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Medical Social Workers' Best Practices in Supporting Autonomy at End of Life

by

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MSW Clinical Research

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

Master of Social Work

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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

The purpose of this qualitative research study was designed to explore the topic of medical social workers' best practices in supporting autonomy at end of life, specifically within a hospital setting. A total of eight licensed social workers with a minimum of five years' experience practicing in a hospital setting located in the Twin Cities Metropolitan Region were interviewed. The results indicated that patient and family dynamics, education on end of life, advance directives and medical social workers' role in supporting autonomy effect and influence best practices when supporting autonomy at end of life. Supplementary research should be considered to further explore specific methodology and technique used by medical social workers when working with patients at end of life in addition to explanations behind lack of core curriculum relating to end of life coursework in social work undergraduate and graduate programs.

Table of Contents

Introduction and Purpose Statement 5

Literature Review and Research Question 7

Autonomy & Decision Making Capacity 7

Advance Directive 9

Open Communication..... 10

Patient and Family Expectations 12

Patient-Centered Care..... 13

Social Work Role in Supporting Autonomy at End-of-Life..... 15

Conceptual Framework..... 17

Methods..... 18

Design/Methodology and Rationale..... 18

Sampling Procedures and Rationale 18

Protection of Human Subject..... 18

Data Collection Instrument and Process 19

Data Analysis Plan 20

Strengths and Limitations..... 21

Findings..... 22

Family Dynamics are Complex..... 23

Fear 23

Protection..... 24

Barriers in Communication 24

Zero 25

Learned on the Job 25

Advance Directive 26

Write it Down 26

Have a Conversation..... 26

Main Role in Supporting Autonomy 27

Redefining Hope..... 27

Providing Education 27

Meeting the Client Where They Are At..... 28

Quality versus Quantity of Life 29

Being Mindful..... 29

Patient Control..... 30

Own Your Feelings 30

Discussion	32
Patient and Family Dynamics	32
Education on End of Life	33
Advance Directive	33
Social Work Role in Supporting Autonomy	34
Implications for Social Work Practice	36
Implications for Future Research	37
Conclusion	38
Appendix A – Consent Form	41
Appendix B – Interview Questions	44

Introduction and Purpose Statement

The purpose of this qualitative research study was to further explore medical social workers' best practices in supporting autonomy at end of life, specifically within a hospital setting. Death, despite its inevitability, whether it is due to terminal illness, old age or natural causes, is unexpected. However, one way to promote peace of mind and combat life's unexpected events is to invest both time and energy toward learning how to verbalize and document end of life wishes in an advance directive to ensure end of life care wishes are intimate and personal for all individuals. Therefore, it is important to recognize the role of medical social workers in regard to end of life, specifically when advocating for patient autonomy.

Being a social worker means being a communicator. It means actively listening, engaging, connecting, encouraging, and feeling with people. As a society, we have lost our ability to feel with others, specifically the older adult population. We have forgotten that they too, have intrinsic value, especially in end of life. Therefore, what we need to remember is that we will never truly understand a person until considering things from their point of view, or as Atticus Finch stated in *To Kill Mockingbird*, "until climbing in their skin and walking around in it" (Lee, 1960, p. 33). Therefore, as social workers, it is our responsibility to act justly and to advocate for those considered vulnerable because then and only then will we be successful in establishing that necessary connection and change. According to the National Association of Social Worker's Code of Ethics, "social workers understand that relationships between and among people are an important vehicle for change" (NASW, 2008, p 6). Furthermore, it states that as social workers, we strive to strengthen, promote, restore and enhance both the well-being and relationships of all people (NASW, 2008, p. 6). This mindset is especially important when considering, and working with patients in end of life.

Brené Brown, social worker, author and research professor at the University of Houston emphasizes that, “rarely can a response make something better, what makes something better is connection” (Brown, 2013). She continues to elaborate the idea of connection in her presentation on empathy versus sympathy by highlighting the importance of how “empathy fuels connection whereas sympathy drives disconnection” (Brown, 2013). Therefore, reiterating the idea of in order to form a connection, active listening and communication must first take place when discussing end of life. Meaning, as a society, we must do better. We must embrace that death is a part of life and medical social workers must be at the forefront of this task. Thus, this review will discuss different articles and issues regarding autonomy, advance directives, open communication, patient and family expectations, patient-centered care and the importance of implementing medical social workers' role in supporting autonomy at end of life. The following section will further describe the focus of the research question and highlight the content within the literature review.

Literature Review and Research Question

There have been various studies conducted and completed by experts in the field of end of life care, specifically, patient autonomy and the role medical social workers play in implementing their best practices in relation to end of life. However, the literature highlights the need for additional information and feedback from clinical social work curriculum and enforcement of best practices in upholding patient autonomy. Previous studies have identified a number of dominant themes that will be discussed in this literature review, including the importance of autonomy, advance directives, open communication, patient and family expectations, patient-centered care and medical social workers' role in supporting autonomy at end of life.

