

5-2016

# An Exploratory Study: How do licensed social workers approach complex end-of-life conversations with patients, families and physicians

Angela Mueller

*St. Catherine University*, [muells96@gmail.com](mailto:muells96@gmail.com)

---

## Recommended Citation

Mueller, Angela. (2016). An Exploratory Study: How do licensed social workers approach complex end-of-life conversations with patients, families and physicians. Retrieved from Sophia, the St. Catherine University repository website: [https://sophia.stkate.edu/msw\\_papers/636](https://sophia.stkate.edu/msw_papers/636)

This Clinical research paper is brought to you for free and open access by the School of Social Work at SOPHIA. It has been accepted for inclusion in Master of Social Work Clinical Research Papers by an authorized administrator of SOPHIA. For more information, please contact [amshaw@stkate.edu](mailto:amshaw@stkate.edu).

An Exploratory Study: How do licensed social workers approach complex end-of-life  
conversations with patients, families and physicians

by

Angela M. Mueller, B.A.; B.A.S.

MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
St. Catherine University and the University of St. Thomas  
St. Paul, Minnesota  
In fulfillment of the Requirement for the Degree of  
Master of Social Work

Committee Members  
Robin Whitebird, PhD, MSW, LISW (Chair)  
James Friedman, RN  
Jacqueline Hutchinson, LICSW

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

**Abstract**

This paper adds to the growing body of literature in social work research by exploring how social workers' facilitate complex end-of-life conversations with patients, families and physicians. Limited research, and practice efforts have focused on end-of-life care and social work involvement. Importance and perceptions of healthcare proxy/advanced directives use have been previously examined to understand social workers' expanding role in end-of-life planning. Findings from this study have illustrated the approaches social workers use within complex end-of-life conversations which span across patients and their families, their physicians and the greater population. Processes that were found, although variable, were cohesive within areas of conversation involvement, beginning approach, intentionality within context and developed relationship outcomes.

### **Acknowledgements**

Thank you to my committee members, you have been my rock through this process, and I thank you for never giving up on me.

All participants, you made this experience an unforgettable one filled with an abundance of learning and immense appreciation for the amazing work you do every day.

Family & Friends; the constant support and love you have poured into me every day of this new adventure during this project. & everything in-between. I wouldn't change one second, minute, day, month or even year in putting this all together- it has all been worth it and am grateful for all of you.

**Table of Contents**

Introduction.....	pg. 5
Literature Review and Research Questions.....	pg. 6
Conceptual Framework.....	pg. 11
Methodology.....	pg. 12
Results: Domain Themes & Subthemes.....	pg. 15
Discussion.....	pg. 40
Strengths and Limitations.....	pg.41
Implications.....	pg.41
References.....	pg.44
Appendices.....	pg. 48
Appendix A. Letter of Informed Consent.....	pg.48
Appendix B. Interview Questions.....	pg.49

Across the United States there is significant variation in the ways that people age. There is also great need to understand how as a society the United States will adapt and adjust to the aging baby boom generation. This also includes understanding how people view death and dying, and how individuals prepare for it. (Kane, Hamlin & Hawkins, 2005).

Death, for many is an uncomfortable subject of discussion. This contributes to the difficulty in approaching end-of-life conversations. Most individuals and families look to medical professionals to facilitate these topics. But research has found that many in healthcare struggle with early and effective conversations of end-of-life care, including physicians and nurses (Periyakoil, Neri & Kraemer, 2015). Extensive research has focused on health care professionals' involvement, specifically centered on the role and attitudes of physicians' and nurses' in end-of-life care (Gutheil & Heyman, 2011; Heyman & Gutheil, 2006).

Limited efforts have focused on end-of-life care and social work involvement. Perceptions, (Kramer, 2012), importance, and use of healthcare proxy/advance directives (Heyman & Gutheil, 2006) have been previously examined to understand social workers' expanding role in end-of-life care planning (Hobart, 2002). Social work needs to have a stronger base of research dedicated across the board to approaches in end-of-life care conversations (Arnold, Artin, Griffith, Lund Person & Graham, 2006). The findings from this work will attempt to reduce the gap in social work research by understanding how hospice and palliative care social workers' approach complex end-of-life conversations with patients, families and physicians.

### **Literature Review**

People are actively aging everyday. They are living longer than ever before with the advancements of technology and medicine. In 2014, the Administration of Aging said that one in seven, or 14.1%, of the population is an older American. In addition they report that an average life expectancy for those reaching 65 adds an additional 19.3 years (2014). Vincent and Velkoff project that between 2010 and 2050 the growth of the aging population will rapidly increase (2010). In 2050, those Americans who are aged 65 and older across the United States are projected to be approximately 88.5 million which is more than doubled than it's expected increase of 40.2 million in 2010 (Vincent & Velkoff, 2010).

### **Chronic Disease**

Similar growth is needed across medical professions to attend to the complexity in care of the aging population. Complexity arises as people live longer, typically resulting with many years of living with chronic illness (Hobart, 2002). Chronic illness can include many different diseases at the end-of-life though the most common include “diseases of the heart, cancer, cerebrovascular disease, and chronic obstructive pulmonary disease” (Kane et al, p. 50, 2005). Approximately 75% of people living with chronic illness die in hospitals or medical centers (Hobart, 2002). Medical technology has created a new challenge in putting quality of life against length of life. For many Americans, these challenges are uncomfortable to contemplate and discuss as they coincide with end-of-life care decisions (Hobart, 2002).

Periyakoil, Neri & Kraemer have found that many “doctors do not necessarily believe that high-intensity treatments are desirable at the end-of-life” for any patients,

regardless of chronic illness or not (p. 2, 2015). In addition, it is evident that medical decisions for patients with one or more chronic diseases can intensify the later years in ones life if not addressed openly (Hobart, 2002). “Patients fear losing their lives to the medical system. They dread being trapped in insensitive medical institutions, tethered to inhumane machines [keeping them alive], robbed of personal privacy and subjected to accompanying indignities” (Hobart, 2002, p. 181). But when these conversations are addressed proactively outside of a crisis (Hobart, 2002), and a process is allowed to occur, more options become available like palliative care, or if the patient qualifies, hospice cares.

### **Transitions of Care**

*Palliative Care.* The World Health Organization (WHO) defines Palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (2015)” Additionally, the interdisciplinary team creates, develops and coordinates support and services that align with the goals and needs of patients, families and care providers (Friedman, 2015). Palliative care has also been recognized as a whole-person approach in healthcare for families and patients living with chronic illnesses and conditions (Gardner, Gerbino, Warner Walls, Chachkers & Doherty, 2015). Much of the discomfort around this transition of care towards a more palliative focus includes perceptions of failing medically and as a result, giving up on the patient (Arnold, et al., 2006).



***Hospice Care.*** As people move closer to the end of their lives, hospice care is often considered for transition, during the last years, months, and days of life. The National Hospice and Palliative Care Organization (2015) defines hospice as, “the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes (National Hospice and Palliative Care Organization, 2015).” In the last ten years there has been consistent growth in the number of hospice patients served and programs created (Weisenful & Csiat, 2013). With an average of 19.7 days enrolled in 2010, many families are left saying that they wished they would have been involved with hospice sooner in the last months of the patients’ life (Weisenful & Csiat, 2013). This also creates difficulty in truly getting to know the patient and accurately assessing what matters most to the patient as they enroll in hospice (Arnold et al., 2006).

