available to terminal clients. As a result, the lack of education and training regarding PAS leaves social workers ill prepared to effectively manage a sensitive topic like that of PAS.

One recommendation that resulted from this study emphasizes the need for increased education within the social work school curriculum both at the undergraduate and graduate level. Increasing the amount of course work related to end of life options can aid students and future social work professionals in gaining the necessary skills and knowledge to discuss PAS with clients. Additionally, such exposure can help students feel more comfortable and competent when talking to clients about the EOLO that are available to them.

Another recommendation for education would be to provide social work professionals with additional training and educational courses regarding the law and ethical dilemmas that surround PAS. Such additional training and education would provide social workers with a better understanding of the law and ethical implications behind PAS which would ultimately aid them in providing clients with adequate resources and information regarding PAS. Furthermore, an educational framework on the most appropriate and effective methods of educating clients

about PAS can be beneficial to ease feelings of incompetence among social workers dealing with terminally ill clients.

Research

The current study only brushes the surface of understanding how personal beliefs and professional ethics interact to aid or hinder a social worker in their practice when talking with a client about PAS. Within this study, there was more information found regarding the lack of education and unfamiliarity with the law than was previously expected. In order to get a better understanding of how social workers personal beliefs interact with professional ethics during client interactions about PAS there needs to be more in-depth research that takes place. Due to the nature of these research, there are several limitations that should be taken into consideration.

Limitations

One of the greatest limitations of the current research was the sample size and type of sampling that was done. This research study was only able to accumulate 15 participants. Due to the nature of the subject many agencies did not want to partake in the study as a whole. Although social workers within the agency were not obligated to participate when an agency agreed to letting researchers interview the social workers, many agencies did not want their social workers to be involved in such a controversial study. Due to lack of agency participation, the sampling of participants became a snowball sample. Social workers who participated in the study let other social workers in the hospice field

know about the study, and ultimately researchers were able to get 15 participants due to word of mouth. Since researchers were only able to interview 15 participants, another limitation was that participants were all located within the Inland Empire Region between San Bernardino and Riverside County. It is important for future research to include not only more participants, but participants from different areas, not only in California, but in other states that have made PAS legal.

This research study's demographic make-up of the participants was not as diverse as the researchers hoped it to be, therefore, another limitation to this research was the lack of diversity. While social workers are predominantly female, there are still a lot of males within the social worker field. The researchers were only able to interview 2 males, which made up 13% of the participants, but interviewed 13 females, which consisted of 87% of participants. Additionally, the religion of participants was not very diverse with 40% of the participants being of Catholic faith and 20% of the participants being of Christian faith. Lastly, the diversity in race and/or ethnicity was severely lacking with 53% of participants identifying as Hispanic or Latino, 40% of participants identifying as White/Caucasian, and 7% of participants identifying as African American. There were no other ethnicities represented in this sample, which can skew the results due to the way some cultures feel about PAS. Therefore, future research should include a more diverse sample of participants from different backgrounds, cultures and religions.

One limitation that is often seen in qualitative research with one-on-one interviews is the social desirability bias. When participants were interviewed, researchers could only report what the participants stated, but what a participant stated may have been skewed due to the desire to impress the researcher. The participant may have given answers that may have been seen as a more favorable or socially desirable answer in order to be viewed more favorably by the researcher.

Since this is a Master's Research Project, students were only given a short amount of time to fully collect data, therefore another limitation to the research was that researchers had time constraints. The project must be turned in by given deadlines, therefore there was a constraint on the recruitment and interview process for research participants. Within that time constraint, it was very difficult to find hospice social workers who had agencies that were willing to let the social workers participate. Therefore, in future research it would be more insightful to add other types of medical social workers to the participant make-up. Hospice social workers are not the only types of social workers that deal with end of life care; therefore, it is important to talk to social workers in hospitals, dialysis centers, and long-term care facilities.

The last limitation to this research was that there is a lack of research in this area of social work. This was a limitation due to the fact that the researchers had to make up the interview guide based on what the researchers thought would be relevant and allow for more explanation. Without extensive previous

research, it was difficult to find a guideline or interview tool that had a previously rated validity score. Therefore, the recommendation is that researchers continue to review PAS and delve deeper into the subject. The more research that is done, the better of an understanding the social work community will have on how prepared social workers are to handle PAS cases.