Autonomy & Decision Making Capacity

Autonomy can be defined as recognizing the right of “an individual to make their own health care decisions in all circumstances” (Galambos, 1998, p. 278). Patient autonomy goes beyond the ability for one to make decisions by simply expressing and acting on end of life wishes. This is important to understand, especially within healthcare, because end of life decisions and conversations often arise within a hospital setting. Patients in general are considered competent to make decisions unless otherwise noted (Mitchell, 2015). Patient decision-making capacity is determined by a number of factors including: expression of choice, consistency, reason for choice, ability to communicate, knowledge of facts, significance of the decision, reasoning ability, and rationality (Sandman, 2012; Mitchell, 2015). Providers play a key role in both analyzing and honoring patients' decision-making capacity.

As important as it is for patients to demonstrate decision-making capacity, it is of equal importance for them to engage in shared decision-making with their medical provider. Shared

decision-making can be described as collaboration between both the patient and provider with open communication and understanding treatment preferences (Sandman, 2012). This affords both parties to actively engage and participate in the plan of care on an equal platform and with a sense of mutual understanding.

Differences exist between patients who demonstrate cognitive ability to participate in decision-making versus those whose cognition is mildly or significantly impaired. Shared decision-making becomes important and the discussion should be guided by medical providers, when in a hospital setting. Medical providers often gauge these conversations differently for those who are capable versus incapable in expressing end of life decisions. For those who can make their own decisions, providers discuss patients' goals for treatment, advance directives and inquire about who the patient has deemed as their proxy should they no longer be able to proclaim their wishes. Discussions are weighed differently when conversing with family members who have become the sole decision-maker due to the patient being incapable of making decisions. These conversations revolve around quality of life, empathy and treatment recommendations (Winzelberg, 2005). Patients and providers discuss the wishes in order to reach common ground and honor autonomy.

Autonomy is of equal importance to honor at end of life due to the value placed on quality versus quantity of life. In 1991, the passing of the Patient Self-Determination Act provided patients with information on choice regarding treatment options, end of life information and advance directives upon admission to hospital setting (Galambos, 1998). This affords patients and families the opportunity to, initiate, and engage in, end of life decisions through conversation. Therefore, an example of honoring patient autonomy within a healthcare setting can be illustrated within an advance directive, sometimes referred to as a healthcare directive.

Advance Directive

An advance directive is a document that outlines patient preferences for end of life treatment in the event of incapacity. An advance directive can come in the form of a living will or a power of attorney. Each patient is provided the initial chance to document their end of life wishes upon entering the hospital (Mitchell, 2015). While completing this document helps simplify difficult decision making processes, it is not mandatory in all places. The Minnesota Health Care Directive Statute of 2017 defines a healthcare directive and provides necessary guidelines in selecting a power of attorney to make decisions for the patient when the patient is unable to make those decisions (Health Care Directive Statute, 2017). However, it does not require one and as a result, one-fourth of Americans do not have an advance directive (Center, 2013). With an advance care directive decision making is shifted from the individual to the family and/or provider (Benson, 2012). For example, without the designation of do-not-resuscitate (DNR), the family and provider, have the obligation to carry out all means of resuscitation even though that may not be the patient's wishes. This obligation causes an increase in family and provider responsibility and unnecessary medical expenses (Center, 2013) at patient's end of life. Advance directives afford the opportunity to limit both family and provider responsibility and reduce medical expenses.

Minnesota law provides access to this document and yet individuals choose to avoid its completion. A 2003 collaborative study by American Association of Retired Persons (AARP) and the Minnesota Center for Survey Research, at the University of Minnesota, surveyed 804 Minnesota residents 18 years and older regarding discussions on end of life wishes (Silberman, 2013). The results of the survey indicated that 73 percent did not complete an advance directive and of that percentage, 32 percent considered it not a priority and 24 percent did not know how

to attain the document (Silberman, 2003). These results support a key flaw in the process in not making the advance directive mandatory.

The issue of lack of advance directives becomes both a personal and public one. This is important to recognize because in doing so, one will see that it can be avoidable when appropriate action and follow through is taken in the form of simply setting aside the time for conversation (Advocacy Practice for Social Justice, 2016). Creating time for conversation around end of life wishes must involve both the patient and their power of attorney for the intent of creating a comfortable connection that results in understanding. That connection and understanding is key to carrying out end of life wishes because power of attorney's cannot, nor should they, guess the individual's wishes (Fagerlin, 2002). A statute even with honorable intentions is of little value when its proposal is not carried out. In essence, the law provides an opportunity for patient autonomy. Medical social workers can influence autonomy by providing patients an advance directive when admitted to a hospital setting and aiding them in its completion.