### **End-of-Life Conversations**

Before these end-of-life approaches to care can begin, a conversation must be activated; understanding transitions through goals of care and family involvement & considerations must be explored.

***Transitioning Goals of Care.*** When people are at the ends of their lives, they are also in the most vulnerable part of their lives as well. If and when conversations can be had, a change in focus is often observed. These patients are at important parts of their lives where death and dying is extremely real. The need for medical professionals to conduct conversations is necessary, though medical professionals are often reluctant when a

relationship with the patient isn't present (Periyakoil, Neri & Kraemer, 2015). This is important to recognize.

An understanding can be developed in what matters most to the patient and their family, which allows for a reduction in ineffective and burdensome treatments that may misalign with the patients true goals (Periyakoi, Neri & Kraemer, 2015). Hobart describes the importance of medical professionals creating a relationship with patients by developing a trusting and safe environment where patients can think about and discuss their own plan of care rather than making decisions in a moment of health care crisis (2012).

Periyakoil, Neri & Kraemer (2015), discuss that patients who have end-of-life conversations with their doctors and medical team are “less likely to experience physical distress at life’s end”, along with being “less likely to undergo life-limiting interventions, and more likely to be referred to hospice earlier” (p. 2). There also seems to be extreme importance in guiding patients to include family members during these discussions, so their wishes can be seamlessly passed on (Hobart, 2002).

***Family Considerations & Involvement.*** When wishes, goals and end-of-life are brought up, often families and friends are typically a part of what matters most to patients. Heyman & Gutheil (2006) indicate that when patients request to have their wishes known, it can result in “reduced fears, increased autonomy, and improved family communication” (p. 48). It is important that medical professionals conduct effective conversations with patients and families early in the trajectory for any chronic illness (Periyakoil, Neri & Kraemer, 2015), as this can reduce the misunderstanding of care options that can occur later in the disease (Kane et al., 2005). Additionally, Kane et al.

found that family members found relief in discussing the patients' wishes as they could then voice the patients' decisions that they had made before crisis (2005). Even with the relief of conversations, patients, families and medical professionals can still become uncomfortable with goals of care transitions. Social workers are often at the forefront of these transitions, at times before, during and after crisis (Gutheil & Heyman, 2011; Hobart 2002). This is where social workers are key in providing value to the idea of 'context matters' in end-of-life conversations (Healy, 2005).

### **Social Work and End-of-Life**

*Role with Patients and Families.* In a variety of ways, social workers incorporate individuals and their families when "assessing, educating, facilitating and addressing" difficult end-of-life situations (Heyman & Gutheil, p.763-764, 2011). Social worker's expanding role (Hobart, 2002) creates a safe place to hold open communication, patient advocacy and familial support in often an uncomfortable time in people's lives (Gardner et al., 2015). Arnold et al. (2006), describe this relationship with families as "... such compassionate connections provide opportunities for social workers to empower, educate, and assist patients and families in achieving goals to create meaning at the end-of-life" (p. 64). In addition, social work practice that contributes to palliative care and end-of-life care is focused on understanding the potential of patients and families; they are able according to Kramer, Christ, Bern-Klug & Francoeur (2007), "...practice across the lifespan... addressing mental health needs [along with grief] and psychological aspects of well-being..." (p. 418) when the family may be experiencing these things. Gutheil & Heyman (2011) discuss that it is crucial that social workers are "comfortable in assisting individuals and their families with sensitive and potentially painful issues" (p.

764). The challenge created is described by Back, Trinidad, Hopley & Edward (2014), “there just isn’t ample amounts of evidence available to “support any particular communication” style used in social work practice (p. 1019).

***Role with interdisciplinary teams and community.*** The social work lens focuses on a strengths-based holistic perspective that expands through the individual and familial situation and reaches interdisciplinary hospice and palliative care teams, across care systems and within community needs (Gardner et al., 2015). As core and integral members to the interdisciplinary health care team (Kramer, 2012; Heyman & Gutheil, 2006, Reese, 2011) social workers have the ability to help create a framework with patients, families and their care teams to view end-of-life discussions as a process that can occur overtime (Hobart, 2002). Hobart (2002) explains that this additionally allows for individuals to “modify and develop their end-of-life care decisions within the context of their changing lives” (p. 190-191). It can add to communication with key care team members and families, enriching the end-of-life experiences as much as possible (Gardner et al., 2015).

Unfortunately, there has been research that has pointed towards evidence where health care professionals have had difficulty in approaching and understanding end-of-life conversations both in practice and within the community (Kane et al., 2005; Periyakoil, Neri & Kraemer, 2015). In the recent years there has been a significant amount of research on dying individuals and families, there remains a gap in knowledge about what efforts can actually improve care (Kramer et al., 2007).

### **Conceptual Framework**

#### **Bio-psycho-social-spiritual**

In totality this framework does not simply imply the biological, psychological, and social aspects of the person (Engel, 1992), but also the spiritual aspects of the whole person as well (King, 2000; McKee & Chappel, 1992). In this model, the biological, the psychological, the social, and the spiritual are only distinct dimensions of the person, and no one aspect can be disregarded from the whole. Each aspect can be affected differently by a person's history and illness, and each aspect can interact and affect other aspects of the person. This research will be focused on developing a scope to analyze a holistic approach in complex end-of-life conversations.

### **Human Dignity**

This framework will serve as a fundamental piece in understanding the social worker's processes and approach in end-of-life conversations. Respect of the inherent dignity and worth of individuals is a fundamental aspect of social work practice. This includes treating each person in a caring and respectful manner, while being mindful of individual differences and cultural and ethical diversity. It also includes understanding of human rights and through basic intuition. Through this perspective, social workers seek to promote the responsiveness while working within organizations, communities and social institutions by responding to individuals' needs and societal issues.

### **Methodology**

#### **Research Design**

The purpose of the current study was to subjectively investigate the perspectives of hospice and palliative social workers regarding end-of-life conversations. An exploratory study design was utilized by conducting semi-structured interviews that allowed participants to share experiential knowledge related to end-of-life conversations

including approach of difficult conversations. Qualitative research “refers to the meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things” (Berg, 2007, p. 3), and was thought to be a good fit for the executed study, as the research design facilitates the collection of rich exploratory data.

### **Sample**

Through a convenience sample, this study recruited 9 licensed social workers that had current or past experience of working in an end-of-life care setting. One male and eight females were apart of recruitment. Experience varied within a range of 2-20 years. The study focused on the participants’ professional opinions and subjective experiences that relate to the research question, “How do licensed social workers approach complex end-of-life conversations with patients, families and physicians?”

### **Protection of Human Subjects**

This qualitative study has been written by the principal investigator and was reviewed and approved by a contributing research committee. For the purpose of this study, the investigator modified a consent form template that was provided and originally created by the University of St. Thomas. The consent form can be found in Appendix A of this paper. The first portion of the consent form specifically provides the participants with pertinent study information and addresses the purpose of the current research. The consent form also explains the reasoning behind the participant selection, gave an overview of the research procedure and explains how the data was collected, used, protected and destroyed after the project was completed. The form presented the potential risks and benefits of participation, discussed issues of confidentiality and provided recognition of the voluntary nature of the research study. In addition, the consent form

provides contact information for the researcher, course instructor, and the University of Saint Thomas Institutional Review Board (IRB). The second portion of the consent form includes the provision of informed consent, which was signed and dated by both the researcher and all participants. Data was collected and stored on both a password-protected cell phone and laptop, and will be destroyed after three years of data collection.