Conclusions

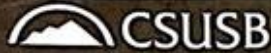
With a growing aging population, the likelihood that social workers will encounter terminal clients dealing with end of life issues is a reality. As a result, it is crucial that social workers are familiar with all end of life options available to terminal clients. The concept of PAS is one that raises potential ethical dilemmas within the social work field as it relates to patients' rights to self-determination and dignity. Social workers should be informed and knowledgeable about laws in order to navigate through complex legislation. While this study aimed to explore how social workers' personal beliefs and professional ethics influence their practice when interacting with a client about PAS, the study found more information surrounding the lack of education, training and familiarity with the law.

The study revealed that social workers had minimal familiarity with the law surrounding PAS and the process itself. Additionally, the study found that social workers reported having little to no education and/or training regarding PAS. Furthermore, most social workers reported that although they may practice or identify with a religion, it did not influence the end of life options provided to

clients. Finally, the study found that social workers did not have a guide or manual that they can refer to for clients requesting PAS.

Such findings illustrate a need for social workers to increase their awareness about current laws and for agencies to provide pertinent information to social workers dealing with end of life care. In terms of education, there needs to be an increase in educational courses within the social work school curriculum both at the undergraduate and graduate level to aid students in gaining the necessary skills, knowledge and confidence to discuss PAS with clients. Additionally, the findings also suggest a need for advanced educational training and courses to help social workers better understand the law and ethical implications behind PAS. Ultimately, the NASW and prospective agencies should consider developing a protocol and educational framework to assist social workers in feeling more competent and confident in providing services to clients requesting PAS. The potential development of such protocol can also help decrease ethical dilemmas among social workers as it relates to PAS

APPENDIX A:
INFORMED CONSENT



WE DEFINE THE *Future*

School of Social Work

California State University, San Bernardino
Social Work Institutional Review Board Sub-Committee
APPROVED 5/19/2019 VOID AFTER 5/16/2020
IRB# SW1937 CHAIR *[Signature]*

CALIFORNIA STATE UNIVERSITY, SAN BERNARDINO
5500 University Parkway, San Bernardino, CA 92407
909.537.5501 | fax: 909.537.7029
<http://socialwork.csusb.edu>

INFORMED CONSENT

The study in which you are asked to participate in is designed to explore Social Worker beliefs, values and ethics. The study is being conducted by Jazmine Camacho and Jessica Huver, both graduate students, under the supervision of Dr. Herbert Shon, Assistant Professor in the School of Social Work at California State University, San Bernardino (CSUSB). The study has been approved by the Institutional Review Board Social Work Sub-committee at CSUSB.

PURPOSE: The purpose of the study is to explore Social Worker beliefs, values and ethics regarding end of life care for terminally ill clients.

DESCRIPTION: Participants will be interviewed one-on-one with the researcher and asked open-ended questions about their beliefs, values, and ethics and whether their personal beliefs conflict with professional beliefs. Participants will be asked to reflect on past client encounters.

PARTICIPATION: Your participation in the study is completely voluntary. You can refuse to participate in the study or discontinue your participation at any time without any consequences.

CONFIDENTIALITY: Your responses will remain confidential and data will be reported in group form only. Your responses will be kept on a password encrypted USB drive.

DURATION: Participation will take on average 45 minutes to one hour for the interview.

RISKS: While risks are not anticipated, there may be some small psychological discomfort due to the topic of the interview being about death and dying. You are not required to answer and may skip a question or end participation in the study at any time.

BENEFITS: There are not any anticipated direct benefits for participants of this study.

CONTACT: If you have any questions regarding this study, please feel free to contact Dr. Shon at (909) 537-5532

RESULTS: Results of the study can be obtained from the Pfau Library ScholarWorks database (<http://scholarworks.lib.csusb.edu/>) at California State University, San Bernardino after July 2020.

I agree to be audio recorded: _____ YES _____ NO

This is to certify that I read the above and I am 18 years or older.