Open Communication

Medical social workers can support autonomy at end of life through the influence of open communication. Open communication means giving oneself permission to be both vulnerable and assertive when expressing end of life wishes. It affords opportunity to provide clarity and mutual understanding between patients and their families (Broom and Kirby, 2013). Talking about end of life decisions is not simple. However, open communication ensures patient wishes are honored and increases positive experiences for both the patient and family. Open communication ensures patient wishes because it aims to relieve tension between patients and their families by initiating transparency throughout the end of life process. Transparency is key

in regard to communication between patients and families because if not transparent, patient wishes for end of life will differ from that of their family.

This differentiation creates a sense of separation and often results in patients themselves feeling guilty, burdensome and considered themselves to be stressors (Broom and Kirby, 2013). These feelings indicate their perspective as to what their families thought rather than the perspective of the families themselves. Furthermore, if not communicated, patients identify with the sense, or need, to fight up until the end of their life in order to fulfill family expectations regardless if it results in an altered sense of dignity (Broom and Kirby, 2013). On the other hand, family expectations may be just the opposite. Their expectations, though often in alliance with wanting the patient to fight, are initiated from fear and inability to appropriately cope with their loved one nearing end of life (Broom and Kirby, 2013). Thus, these feelings are a result of closed communication because they simply were not communicated. Instead, they were preconceived perceptions of end of life wishes rather than actual and openly communicated wishes. This lack of open communication between patients and families creates disconnect.

Therefore, in order to increase positive experiences for both the patient and family during end of life, open communication must be fluent between both parties. This fluidity results in an increase in familial support and instills a sense of empowerment for both the patient and family (Broom and Kirby, 2013) because it creates a sense of connection and mutual understanding. Both connection and mutual understanding are needed in order to decipher wishes of both the patient and family and to decrease tension throughout the end of life process. Though open communication cannot or will not alter the end result, it affords the opportunity for connection at a time when connection is most imperative. Thus, open communication increases positive experiences by simply affording patients the opportunity to speak openly knowing that someone

was listening when talking about the end of their life (Pevey, 2005). Additionally, establishing this communication style increases both the patient's willingness to share while lessening the boundaries between them and their families. Open communication is therapeutic because it provides patients a sense of comfort (Pevey, 2005). The simple gesture of open and honest dialogue illustrates connection and the idea that the patient is not in it alone. And not being in it alone is the purpose and intent of open communication.

Patient and Family Expectations

In addition to open communication, it is of equal importance that patient and family expectations are acknowledged and stated when discussing end of life wishes. This is because patient experiences and expectations differ from those of family experiences and expectations. Patients at end of life put their family before themselves. Patients have had time to grasp the idea of end of life because it is happening to them. So they have learned how to manage, or cope, with their situation (Broom and Kirby, 2013). They may not be at peace. They may not be accepting, but they have gained an understanding that their families have not or cannot. They in a sense come to grips with the emotional complexities of dying. And because of this understanding, patients at end of life choose hospice or admittance to skilled nursing facilities. These choices reflect their effort to aid or assist their families in the dying process (Broom and Kirby, 2013). More often than not, patients think that in making these choices, they are making it easier on the family even though they want to be at home. That is where confusion occurs. Patients are trying to make choices to ease the burden on the family while the family tries to ease the burden on the patient (Broom and Kirby, 2013). There is no right or wrong choice in caring for an end of life patient when the expectations are aired through open communication.

And in stating their wishes openly, patients at end of life gain dignity and a type of control over a situation that is out of their control. Because family expectations and relations become ever so important, patients want to tidy things up. They come to realize the necessity of repairing broken relationships not only for themselves but more importantly, for the family that remains (Broom and Kirby, 2013). Time becomes valuable and there is no time to waste on words left unsaid.

Family, on the other hand, often demonstrates confusion and reluctance in the accepting that patients, or their loved ones, were at peace (Broom and Kirby, 2013). Families want their loved ones to “rage, rage against the dying of the light” as Dylan Thomas stated in his poem “Do not go gentle into that good night.” And that never say die idea makes sense from the family perspective. They, too, value time, time that is far too quickly slipping from them. No matter how long loved ones are with their families there is never enough time. That being said, they struggle in understanding how loved ones at end of life surrender the fight (Broom and Kirby, 2013). As difficult as dying is, it is complicated by the expectations of both the patient at end of life and their families.