### **Data Collection**

A semi-structured interview that consisted of ten open-ended questions and several follow-up questions served as the principle means for collecting data. The interview questions can be found in Appendix B within this paper. The researcher developed questions after a review of the existing literature regarding approaches to end-of-life conversations and “bad news” of end-of-life social workers. Interview questions were centered upon the experience of end-of-life conversations, patient, family and physician involvement and interaction, role of the hospice/palliative care social worker on an interdisciplinary team, and factors that affect end-of-life conversations. All interviews were recorded using a digital recording application on the principle investigator’s personal cell phone, which lasted between 30 minutes to an hour upon completion. Additionally, the principle investigator kept field notes through the data collection process which enhanced data analysis.

### **Data Analysis**

The purpose of the study was to explore licensed care social workers’ perspectives of their approach in having complex end-of-life conversations with patients, families and their physicians. Through the development of sub-themes and dominant themes was used for future data analysis. As previously discussed, a digital recording

program was used to record the interviews with the study's participants. Following the interviews, the recordings were transcribed and examined by the primary investigator using first-level coding as presented by Padgett (1998). The investigator completed a content analysis via reading through all collected data iteratively, noting analytical memos, and identifying recurring concepts, themes and words (codes). When common codes were identified, the researcher examined them deductively to gather excerpts (content units) together in ways that related to overarching themes, similarities, and differences. Excerpts were then analyzed individually and were grouped into similar meanings or categories.

After the first-level coding was completed, a second-level coding was created, where codes were translated into themes and subthemes were developed (Padgett, 1998). All excerpts were then examined and compared across various responses. Themes that showed importance to the identified research questions were created, and themes were compared for similarities and differences, and relationships and trends were assessed.

## **Results**

### **Who's involved**

This category was formed with analytic data within each interview. There was a natural involvement that social workers described as the themes and began to identify patients and families as key components to the end-of-life conversations they were facilitating. Social workers also formulated a trend of including the interdisciplinary team along with physician and societal influences. The following will describe the themes found within this category.



*Patient & Their Family.* Analysis of the interview data demonstrated that each participant discussed patient and family involvement within end-of-life conversations. The majority of participants spoke about how every patient and family is different in context and conversation. One social worker spoke about their approach when they met with a patient and the patient's family:

I try to meet with the person one to one if they are able to tolerate that and have those one to one discussions with me, and then bring in the family to see where everyone else is at with their coping, where everyone else is at with their understanding of the disease, and then just talking about how as a support system are all of you going to support this person, in that. And sometimes there are very different views.

One social worker stated, "I'm sure you've heard, but it's different with each family, but I try and feel out how open each family and patients are to talking about it, so I usually ask how much information would you like to know about certain things."

When it came to discussing family involvement, participants mostly spoke about how family dynamics really can interfere with information shared or information withheld. Social workers continuously spoke about shaping the conversations to the patient and family's readiness. One social worker mentioned that, "Families tend to like to speak for patients who are very ill, and interpret their thoughts, and a lot of times when you meet one on one with the patient you really get a more clear honest view of where the patient is at." Another social worker discussed the difficulty families may experience and said, "Partly it's difficult for people because in our culture, we have this thing that

that's something we don't talk about so the more it just gets opened up as a natural topic of conversation. And for some families it is, but for some families its not."

Many social workers spoke about how their approach and lens of understanding families systems was apart of their natural work with families. One social worker mentioned, "from the family systems standpoint, it can be that the family members just aren't ready to talk or some are and some aren't, the patient isn't ready to talk the patient is very afraid of what's going to happen after they die, every family is different, but these are all very common instances that you can encounter."

Another commonality within patient and family work includes the dimension of the patients' ability to be involved in conversation. One social worker described situations where "...sometimes those conversations are with family members because the patient isn't conscious and now we are working with a surrogate decision maker who is named or is by default." But ultimately a huge theme that was present in every discussion includes the importance of the support system that each patient brings with them. One social worker said "... we want friends and people in their support system there that are most around in their daily life, know what the person's baseline is, who can really speak to what the patient would want and not what they would want for the patient. Which can be very difficult sometimes."

***SW Role & the Team.*** The participants unanimously spoke about their interaction with their teams and their roles within the team. Most spoke about their specific lens and how their roles are integrated within the teams that they are a part of. One social worker elaborated on their expertise within social work and said,

We use our clinical skills to attend to the whole person and really bringing knowledge about the family system and how the system plays into all of this, it's very easy to forget because as social workers we tend to take for granted that everyone thinks that way, and it's shocking that not everyone does, and even sometimes the doctors aren't happy with me when they don't understand.

Another social worker spoke about their role in team and said, "I would say, I'm a lot of the actual verbal conversation peace. I have a lot of experience doing that. Where as the rest of my team are physicians, nurse practitioners, physician assistants, and chaplains, and so while they are all skilled in conversations as well they're much more medically and symptom focused."

Through many of the examples given, each social worker described their teams as different than other specialties. One social worker spoke about end-of-life teams and said; "... palliative care is really by design interdisciplinary... And so it's really the only medical specialty of which I am aware that is by design team oriented. There are obviously lots of other medical specialties of which there is an interdisciplinary team, medical specialty itself doesn't define itself that way, where as palliative care and hospice do."

Each social worker spoke about their involvement with co-visits when they had conversations with patients and families. Many gave examples as to how they have seen beneficial outcomes to participating in co-visits with their team members. One social worker described their experience as, "... often times the doctor will say that doing co-visits are so nice because often you are able to trade off and observe, and then that person picks up and it's really a dance between us. If there is more than one family member in

the room then you can sort of tend to the family members and get kind of an overall assessment and understanding of overall dynamics and how people are supporting each other.”

Many of the social workers discussed the cohesiveness of the team and the alignment of team morale. One social worker said:

... in palliative care there really is no hierarchy like our attending physician runs the medical ship, but all of our opinions and insight into each of our patients are really level playing field. There are even some patients that I will see more than the medical team if that is where their needs are. So I would say mine is definitely more psychological, social, looking at the person in their environment, really highlighting the strengths that that person possesses, and really highlighting that to my team, and then I also have to take into account what the rest of my team is saying to kind of put my role into perspective.

This was a theme between social workers interviewed, regardless of the medical specialty they held. One social worker spoke about how “It is an IDT, an interdisciplinary team, feedback and input is well weighted and respected... everyone on our team has input, as a clinical social worker, I’m looked at for everything from end-of-life planning and options, a lot of mental health stuff, family dynamics stress, grief, loss, how to frame conversations, resources, the gamut- it’s from A-Z, but yet we do everything as a team.” The interconnectedness of the team really was highlighted and expanded as one social worker explained the interactions with other team members. They said, “...sometimes our physician assistant and myself will go together, sometimes if it’s a person who’s got great housing situation, great job, good family support but their pain is really

unmanageable – they might not need me so much but the physician, so we kind of just tag team on what the primary medical team tells us in the consult and we pitch hit that way.”