_____ Place an X mark here

_____ Date

The California State University • Bakersfield • Channel Islands • Chico • Dominguez Hills • East Bay • Fresno • Fullerton • Humboldt • Long Beach • Los Angeles
Maritime Academy • Monterey Bay • Northridge • Pomona • Sacramento • SAN BERNARDINO • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus

Scanned with CamScanner

APPENDIX B:
INTERVIEW GUIDE

INTERVIEW GUIDE

1. When clients have come to you seeking options to end of life care, how comfortable have you been at explaining Physician Assisted Suicide?
2. Based on your experience, how many encounters have you had with clients requesting PAS as an End of Life Option? What was your initial encounter like? (Did you feel prepared, nervous, overwhelmed?)
3. Do you know what to do if a client requests Physician Assisted Suicide as an End of Life Option? If so, how would you or have you handled it?
4. Are there any protocols or guidelines for social work practice regarding End of life Care specifically PAS that you abide by or refer to?
5. How familiar are you with Physician Assisted Suicide under the California End of Life Option Act? What do you know about this law?
6. What type of training or education would make you feel comfortable talking to a client about Physician Assisted Suicide?
7. Have you had any training or education in end of life care? If so, what did it consist of and how has it prepared you for interacting with terminal clients?
8. How has your faith and/or spirituality interacted with what the NASW code of ethics states when considering end of life care options for your clients?
9. What are your personal beliefs about Physician Assisted Suicide?

10. Do your personal beliefs about Physician Assisted Suicide help facilitate your interactions and discussion with patients who request PAS as an End of Life Option?
11. What does your religion and/or spirituality state about Physician Assisted Suicide?
12. How would you say the NASW Code of Ethics translates to Physician Assisted Suicide? Would you say that the NASW Code of Ethics consider Physician Assisted Suicide to be ethical?
13. Do you believe the NASW should consider developing a guideline or protocol for social workers dealing with clients requesting PAS? If so, why?

Created By: Jazmine Camacho and Jessica Huver

APPENDIX C:
PARTICIPANT FLYER



Hospice Social Workers Needed for Research

*

Who: Hospice Social Workers

What: Volunteer for 45 minute one-on-one interview with our researchers

When: Between March 2019 and September 2019 (we will work with your schedule!)

PURPOSE: The purpose of the study is to explore Social Worker beliefs, values and ethics regarding end of life care for terminally ill clients

If Interested in Volunteering please contact us to set up an appointment

Jessica Huver: 951-543-1289 or Huvej300@coyote.csusb.edu

Or

Jazmine Camacho: 006124582@coyote.csusb.edu



CREATED BY: JAZMINE CAMACHO AND JESSICA HUVER

APPENDIX D:
DEMOGRAPHIC SURVEY

DEMOGRAPHIC SURVEY

1. Please indicate your gender: _____
2. Please select the category that includes your age.
 - 18-24
 - 25-34
 - 35-44
 - 45-54
 - 55-64
 - 65 and older
3. What best describes your marital status?
 - Single, not married
 - Married
 - Living with partner
 - Separated
 - Divorced
 - Widowed
4. What is your religion?
 - Christian
 - Catholic (including Roman Catholic and Orthodox)
 - Protestant (United Church of Canada, Anglican, Orthodox, Baptist, Lutheran)
 - Jewish
 - Muslim
 - Sikh
 - Hindu
 - Buddhist
 - Atheist (do not believe in god)
 - Other _____
5. What race/ethnicity do you identify as?
 - White/ Caucasian
 - Hispanic/Latino or Spanish
 - Black/African American
 - Asian/ Pacific Islander

- Native American
- American Indian or Alaska Native
- Other (please specify)

6. What is your highest level of education?

- Less than high school
- High School Diploma or GED
- Some College (2 year- Associates Degree)
- College (4 year- Bachelor's degree)
- Master's Degree
- PhD or other advanced professional degree
- Other _____

7. How many years of experience do you have as a social worker?

- Under a year
- 1-2 years
- 3-5 years
- 6-9 years
- 10-15 years
- 15+ years

8. How many years of experience do you have in Hospice?

- Under a year
- 1-2 years
- 3-5 years
- 6-9 years
- 10-15 years
- 15+ years

9. How would you describe your current employment status?

- Full time employment
- Part-time employment
- Freelance/ Contractor
- Student Intern
- Other _____

CREATED BY: JAZMINE CAMACHO AND JESSICA HUVER

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ASSIGNED RESPONSIBILITIES

Upon embarking on this research project collaboration, both researchers agreed that they would share equal responsibilities throughout the study. Both researchers possessed unique research qualities and strengths that facilitated the formation of this research project. Additionally, both researchers were in constant communication regarding modifications and alterations that needed to be made. As a result, no complications arose throughout the research project collaboration and both parties were satisfied with the efforts put forth to complete the project in a timely manner.