Patient-Centered Care

Patient-centered care was another dominant theme within the literature. Patient-centered care revolves around meeting the patient's needs. To do so, requires open communication and caregiver education. Open communication is necessary in order to achieve a sense of mutual understanding between the caregiver and the patient. Caregivers who engage in open communication do so in a way that relays a sense of loyalty and realism to the patient (McMillan and Small, 2007). This type of care is necessary to provide autonomy because it works to establish groundwork for achieving patient's end of life wishes. In order to best achieve patient's

end of life wishes, their caregivers need to be equipped with the knowledge and skillset necessary to do so. Patient-centered care reflects the efforts of the caregiver. It is the caregiver's responsibility to maintain a sense of composure throughout the patient's end of life and aim to achieve symptom management, practice problem solving and seek professional assistance when needed (McMillan and Small, 2007). When the caregiver is supported with additional professional assistance and has been educated on the patient's condition, both the caregiver and patient experience less stress (McMillan and Small, 2007). This leads to providing a higher quality of physical and emotional patient-centered care. This higher quality of physical and emotional patient-centered care is beneficial for both the caregiver and the patient. The physical benefits of patient-centered care result in a reduction of pain and weakness, whereas, the emotional benefits consist of an increase in symptom management, resulting in an improvement of quality of life (McMillan and Small, 2007). Patient's experiences improve when patients, themselves, are the focus of their care.

In order for patients to be the focus of their care, they must receive consistent interaction from their caregiver (Pevey, 2005). When caregivers are present, both physically and mentally, patients reap multiple benefits from their consistency. Their presence ultimately decreases patient's loneliness and fears and increases physical touch and pain management (Pevey, 2005) during end of life. This notable shift in comfort and symptom management is a direct result of patient-centered care provided by the caregiver. This type of care is necessary to maintain patient autonomy.

Likewise, in order to maintain patient autonomy and achieve patient-centered care, patients need to be responsible for communicating their end of life wishes to their caregivers. Communicating end of life wishes is difficult. However, they are better able to understand, as

well as, communicate end of life wishes through the use of metaphors (Southall, 2012).

Metaphors helped patients communicate in a way they felt most comfortable. Using metaphors make the message clear while softening the rough edges of reality. Caregiver support together with patient participation are key components in improving patient-centered care.

Social Work Role in Supporting Autonomy at End of Life

Medical social workers play an important role in supporting autonomy at end of life as the patients advocate. They work to provide support and resources to help the patient make an informed decision regarding end of life (Peterson, 2012). They factor in patient emotional, physical and environmental needs into the shared decision-making process. Their lens differs from that of a medical provider. The medical lens focuses on saving lives, whereas, a social workers lens tends to focus on the quality at the end of life. Social workers invest in, and uphold the standards of human dignity by advocating for patient autonomy. Highlighted within the Social Work for Social Justice 10 principles, the human dignity principle illustrates the importance of individual worth and promotes empowerment for one's ability of choice. Therefore, one way for medical social workers to promote autonomy at end of life is to offer patients' an advance directive. This is because, once filled out, an advance directive honors the autonomy and thus promotes and affords individual choice

Another main role that medical social worker play when supporting autonomy at end of life is simply being present. Brené Brown's work emphasizes empathy, a feeling with, rather sympathy, a feeling for. Brown goes on to discuss the four qualities of empathy: perspective taking, staying out of judgement, recognizing emotion in other people and then communicating that emotion (Brown, 2013). Empathy provides a connection. The connection of being present. In order to form a connection, active listening and communication are important. But so is

physical presence (Ordille, 2016). And that physical presence provides therapeutic empathy for both patients and families.

However, in order to provide and maintain such connection, medical social workers must be provided more education on end of life within both undergraduate and graduate programs in order to increase their end of life care skillset. Currently, a single course, if any, on death and dying is offered within most accredited social work programs (Murty, 2015) thus, presenting a gap within knowledge and expectations of medical social workers when working with this population. Therefore, advocacy needs to be done on a macro-level because in order to provide services to patients in end of life, educational opportunities and resources need to be offered. Fortunately, the School of Social Work at the University of Iowa initiated a Field of Practice in end of life care in their Masters of Social Work program in 2001 increasing resources and training in the study of death and dying (Murty, 2015). The University of Iowa's standard to implement more end of life care course material in their program is one that should be viewed as a model for all higher level social work education.

In order to arm medical social workers with the necessary tools to combat life's unexpected event, death, more needs to be done. More training. More funding. More support. Only with more, the patients at end of life will be better served.

Conceptual Framework

A conceptual social work framework as it relates to the topic of medical social workers best practices in supporting patient autonomy at end of life is identified in the National Association of Social Work Code of Ethics as *dignity and worth of a person*. The social work framework is described as promoting “self-determination in an effort to enhance clients’ capacity and opportunity to chance and to address their own needs” (NASW, 2008, p. 5). Thus, similar to the human dignity principle, an advance directive, when filled out, respects the dignity and worth of all individuals (NASW, 2008). This is significant for the sole purpose of it directly relating to the importance of individual worth and empowering one’s ability of choice by honoring autonomy at end of life.

Methods

Design/Methodology and Rationale

This research study utilized qualitative research methods to explore best practices when supporting patient autonomy at end of life. Participants were sought to gain additional perspective of honoring patient autonomy at end of life, specifically in a hospital setting in the Twin Cities Metropolitan Region. Eight semi-structured interviews with licensed medical social workers were completed. A qualitative methodology was selected to explore the complex phenomenon of autonomy at end of life in a narrative approach.