Another way that the social workers talked about their cohesiveness with their team members included value and lens of practice. One social worker talked about their experience and said “the doctors really value the social workers input to where the patient was at, emotionally, psychologically and [with] the family to help them understand the education piece again. When we would have family meetings I would try and ask questions that I would think the family would want to know, that the doctor may not have touched on.” This was reflected again in how team conversations have both expanded and challenged team perspectives in best practice to make sure teams are aligned with the patients goals. This social worker said:

We also have the luxury of bringing doctors and nurses back a little bit in saying you know, it’s okay to not treat things if that’s what the patient wishes. So we do become more of an advocate for patients and families more so than I think some of the other disciplines, I think we are able to take their side and feel comfortable about that. As we are working within the medical model that is aimed to treat and have no symptoms and everyone be happy and sometimes that’s not the wish of the patient or the family and sometimes we are able to advocate in that too.

Along with challenging the team and advocating for the patient and families perspectives, it was also brought up a number of times where support to the team is needed and provided. One social worker talks about how “... much of what we do is also supporting the team too regardless of who you are if you are around hospice and death you need

opportunities to process your own mortality and I think social workers are unique in that they can assist in that”.

It was talked about how difficult conversations don't stop there and are often carried into the team regarding ethical discussions including the extent of treatment offerings. A common discussion was highlighted by this social worker, “So one phrase that we use a lot down here is, ‘just because we can, doesn't mean we should’ and what do we offer people, that's obviously not for me to say, but having those realistic conversations is this something that we should be offering, and these are conversations we are using having within the team.”

***Physician & Societal Influence.*** Differences between ease of conversation were regularly addressed as social workers described the resistance that can be received outside of the end-of-life interdisciplinary teams from other physicians. This social worker said:

So within our own team, it's usually pretty smooth, but once you are working with a primary team, and especially multiple specialties it gets a little more complicated. It's really – it can be really challenging for patients and families because they can and do get told different things by different people and how do you really make what for you or for your loved one a good decision if you don't really have clear, direct, honest information, and or you are getting conflicting information.

Another social worker said, “... medically we are really good at stabilizing people, but we're not as good at the end-of-life stuff or the goals of care stuff as a whole.”

Difficulty in these conversations extended from external medical teams to cultural norms as well. One social worker spoke about how “as a society, death is not—it’s kind of a taboo subject, in talking about what people want and—just dying being an okay thing, instead of people being so scared of it and about it, and talking about it, because if we talk about it—it might happen. That’s huge. I think that the medical providers not wanting us to have those conversations because we’re not wanting to give up. I see it often, ‘Oh, we aren’t going to get palliative care involved yet, we’re not there yet’ but palliative is not just end-of-life, you know?” Again, was highlighted by this social worker who said, “Denial, society, we live in a youth oriented society, yet alone die, it’s kind of taboo to talk about death, so here you are in a field where people die and you are working with people who are dying who are coming out of a society where no one talks about death. So I think that’s a huge barrier. Many of these people have been in treatment and when they are in treatment they are seeing oncologists who are treating them, treating them, treating them, and for those oncologists, when it doesn’t cure them, that’s a huge failure.”

Another factor within this theme that was discussed was that of aggressive treatment and the belief that there is always something that can be done. This social worker said:

The folks that come here are generally speaking the people who are pursuing aggressive treatment, so it’s not unusual to have situations here where either the patient or the patient is not interactive and you’ve got the family saying something like this, the doctors told us many times over the years that there was no hope or he was going to die, and look at this, x number of years later. And it

could have been one time or typically it's multiple times, so what gets reinforced is the belief that you'll always be able to do something. And so for some families and some patients, it can really be difficult and say, either there aren't curative interventions left or maybe that's not what I really want.

There were also multiple references discussing the barriers regarding the lack of physician support or involvement. One social worker mentioned "the fact is that doctors don't go into medical school to let people die" and went on to say, "(long pause) ... and just because a conversation has been had doesn't mean it's necessarily an effective conversation or an effective mode of conversation. But at the same time it can maybe not be received the right way from the physicians." Another social worker described their experience further in detail:

It's less frequent but it does happen that one of the fellow medical provider's team doesn't want you to talk to family members about death or dying with the option to switching to comfort care. Often those providers won't even consult us, so it can really depend... where the message is, do not talk to my patients about shifting the focus of their care—at any point". Another specialty social worker continues by saying, "an influence is definitely the physicians as I get a lot of negative responses when I ask if the patient may be hospice appropriate because once again they want to treat, treat, treat.

A common physician difficulty is displayed in this social workers discussion of their experience:

... Let's say you have a patient you've been seeing for 3 years in oncology and the patient is really starting to say I don't know if I like coming in every couple of



weeks for chemo, I don't know about this radiation, I'm tired all the time, I'm sick all of the time, I'm losing my hair, I can't go out to eat anymore because I feel so sick. Patients will be saying that to providers and the providers themselves are not comfortable- so they will continue to offer treatment that is actually harmful to people versus electing palliative care or hospice at that point and so sometimes it's more telling the provider it's okay because the patient is already there- mentally they are already there, but the patient doesn't want to let down the doctor that saved their life for the last 3 years and vice versa.

### **Where they start**

This category emerged through a variety of questions within each interview. There is a natural beginning to every relationship where social workers described the themes as assessing where the patient and families were at, aligning with them to understand their situation and working to build trust within the relationship. The following will describe the themes found within this category.

*Assess.* Social workers across the profession have learned to assess a situation to receive a holistic perspective of what the patient and family is experiencing. A number of social workers explained their approach within assessing each experience. This social worker spoke about a scheduled visit and how they envision what they will say:

So going in tomorrow, I'm going in with the chaplain, we're doing a co-visit and how to frame that conversation, will be all about using myself clinically, I'm the clinical tool. Go in, and greet them with an open heart and meet them where they are at, and make assessments through out that time, what do they need to hear, what are they wanting, maybe they don't know what they want, maybe they don't

know what they need, and so that question around giving them the parameters of hospice, what we are as a philosophy of care and how we can help support them in their goals of care, those conversations are this nebulous thing that we do. Another spoke about how quickly they are able to assess the situation and said, "... as a social worker, usually when we meet people usually within 5 minutes we've got a good feel of patient education level, their understanding, their coping and then you just formulate for yourself how you are going to approach that."

One social worker painted a picture of what her initial interactions have looked like and said, "... it's individualized, always. It's meeting someone, looking in their eyes; if they don't want to look into my eyes already I know something. I will tailor my conversation differently. I try to be personal so I use that technique or that's that trait of joining." Another social worker described the assessment as a type of instinct and said, "... you just really have to have some instinct, and just a lot of compassion, take things slow, these are hard conversations for everyone, and just deciding what the person needs to hear in the moment and just meet them where they are at, it's a process certainly, not just a one time conversation obviously."

Many social workers that were interviewed spoke about how different each conversation is from another, furthermore how different each patient and family are from any others. Because of this, one of the social workers mentioned, "it's really hard to have any consistent approach other than the first in developing rapport and just listening. Needing tool we always have to assess. At the first visit, to assess what their needs are, assess how we are going to be most effective in meeting them, but from there, the technique really varies a lot."