Sampling Procedures and Rationale

Eight female licensed medical social workers in the Twin Cities Metropolitan Region who have experience with gerontology and death and dying, specifically, end of life care, were sought after and selected for this study. The qualifications of the participants included having bachelor's or master's degree in social work with a minimum of five years' experience within a healthcare setting. Medical social workers who did not meet these qualifications were excluded. The selection process was be a result of the snowball method (Grinnell, Williams and Unrau, 2016). The initial participant was selected after having responded to an email addressed to medical social workers within the Allina Health system. The sample then increased to a total of eight participants due to professional connections made with the initial participant with other medical social workers in the Twin Cities Metropolitan Region.

Protection of Human Subject

The researcher used a template provided by the Institutional Review Board (IRB) at St. Catherine University to aide in the protection of the participants. Specifically, this template allowed the researcher to create a consent form for the participants. Prior to providing the

participants with the document, the researcher sought approval from the instructor of the course. The purpose of the consent form addressed the following: information regarding the researcher, the purpose of the study, why the individual met the criteria as a possible participant, the processes incorporated to complete the interview as well as how information will be obtained, the risks and benefits of participating, issues of confidentiality, the voluntary nature of the study and consent to participate in the study and contact information for both the researcher and the course instructor (See Appendix A for complete consent form). Prior to beginning the interview, the consent form was signed by both the researcher and the participant. The researcher was granted approval from the IRB at St. Catherine University in order to ensure protection of participants.

Data Collection Instrument and Process

The primary tool for data collection for this qualitative research study was done so by conducting eight 45-60-minute semi-structured individual interviews. Prior to the interview, designated questions were provided to the participant. The interview consisted of eleven primary open-ended questions and two follow-up questions that stemmed from the original research question seeking to explore the original research question: *What are Medical Social Workers' Best Practice in Supporting Autonomy at End of Life?* Thus, primary questions probed participants to further discuss not only their experience interacting with patients and families as licensed medical social workers, but specifically focus on how medical social workers' can best support patient autonomy at patient end of life (See Appendix B for a complete list of interview questions).

Data Analysis Plan

A digital audio recorder on the researcher's private and personal cell phone was used to record, review and transcribe the interviews. The transcription process for each interview was completed by typing on the researcher's password protected laptop. After each interview transcription was complete, the researcher conducted a line by line coding process in order to depict initial categories and themes within the interviews (Grinnell, Williams and Unrau, 2016). Once coding was completed for each interview, the researcher then revisited each interview individually, and again, collectively, to confirm and rearrange information into concrete categories (Grinnell, Williams and Unrau, 2016). The data collection was also re-reviewed and highlighted for the purpose of discovering both apparent and underlying themes and sub-themes.

Strengths and Limitations

Previous qualitative studies and literature reviews support the strengths of this study in regards to the role social workers play in supporting autonomy at end of life, specifically within a hospital setting. Medical social workers assist in advocating for patients' end of life wishes by modeling open communication in order to best practice patient-centered care. Additionally, support of these strengths are reinforced from the patient perspective by emphasizing autonomy, open communication and the importance of completing an advance directive. Patient autonomy at end of life is best fulfilled when patients are supported by medical social workers and are motivated to discuss and document their wishes in the presence of family.

However, despite these strengths, further research in the area of specific best practices medical social workers use in supporting patient autonomy at end of life is needed. Medical social workers often are involved in end of life scenarios and discussions with patients and families in a hospital setting. However, they are offered little to no core education on death and dying and end of life throughout their undergraduate or graduate careers. Furthermore, gaps in research continue to exist in determining the cause behind lack of effort made by patients to complete an advance directive in order to express their end of life wishes.

Findings

This qualitative research study consisted of a total of eight middle- aged female medical social workers who practice in the Twin Cities Metropolitan Region. All participants in this study had previous professional backgrounds and experience in settings such as: home care, hospice, nursing homes, memory care, and mental health or clinic settings. Participants met previously stated qualification of having five or more years' experience as a medical social worker with five of the eight participants having a graduate degree in social work. This study was designed to explore medical social workers' best practices in supporting patient autonomy at end of life. Upon completion of data analysis, five themes were identified with subsequent sub-themes emerging from each theme. The five themes were: family dynamics are complex, education on end of life, advance directive, quality versus quantity of life and main role in supporting autonomy. Noted within the theme of family dynamics are complex, three sub-themes were identified as fear, protection and barriers in communication. Two sub-themes in education on end of life were identified as zero and learned on the job. The theme advance directives had two sub-themes: write it down and have a conversation. There were three sub-themes within the theme quality versus quantity of life and they were identified as: being mindful, patient control and own your feelings. Within the theme of main role in supporting autonomy, three sub-themes were identified as redefining hope, providing education and meeting the client where they are at. Refer to Table 1 for a visual representation of identified themes and subsequent sub-themes.

Themes	Family Dynamics are Complex	Education on End of Life	Advance Directive	Quality vs. Quantity of Life	Main Role in Supporting Autonomy
Sub-Themes	Fear	Zero	Write it Down	Being Mindful	Redefining Hope
	Protection	Learned on the Job	Have a Conversation	Patient Control	Providing Education
	Barriers in Communication			Own your feelings	Meeting the client where they are at

Table 1. Themes and Sub- Themes

Family Dynamics are Complex

Participants noted that family dynamics influenced patient end of life decisions. Three sub-themes were identified from participant’s responses: fear, protection and barriers in communication.

Fear. Participants identified with fear in both the context of being afraid of their illness and what their diagnosis meant for their future and how to discuss their plan of care with their family. Participant six reported:

“Patients and families are often afraid of what is going to happen to them both. The dying person and those left behind. Patients are often more honest when meeting alone with the medical team because they are going to talk to the doctor, they are going to learn what their agenda is. They also don’t want to let the family down so they are going to be stronger when the family is in the room.”

“Sometimes it’s just the fear of the unknown. You know – what’s going to happen to me? What’s going to happen to mom when dad dies?”

Likewise, participant eight stated: *“A lot of those (end of life) conversations follow relationship patterns of communication. Sometimes it is fear and also the white elephant in the room and other people might be, alright, lets figure this out. So they are different, but can be alike, too.”* In addition, participant seven reported: *“I think sometimes to name an experience is helpful. To say ‘boy it feels like this to me – I can’t imagine what it feels like to you. Or, I’m wondering if you’re feeling this way...giving them (patients) words when they aren’t ready or too fearful to*

articulate them.” Lastly, participant five said: *“What’s going to be good for them – what will lessen their fear – is seeing that their family is comfortable. Before they (patients) make a decision, they want their family’s permission.”*

Protection. Similar to the idea of fear and being afraid of naming and discussing their illness with family, participants identified the idea of protection at the heart of end of life discussions. Despite its honorability, participants found the idea of protection in end of life discussions to be counterproductive. According to participant seven:

“I think some people feel safer with their families there and some people are truly inhibited because they don’t want to cause their family pain – they may know in themselves that it’s the end of their life but they don’t want to cause their family pain – so sometimes you have a situation where everyone is protecting everybody so then you’re going nowhere fast.”

Participant four said:

“I would say that it is particularly interesting that often times their (patient) verbal and non-verbal behavior is different when in the presence of family. I have found that patients are often protective of their family and may not share as much detail about their own fears or concerns.”

Participant five stated:

“I think unfortunately more often than not they more heavily influence an individual – most people look to their family for permission – and sometimes it’s a relief because the family has been fighting the fight with them and see how run down they are but other times they are like no way - mom is not ready for this and you have to keep fighting. Patients say – I don’t want to be a burden on my family, I don’t want to be at home and die there if my family is going to continue to live there.”

Participant one reported: *“There is a lack of communication between people and in society, really. No one really wants to talk about it because we are all trying to protect each other from the absolute inevitable.”*

Barriers in Communication. Participants noted barriers in communication stem from patient fears regarding illness and their duty to protect family during conversations on end of life.

Thus, participants identified these factors to be inhibiting of honest and open discussions.

According to participant seven:

“I think sometimes you have to get a feel for the family. If you have a family who is going to be totally angry – sometimes you say “you know this is some really hard stuff and I see how much you guys really love each other” and I have found that really loving families are great but there’s a real weakness which is that everybody tries to protect everybody and then we can’t talk. So we ask patients and families to be loving and brave. And this is really hard stuff. Stuff you never wanted to talk about. You didn’t want to think about and now it’s sitting in front of you.”

Participant one reported:

“I always believe the patient knows they are dying, however, a lot of times, families will say let’s not talk about death with the patient...I think when it comes to our loved ones, we are always trying to protect them –patients at end of life may not want to talk about death in front of their loved ones to be sad and the opposite is true – loved ones don’t talk about death in front of patient because they don’t want them to feel sad or for their feelings to be hurt.”

Participant four said: *“Often times patients can feel really overwhelmed with the information – they may hear little pieces here and there but might not be absorbing the whole content of their situation.”*

Participant eight stated: *“It’s not a topic that people want to talk about. You’d be amazed at how many people don’t want to talk about that.”*

Education on End of Life

Participants noted limitations in core and elective courses in regard to education on end of life. The sub-themes identified within this theme were zero and raw practice.