*Align.* After assessing the patients understanding of their condition, or how they are coping with the information they recently received, all of the social workers spoke about meeting the patient where they were at. One social worker describes their technique when they align with a new patient:

First I'll go up to the patient if they are in the living room in a hospital bed or if they are sitting on the couch and ask them, often, have you ever been in an experience like this before, have you ever had anything to do with our program or a program like this? Sometimes I don't even say hospice, sometimes I'll ask straight away, have you had any hospice experience. Sometimes we know a little already in the initial information visit, with the nurse. And then it's just asking, well what was your experience like, and now that you find yourself in this position where you are the recipient of the program, how is that for you. Giving them enough space for them to answer. Really being gentle and allowing it to unfold. Answers don't always just come up like that.

One social worker spoke about how they aim towards alignment by finding out what the patient has already experienced, and said, "Tell me what you understand about your disease, what have you been told by your specialist about your diagnosis and prognosis and what your mortality is going to look like in the next few months? And feeling like with my social work training having the space to be a container for those emotional conversations."

One social worker described "it's like a glass ball, where do we need, where do they need us and sometimes it's just holding a safe container for that immense grief. Knowing that they aren't alone in it." Another stated "it's about how do you want to use

your energy and when people don't want to be using their energy coming back and forth to the hospital, then we can be there for them and help them. Ideally we make sure their care is aligned with their goals with, what they are hoping for. We are walking the journey with them.”

Many social workers described aligning, this social worker said, “we really work that the care that the person is getting is inline with their goals, and we're able to take the time and work to process through what a person has been told to expect, what they are hoping for and what they are worried about. Those are pretty broad terms but in that way, we are able to make sure that the treatment that people re getting aligned with what they are wanting to hoping for especially if people are saying ‘I don't know how much more I want to do’ we are able to help people process.”

Most social workers also talked about the importance of knowing where the medical team stood with their thought processes, and aligning with them as well, one social worker said “I want to know the options the person has before going into those conversations. So if oncology is still going to offer chemo and radiation, and that is something that the patient would want, we aren't going to talk about hospice yet.”

A social worker described this time in the relationship as “working to assess how a person is coping with the medical information they have been given, working to assess their understanding of what's going on, just those core things will often lead to, assuming a person is open in engaging, open to talking to you. Just those very basic things will often let themselves reveal the emotional processes that a person is going through.”

Another social worker explained:

Fundamentally, my approach is to be pretty matter of fact about it, and in that way to communicate that it's okay to talk about it here, and this is a normal thing that can be talked about, again not pressuring people but opening and opening the door, and not like I know you don't want to talk about this, but that's why I think the matter of fact is really pretty important, and this is one of the things we can talk about here if you want to. If they say oh, no I don't want to talk about that- it's okay, if you don't want to, but if you decide you do need to, it's okay to here. And so I think that's really fundamentally my approach, and for some people they are way ready to talk about it- for some people it's like no one else will talk about this.

For each social worker, they spoke about how they look at a patient with a holistic lens, this social worker said "it's probably because we do look so holistically, I'm looking at who is this individual, it's not about their diagnoses, who is the individual, what life have they lived, and how do they live now, what do they want to keep living. What is important to them? Always explore."

***Trust & Guidance.*** Through interviews it was discussed that for end-of-life conversations to occur, there must be some trust and guidance built within the relationship. Every social worker spoke about the importance of trust and relationship through guidance. This social worker spoke about how they see the social work role as unique in doing so, and said "it can be a very influential role in the hospital— if I have that opportunity. We can be the ones to help guide conversations so if we go into a care conference and if I know the family I can tell the physicians prior during the pre-care conference, this is where this family is at, this is how we can better help them understand,

this is the language we can use, so a little bit more of that understanding the stages of change” and went on to explain the importance of early interaction, “I try to get in to see these families earlier than later so I can build that relationship so they can understand that it’s not just about getting them out of the hospital.”

As mentioned earlier this can be different for each patient who has varying disease processes. One social worker said that “... all of those have different stages of where you might be with a diagnosis and things like that, and it depends on the provider and it depends on how well I’ve gotten to know them, and my ability to get to know families and have a good understanding and impact with all of that comes at varying different levels depending on their need when they come in, and how quickly I am asked to be involved” and went on to say “... people are really sick here, really really sick, and figuring that out is important and seeing them by myself to create that effective communication right away with patients and families to establish and build those relationships is key.”

Another important part of the building of relationships is that sometimes it takes time and multiple conversations for patients to feel comfort in making decisions. One social worker says that “if those conversations would be happening over time, we didn’t talk about that the first time I ever met her, but you build the relationship, you start to talk about what does this mean to you, I mean I could give you countless examples of patients where they started out believing, that they could get better from their illness, and different people transition in different ways at different times, but its that ongoing relationship and the conversations all along”. In accordance to timing, this social worker described the depths of conversations and said, “I think [these conversations] can happen on varying

levels, some families I've know for 3 weeks and I've spent some time with the families. It's hard to have a spiel when you go in and everyone is at such a different place with things. It's kind of that quick relationship building, getting them to trust you and not feel like you are pushing them out the door, or are just giving up [on them]." Along with the relationship building another social worker described the "flexibility with that there. But open and honest conversations tend to be the most helpful, even when patients and families are frustrated and upset."

When that relationship and trust has been built, social workers have the ability to guide conversations and use their creativity to generate understanding. This social worker described their approach with a former patient:

Case in point, I have a man he lives alone, he's traveled the world many, many times, very scared about planning, but I said, 'Well when you traveled to Rio, you need to get a passport', and he goes 'and a visa,' I say and 'Ah and a visa! So you have to plan for that,' he said 'Yes.' 'And you have to plan what time of year you are going, and what is the weather going to be like there, and how are you going to get to the airport, and who's going to take care of the cats,' he said, 'yeah I do.' I said, 'With that kind of planning and that kind of mindset and that kind of metaphor for when we're changing because we've been given a diagnosis, we also can plan to have a better outcome', and he got it. So we can really enhance by really listening to what they are about, and bringing that in to meet them where they are at so they can relate to that.

**What's their intention?**

The third category in social workers approaches to end-of-life conversations includes areas of intention. Themes within this category include understanding & empathy, interpreting & translating and finally guidance & education. Each theme was addressed and expanded on a number of times during each interview regardless of occupational setting or specialty.

*Understanding and Empathy.* Within the category of intentionality, many examples of understanding and empathy developed as codes. Many social workers spoke about how they really work hard to create an understanding of where the patients are at. One social worker explained that they "... don't really have a tag line in how I go about asking people how their coping with or their understanding of things because that will come out when I ask them to tell me about their understanding of their diagnosis and what they have been told by their providers, how they feel, do you feel like you are dying, do you feel like you are getting worse, and then I just go from there. I really just try to meet them where they are at."

One social worker said that they "typically try to have that one on one conversation with the patient because I like to get to know the patient one on one a little bit before I have a lot of family around." They also spoke about "talking about what [the patients] are going through, establishes a connection with another person who they feel that they can just safely vent their feelings of grief and loss." Another social worker said that families or patients have said, "... that they weren't afraid that you were going to break down and because then I would break down, so there isn't as much invested as when they are having those conversations with family members, although we always encourage those conversations to eventually take place."