Zero. Three participants specifically stated they received zero coursework in relation to end of life studies. According to participant seven: *“I don’t recall that any of my coursework was about end of life. So, zero.”* Participant one: *“Zero. None. I wanted to take a grief and loss class as an elective but it was full so I had to take something else.”* Likewise, participant four stated: *“During my undergrad program, zero.”*

Learned on the Job. Additionally, three participants also reported they did not receive education regarding end of life and instead, learned on the job. According to participant three:

“Everything I learned about medical social worker, I learned on the job. I started when I was 21 and I just remember feeling like a complete dummy and not knowing what to say – in social work, you’re taught a certain avenue to think, but specifically, you’re not taught. You can’t be a social worker if you can’t think on your feet. What I loved is that I could help people and maybe make a damned difference in this world.”

Participant six stated: *"I don't recall having any courses on death and dying. I've learned it all as it has come up at work or through continuing education requirements."*

Participant eight said: *"I didn't really get anything – I just kind of learned as I went. And everything that I learned about death and dying, grief and loss has been through continuing education opportunities and raw practice – just being there with people."*

Advance Directive

Participants noted that advance directives influence end of life care based on their experience and role in a medical setting. Two sub-themes that arose throughout participant responses were write it down and have a conversation.

Write it Down. Participants identified the significance of the act of writing down end-of-life wishes for the purpose of making them known to families and care providers.

According to participant three: *"It's always best if it's written down. The care team understands wishes because it's written down and families are able to accept circumstances if wishes are known."* Participant two stated: *"Expressing end of life wishes through an advance directive is probably best."* Participant five said: *"Most families describe it (advance directive) as a gift. It lightens the burden of having to make those difficult decisions because they can look at it and use it as a guiding tool."* Participant four reported: *"I place emphasis on what a valuable tool it is – how it guides family in honoring wishes."*

Have a Conversation. Participants expressed that it is of equal importance for patients to express their wishes verbally in addition to completing an advance directive.

According to participant one: *"I think an advance directive is like a blue print – it's important to lay out generally what our wishes are – but keeping the conversation going with our loved ones is important. Without dialogue with family and a trusted provider it's never going to happen."* Participant six stated: *"I always tell everyone they should have one – we could get into a car accident or anything could happen. It takes the burden off families from making difficult end of life decisions. But some people just never talk about death. Never. It's taboo."*

Participant seven said:

"I never want to hear you say – I don't want to be a vegetable – because at the time that you're dying they're not going to know what you're talking about – quality of life as a red pepper or a head of cabbage. So I say to them (patients) - I want to know when you want them (agent) to go full speed ahead and when you feel like they can say – she's worked hard enough and it's time to rest."

Participant five reported: *"We want everybody hearing the conversation and understanding where the conversation is coming from so when, or if, there is a time when the advance directive*

comes into play, they know – yeah, mom specifically said she wouldn't want to be kept alive if she couldn't talk to us."

Main Role in Supporting Autonomy

Participants identified themselves as playing a main role in supporting autonomy as the patient advocate by being at the forefront of both end of life discussions and care. They were asked how and what they identified as ways they best advocated to honor patients at end of life. The sub- themes identified within this theme were redefining hope, providing education and meeting the client where they are at.

Redefining Hope. Patients in end of life have differing experiences, expectations and hopes of the dying process than those compared to their family. As medical social workers, we must respect both parties and aide patients and families in acknowledging that death is inevitable. However, we must do so in a manner that validates and redefines the sense of hope that patients and families continue to hold. Participant seven illustrated how they redefine hope when they stated:

"Hope is a funny thing. You have to talk to people about redefining hope and redefining what a miracle is. If you're looking for this big lightning bolt you're going to miss the falling stars. So you have to look for those sweet moments and those are your miracles. You have to redefine what your goals are and what constitutes as something really lovely."

According to participant six: *"Over the course of time you have to restrict what you say because you can't deliver everything to everybody...but at the same time we try not to say there's nothing more we can do for you – still hopeful but it just looks different now."* In addition, participant three said: *"These discussions are hard. This phase of life is hard. But you can always find something positive – even in the worst situation."* Participation seven reported: *"It doesn't mean that your heart doesn't break for some people but you just have to focus on advocating and making it the best it can be for people."*

Providing Education. Similar to preserving and redefining hope, participants also placed value on providing education to patients and families in order to best support patient autonomy.

As medical social workers, participants identified themselves as leaders in advocating for and

providing the interdisciplinary team with education on patient autonomy and patients and families options and education on the end of life process. Participant eight reported:

“We are the advocate on the treatment team for patient rights, patient autonomy. We are the educator – bring education not only to the patient and family, but to the whole treatment team – we are the ones that I think are in great position to show everybody down and ask everybody where and how are we meeting the client where they are at in this hurry up do do do, fix fix fix, go go go setting.”

According to participant four:

“I think the one thing that is really evident in my career is that patients and families don't even know what options exist – they truly don't. It is our job to provide options and education on end of life – to have that conversation – do you want help sorting out feelings, what do you want your comforting environment to look like, how do you want your children to be supported – being able to let them create what their end of life experience will look like is so incredibly important. People just don't know that they can create that.”