Another key aspect that majority of the social workers brought up is shared here by a social worker that said, “I really think that with families and patients, having that open and honest dialogue to understand what does this patient want, how can we best support you through this” and further another social worker said that they are constantly “talking to people about [the patient’s] own goals, and understanding how they define quality of life in their own goals, helping them think about that issue, but also how they might talk about those goals with people who are important to them.”

As stated before, these conversations look differently for every person. One social worker described their approach in enhancing language by asking “...[it’s] not just, ‘well how do you feel about dying, are you scared’ you know, you don’t do that, but even something as gentle as, ‘this is really hard, how do you feel about all of this, where are you with this’ of course, only if they are open and then going further if possible and we then we go deeper into these conversations and that’s really an enhancement, [the way] we can bring in conversations about their world to help connect them to how to get deeper into planning.”

One social worker described this as “I have found that normalizing of what their disease looks like, helps people understand a lot, and then validating, finding out who their main people are.” Another aspect of understanding was centered on social workers understanding the patient’s needs and goals. One social worker shared their approach in saying “it’s all about quality of life, what do you want to do with the time you have? And how nice that you have made the decision that you are seeing that you can now conserve your energy so you can do what you want to do.”

But as many social workers stated, it's not always as easy as it seems. This social worker said, "We focus on what the patients' goals of care are, and sometimes that's really hard to tease that out. So we need to say, you have a stage IV cancer, there are treatments available, they are palliative in nature meaning they will provide comfort, they are not curative, they are not aggressive. What do you want to do? How do you want to spend your days? What does good quality of life look like for you? And then helping the team, because teams are very curative trained and are here to fix, helping the team to understand that and validating that that is okay for the patient to feel that way." This was further addressed by another social worker as they have seen that "end-of-life brings out the absolute best and the absolute worst in people, and so you have to have a little bit of tough skin, you can't take it personally, you're just really seeing raw human emotion all the time... and maybe it's time to pull back and say they are just not there yet, or they are just not ready, and just being okay with that."

*Interpret/Translate.* Another theme within this category included the dynamic role of exchanging information between provider and patient/family. This is an art that forms through alignment and understanding the goals of each party. One of the social workers stated that "... just helping the families understand the doctors and the doctors understand the families is a huge part of my role... and yeah just having those conversations with them and the team and the families consistently." That same social worker continued by saying that:

[Helping the team see] this is where these people are at, what are we thinking about this because this is what this family is thinking and so I think I also play a role in communicating with and translate what the physicians say, 'well we told

them that' well that's not what they are hearing. That's not what they are telling me. And I think that's important because the family needs to understand that they are apart of the medical team as well and the treatment team and how influential just them understanding what's going on can be- can be huge.

Another aspect of this communication is that communication isn't always well received or even clear to the receiving party. This social worker said that misunderstanding occurs because "the medical provider hasn't been clear, sometimes the medical provider thinks he or she has been clear and they haven't been and other times they have been pretty clear and yet this person is not ready to go there. And then after we connect most people hit a point of readiness."

***Guidance and Education.*** This became a theme for a variety of individuals including physicians, hospital systems, patients and their families. For this social worker, they spoke about how education is needed, "...with the hospital as a whole, with the patient and family removed, there is a lot of education that palliative care provides, because medical students, residents and even attending's that have been doing this for a long time they don't have a comfort level around those conversations, they usually want us there and us to lead these conversations which is probably a smart thing so they don't say things that are insensitive." Another social worker expanded and said that "... it's a lot of education because they really, I mean if you look at medical students to long standing doctors educations, they get about 4 hours, in general in end-of-life or difficult conversations, and death and dying out of their entire 12 years of education, so they look to us to be the specialty for that. So I would say education is a huge piece for the team in the hospital setting." A barrier that was introduced a number of times within this theme

included a social worker saying that “providing education and getting good information out there and always being approachable to the medical team so they actually want to use us when they need to. We struggle with it all the time. All the time.”

Education was also expanded on within patient and family conversations as well. One social worker described them as “in those situations, they truly do want the information; they want to know who we are, what we do and what could happen to them and what would our focus be. So very informational focused.” Along with an informational focus, a social worker described these conversations as “a delicate dance in providing appropriate information of where they are in their processing and really honoring how they want to live the rest of their life.” Along the same lines, a social worker expands by saying:

“I find myself providing a lot of education about kind of what to expect, demystifying the whole dying process, a lot of education about the physical symptoms maybe on the front end, collaborate with the nurse to help the patient and family understand the medicines we use and I think once those foundations are set, then it’s more about providing support to the patient and family.”

Expectation is a huge part of the education for families. This social worker explained that “many times for family members it’s important to highlight expectations that will occur so we will often see that people eat less, they will sleep more, to reassure this is a product of the disease process and not always of medications that we use.” Many spoke about how when information is given, comfort can arise. This social worker described this fear and said:

When you don't deal with this on a regular basis, this can be scary. And I think sometimes having information gives people comfort because then they know what to expect. I think that's the one thing that I appreciated about the nurses that I worked with- they never said its going to be x number of hours, but they could say, this is what I'm seeing, and they would explain the physical signs to the family, and they would say you know, it's likely, if there are family members that need to come, we need to call them if they want to be here before they go, they need to come. That's what people want to know.

Along with the education that patients, families and physicians need, many social workers explained that the education extends to a societal confusion as well. A social worker clarified that "... palliative care and hospice are just universally misunderstood. They are confused for each other, there's horrible things that people think about hospice where you just pump people full of morphine until they die, that it's basically euthanasia and just those kind of things. So we are always fighting the stigma, we are always educating"

### **What's their outcome?**

The last category that was discovered within the data analysis includes the outcomes of meeting the patient and family where they are at within their relationship. The components of being present, offering support and last offering time and space were evident in data across interviews and discussed heavily.

***Be present.*** This theme's representation was vivid in each interview conducted. It coincides with the idea that it's not what is said that people remember most, but how you made them feel. This includes the idea of presence during visits and interactions. One of

the social workers commented and said, “just the gift of presence is important, remembering their name- they are amazed when I haven’t seen them in a while and I remember their name, that’s important, treating them as a person, and not just a non-Hodgkin’s patient. Be that listening ear, support person, educator, advocate, they are all key roles for social work to be.”

One social worker said, “a lot of it is being very good about listening, what I’ve noticed in end-of-life processing is that’s what it is, people are processing their lives and they need someone who is willing to spend the time and who is able to listen and reflect back to them.” And finally the idea of joining is presented by a social worker in saying that “... joining with people and being present with them where they are at- a lot of people don’t get that basic thing, a lot of doctors don’t get that a lot of nurses don’t get that, so I think we bring that. We bring this unique awareness and how we use ourselves into the presence of the conversation, the end-of-life conversation.”

***Offer Support.*** Providing support is a common part of social work conversations that they have on a daily basis. The social work participants all spoke to some degree of this being an intentional part of their role. One social worker described it as “... taking some of that conversation to talk about how they are feeling, what their concerns are, and really just providing an open forum allows people to come out and start to discuss their thoughts and feelings and feel supported where they are at.”

Many of the social workers talked about how they guided their patients and families to support one another. This social worker gave an example of the guidance and support they provide with their patients,

We always talked about the four gifts of hospice as well as family and it's like you know, tell people that you love them, tell people thank you, if you need to be forgiven, ask for forgiveness if you need to say I'm sorry, say I'm sorry, and say goodbye, and if you need to say you are going to be okay, say I'm going to be okay, so if we needed to have that conversation, where ever we need to go we would go.

Each social worker reiterated the importance of following the wishes and goals of offering support through filling the gaps when needed without presuming an agenda. This social worker said, "just finding out how can we serve and support this patient in the mean time without offending or pushing, and a lot of times we just need to say we are here to provide medicine so they are comfortable." Furthermore, reducing fear through offering support was also discussed and highlighted with this social worker who said that, "much of it is reducing fear through reassurance and then also to support the family. We also supporting the family as well who are kind of running full speed help to take care of the patient and lift up the patient and also are needing support to process their own feelings."

*Offer Time/Space.* The last sub-theme that was identified over multiple interviews included the approach of offering patients and family's time to really absorb the realities in of their situations. One social worker said,

Having the openness and giving space to be able to ask the questions, for some people it's really important to know physically what it is going to be like. With my particular illness how am I likely to die, those kinds of questions I always refer to the medical providers, that's not my area of expertise, for other people,

there are different issues- leaving my family, what happens next, so it's really important to offer that space when we encounter people who are really fearful about that to kind of assess what that's about.

This was amplified when another social worker spoke about the difficulty that some patients and families have when approached by these discussions, "I think people are pretty clear if they don't want to go there, and I think it's important to not push people into having those conversations. But to give them space and let them know that you are available and you can have them, and I think it is important for medical providers to be honest with people."

Many of the social workers felt that processing was a huge part of how they approached conversations with patients and families. They spoke about how a lot of their time was focused on that, offering the time to process. One social worker said, "what I find is that people need an opportunity to process grief, and social workers are sometimes there at the time that they want to do it so we can be there to kind of expound and really help individuals look inside themselves and look at what they are feeling and what they are going through and what the expectations are."

This theme was especially important to many of the social workers due to the fast pace environment and reputation that healthcare typically holds. This social worker spoke about their involvement with giving space due to unmet expectations. They said, "I think that time and space is super important in medical care, social work in general, but specifically in understanding medical care because sometimes people really just need a day or two to realize that this is it and we can't do anymore. You have come here to



survive as your last stitch effort, you came for some, an outside hospital and there's nothing more that can be done."

### **Discussion**

This exploratory study provides an introductory understanding of the approaches social workers have in end-of-life conversations with patient's families and physicians. The study provides a description of the experiences of a small non-representative sample of end-of-life social workers and therefore is limited in its generalizability to the greater population. However, in the information collected important findings and implications have been identified and provided direction for further research in examining conversations at the end-of-life.

Overall, participants of this study indicated four important aspects of approach including those involved, where to start, what their intention is and what outcomes develop. Although these were the core commonalities, there was a variety of interaction determined by setting and scope for each social worker. Every social worker was a part of a medical organization but the difference of atmosphere and organizational focus was established a number of times especially when social workers spoke about becoming involved in patient lives at different times of their disease trajectory.

When looking at involvement in conversations a big piece included the difference between every interaction and every patient and family. Participants spoke about the difficulty in working within this population regarding acceptance of patients and families, medical professionals and society as a whole. When approach was addressed and where social workers begin with patients and families, the data highlighted the importance of assessing and aligning to start where the patient was at with their disease process. It was

then expanded into the importance of intentionality within conversations, which included understanding, interpreting and educating to create a synchronized goals of care plan to best serve the needs of patients and families. Difficulty in exterior team support was highlighted and discussed as a common barrier in end-of-life care, which aligns with the societal discomfort with death and dying.

The ideal outcome of these conversations was identified and showed the importance of having presence, providing support, and offering time and space within the interactions. Understanding the power of each of those components was clear within the data through each interview. It was also established that although these conversations can be prepared for and can occur, they may not be an individual entity and must continue over time to increase effectiveness and acceptance. Participants agreed that not all patients and families and even at times physicians are ready to accept diagnosis or trajectory, and that it is crucial to allow and respect when that discrepancy occurs.

### **Strengths, Implications, Limitations**

The research represented herein was developed with a qualitative design and content analysis to examine complex end-of-life conversations that social workers have with patients, families and their physicians. The presented research contributes to a vast amount of current research in understanding how social workers approach conversations regarding end-of-life. During the in-person interviews, the principle investigator focused on both verbal and nonverbal behavior, in attempts to minimize misperceptions of the data to strengthening face validity (Monette, et al.). The principle investigator carefully recognized and was aware of personal values and expectations prior to each interview to

reduce observational bias (Monette, et al.). Also, the use of open-ended questions were developed for a deeper understanding and clearer picture of the data gathered.

The findings in this study address a gap in understanding end-of-life conversations among licensed social workers. Overall the results suggest that conversations occur and develop through time. Although these conversations continue and are becoming more common with the greater public, society's perceptions end-of-life care and occurrence continue to be a barrier to opening discussing death and dying. The focus on goals of care and quality of life have opened up a new perspective on end-of-life conversations aimed at demystifying death and dying, though some medical focuses of curative vs. comfort continue to present as a barrier.

The findings aligned with past research as well. The importance of developing a relationship and understanding the goals of the patient were clear within the data found for this study. Important identifiers including a clearer picture of involvement and an orientation of common conversational techniques was highlighted within the data which gives light to the approaches social workers use in end of life conversations.

The limitations that were presented in this study include a number of key factors and have been included to understand the significance of findings and provide space for future research. Because this study will use content analysis and is qualitative in design, it will not be effective for testing or even determining causal relationships, statistical significance (Berg & Lune, 2012). Participant recruitment was another limitation within the research process. It would have been beneficial to recruit a larger sample size to adequately contribute to the discovered findings. Time availability and project scope also

held limitations in developing a comprehensive analysis in regards to available resources and time restrictions.

Findings of this study highlight the importance and need for social workers to continue to educate and connect with other medical professionals to offer understanding and expand patient centered end-of-life care. Social workers need to continue to advocate through policy and legislature for changes to occur systematically within health care. Social work should continue to advance clinical practice for students and new social workers that may benefit from exposure and involvement in end-of-life conversations. Social work practice that approaches end-of-life conversations in this way is crucial in continuing to achieve quality end-of-life care for patients and their families.

### References

- Administration on Aging. (2010). <http://www.aoa.gov/>
- Arnold, E. M., Artin, K. A., Griffith, D., Lund Person, J., & Graham, K. G. (2006). Unmet needs at the end of life: Perceptions of hospice social workers, *Journal of Social Work in End-of-Life & Palliative Care*, 2(4), 61- 83. DOI: 10.1300/J457v02n04\_04.
- Back, A. L., Trinidad, S. B., Hopley, E. K., & Edwards, K. A. (2014). Reframing the goals of care conversation: “We’re in a different place”, *Journal of Palliative Medicine*, 17(9), 1019-1024. DOI: 10.1089/jpm.2013.0651.
- Berg, B.L. (2007). *Qualitative research methods for the social sciences* (6th. ed.). Boston, MA: Allyn & Bacon.
- Berg, B.L & Lune, H. (2012). *Qualitative research methods for the social sciences* (8th ed.) Upper Saddle River, NJ: Pearson Education Inc.
- Friedman, J. 2015. End-of-Life Care in Nursing Homes and Assisted Living. *The Encyclopedia of Adulthood and Aging*. 1–6.
- Gardner, D. S., Gerbino, S., Warner Walls, J., Chachkers, E. & Doherty, M. J. (2015). Mentoring the next generation of social workers in palliative and end-of-life care: The zelda foster studies program, *Journal of Social Work in End-of-Life & Palliative Care*, 11:2, 107-131, DOI: 10/1080/15524256.2015.1074142
- Gutheil, I. A., & Heyman, J. C. (2011). A social work perspective: Attitudes toward end-of-life planning, *Social Work in Health Care*, 50:10, 763-774, DOI: 10.1080/00981389.2011.595479.
- Heyman, J. C., & Gutheil, I. A. (2006). Social work involvement in end of life planning, *Journal of Gerontological Social Work*, 47:3-4, 47-61. DOI: 10.1300/J083v47n03\_04.
- Hobart, K. R. (2002). Death and dying and the social work role, *Journal of Gerontological Social Work*, 36:3-4, 181-192. DOI: 10.1300/J083v36n03\_14.
- Kane, M. N., Hamlin, E. R., & Hawkins, W. E. (2005). Perceptions of preparedness to assist elders in end-of-life care preferences, *Journal of Social Work in End-of-Life & Palliative Care*, 1(1), 49-67. DOI: 10.1300/J457v01n01\_04.
- Kramer, B. J., Christ, G. H., Bern-Klug, M. & Francoeur, R. B. (2007). A national agenda for social work research in palliative and end-of-life care, *Journal of Palliative Medicine*, 8:2, 418-435, DOI: 10.1089/jpm.2005.8.418.

- Kramer, B. J. (2012). Social workers' roles in addressing the complex end-of-life care needs of elders with advanced chronic disease, *Journal of Social Work in End-of-Life & Palliative Care*, 9: 308-330. DOI: 10.1080/15524256.846887.
- Monette, D.R., Sullivan, T.J., & DeJong, C.R. (2011). *Applied social research: A tool for the human services*. Belmont, CA: Brooks/Cole.
- Padgett, D.K. (1998). *Qualitative methods in social work research challenges and rewards*. Sage Publications Inc.
- Periyakoil V.S., Neri E, Kraemer H (2015) No Easy Talk: A Mixed Methods Study of Doctor Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients. *PLoS ONE* 10(4): e0122321.  
doi:10.1371/journal.pone.0122321
- Reese, D. J. (2011). Interdisciplinary perceptions of the social work role in hospice: Building upon the classic kulys and davis study, *Journal of Social Work in End-of-Life & Palliative Care*, 7, 383-406. DOI: 10.1080/15524256.2011.623474.
- Weisenfluh, S. M. & Csiai, E. L. (2013). Professional and educational needs of hospice and palliative care social workers, *Journal of social work in end-of-life & palliative care*, 9:58-73, DOI:10.1080/15524256.2012.758604.
- World Health Organization (2004). *The Solid Facts: Palliative Care*. Retrieved from: [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0003/98418/E82931.pdf](http://www.euro.who.int/__data/assets/pdf_file/0003/98418/E82931.pdf)

## Appendix A



UNIVERSITY of ST. THOMAS  
MINNESOTA

### Consent Form

#### **An Exploratory Study: How hospice and palliative care social workers approach end-of-life conversations with patients, families and physicians**

You are invited to participate in a research study about the approach hospice and palliative social workers use in having end-of-life conversations with patients, families and physicians. I invite you to participate in this research. You were selected as a possible participant because of your occupational experience in this topic. You are eligible to participate in this study because you are over the age of 18, have an LICSW, and have past or current occupational experience with either hospice or palliative care. The following information is provided in order to help you make an informed decision whether or not you would like to participate. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Angela Mueller, a graduate student at the School of Social work, College of St. Catherine/University of St. Thomas and is supervised by Associate Professor at the University of St. Thomas, Dr. Robin Whitebird. This study was approved by the Institutional Review Board at the University of St. Thomas.

#### **Background Information**

The purpose of this study is to explore, examine, and gain a better understanding how hospice and palliative care social workers social workers approach end-of-life conversations with patients, families and physicians.

#### **Procedures**

If you agree to participate in this study, I will ask you to do the following things: Participate in a semi-structured single session interview and answer 8-10 open ended questions (some with additional follow up questions for clarity) regarding hospice and/or palliative care, the role of the social worker within these contexts, and end-of-life conversations with patients, families, and physicians, reserve between 30 and 45 minutes to complete the interview itself, consent to be audio-recorded through the duration of the interview, consent to have findings put into a de-identified report that will be publicly available (will not contain any identifying information), and consenting to having the de-identified interview responses viewed and interpreted by this researcher. Location of interview be determined by participant needs.

**Risks and Benefits of Being in the Study**

The study has no known risks.

The direct benefits you will receive for participating are: There are no direct benefits for participating in this study.

**Privacy**

Your privacy will be protected while you participate in this study. Participants will control the location, timing and circumstances of sharing their information.

**Confidentiality**

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you. The types of records I will create include audio recordings, transcripts and computer records. Each item will be stored on a password-protected laptop and audio recordings will be stored on a password-protected cell phone where only the investigator will have access. All records listed before will be destroyed before June 1, 2016. All signed consent forms will be kept for a minimum of three years upon completion of the study. Institutional Review Board officials at the University of St. Thomas reserve the right to inspect all research records to ensure compliance.

**Voluntary Nature of the Study**

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with any individuals, employers, cooperating agencies, or institutions or the University of St. Thomas. There are no penalties or consequences if you choose not to participate. If you decide to participate, you are free to withdraw at any time without penalty or loss of any benefits to which you are otherwise entitled. Should you decide to withdraw, data collected about you will not be used and will be destroyed. You can withdraw in person, by phone or by email. You are also free to skip any questions I may ask for any reason.

**Contacts and Questions**

My name is Angela Mueller. You may ask any questions you have now and any time during or after the research procedures. If you have questions later, you may contact me by phone 320-293-1467, or email at [muell4899@stthomas.edu](mailto:muell4899@stthomas.edu) or my instructor Robin Whitebird at 651-962-5867. You may also contact the University of St. Thomas Institutional Review Board at 651-962-6035 or [muen0526@stthomas.edu](mailto:muen0526@stthomas.edu) with any questions or concerns.

**Statement of Consent**



I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I hereby give permission to be audio recorded during this study.

**You will be given a copy of this form to keep for your records.**

---

**Signature of Study Participant**

---

**Date**

---

**Print Name of Study Participant**

---

**Signature of Researcher**

---

**Date**

**Appendix B**

## Interview Questions

1. How long have you been a social worker working in end-of-life care?
2. Could you tell me what area in end-of-life care you work in?
3. Could you explain how you see your role in working with end-of-life conversations?
4. Could you explain how you see your role in working with an interdisciplinary team in the context of end-of-life care?
5. Could you tell me about end-of-life conversations you have with patients and/or families?
6. Could you tell me about end-of-life conversations you have within the interdisciplinary team?
7. In what way do you see these conversations benefiting the patient's outcomes?
8. In what way do you see these conversations hindering the patient's outcomes?
9. How would you describe your technique in approaching these conversations?
10. What are some barriers that you have experienced in approaching end-of-life conversations?
11. In your experience, what can a licensed social worker do to enhance end-of-life conversations with patients, families and their physicians?