Participant seven said:

“As medical social workers, you are there to support patients to be as healthy as they can be. You help them figure out what goals are realistic to them – you help them take the next step to being healthier. And that is done by giving emotional support as well as resources and education.”

Meeting the Client Where They Are At. Participant responses to this sub-theme reflected the idea of how supporting patient autonomy is a direct result in meeting the client where they are at in their end of life process and helping patients come to terms or cope with what they are experiencing in the present moment. Four participants identified with this sub-theme. Participant seven stated:

“Sometimes I'll say – we never think of somebody being tethered, physically tethered to this world when it's time for them to go and sometimes taking away the machines frees them and allows their soul to fly and they're no longer tethered. You really try and figure out what the family's language is. Or you have someone whose worked hard their whole life and you say you've worked hard, are you tired, it's okay if you are tired, it's okay to say I've done good work, it's okay to say I'm tired – you need to let us know when you think you've worked hard enough and it's time to rest.”

Participant five said: *“We need to always be thinking – this is your life and these are your final moments – let’s make them the best they can be.”* Participant eight said: *“I think as social workers we always have to go back to our values and our ethics – which is about client right to self – determination, right and autonomy and patient’s rights. A lot of times we had to do education around that and caregiver support.”*

Participant four stated:

“My role is assessing the patient’s knowledge of their prognosis – gauging where they are at with or their understanding of it, what it looks like, and learning what their fears are or concerns might be – it’s important for me to know their starting point – to know where they are at.”

Quality versus Quantity of Life

Participants noted that quality versus quantity of life differs among both patients and professionals, specifically in a hospital setting. The sub-themes identified within this theme were being mindful, patient control and own your feelings and emerged throughout the interview process.

Being Mindful. Five participants identified the importance of remaining neutral when discussing patient preference around quality versus quantity of life. Participants emphasized the significance of valuing each patient as an individual with differing opinions and definitions of what quality and quantity of life meant to them.

This sense of neutrality was reported by participant one:

“I’m very mindful that each individual gets to determine what their quality of life looks like and I think so often as medical professionals we put our own views into what someone else’s quality of life might look like. You don’t get to have an opinion as to what quality of life is for someone else.”

According to participant three: *“Quantity is really the focus of time, no matter what it involves. Quality is absolutely comfort focused.”*

Per participant six:

“Quality may mean being able to recognize your loved ones, go to the bathroom on your own, go outside or enjoy some wine and look at the lake. What is important to you – living as long as possible or living at home free of hospitals? I always try to say - how do you want this to go and how can we help you with the dying process?”

Participant two stated the following:

“Everyone’s opinion is different – that’s what you come to discover. I have always thought quality of life is most important so that’s what I assumed other people thought as well – but what’s important is giving them that choice because some people choose quantity and it makes a difference regarding medical treatment. So, never assume because you never know who will have a total different view.”

Patient seven reported: *“If we don’t do somebody’s death right then what have we done to their family.”*

Patient Control. Similar to practicing with mindfulness when discussing quality versus quantity of life with patients, participants found that it is of equal importance to practice in a way that upholds patient preference and wishes regarding their end of life care. According to participant seven:

“Sure, sometimes it kills you to see somebody suffer or to see somebody’s suffering and the family suffering for that matter and you wish you could do something to enlighten them, but this is the one thing that they can still own. They don’t have control over what’s happening but they have control over how it plays out and it’s theirs to control not ours. But sometimes people need the burden taken from them too – they can’t be the one to make the call that the machine is going to go off.”

Participant four stated:

“I always inquire what their knowledge is of their diagnosis – if they have further questions or if they need further clarification from their healthcare team. Giving them the power to understand is really important – and providing them with the tools to feel as though they are in control is of equal importance.”

Participant five said: *“We live in a society that tells us we need to be fighters- and so for some people, when they get to the point where they just don’t want to do it anymore, and they’re ready, and they accept it, there is just a sense of peace.”*

Own Your Feelings. Participants viewed the sub-theme of own your feelings to be essential to practice objectively and advocate for patients during end of life. Participant eight spoke to this idea when they stated:

“You have to ask yourself – are you afraid of dying – and quality vs quantity – it’s not us to determine that. We can’t be afraid to let people go and we can’t be afraid to let them

hang on. That's not our job. Our job is to join them where they are in their journey, provide them education about what their options are and then be there as their support system to walk alongside them."

In addition, participant five said: "*Own your feelings – keep them in check - it's important that my own biases don't impact their decisions. Their decision needs to be their decision and I need to talk about things as objectively as I can.*" Likewise, per participant one: "*People are so uncomfortable having end of life discussions. And when we, as medical professionals are uncomfortable, how do we expect to have real good candid conversations with patients.*"

Furthermore, according to participant four:

"I think it is super important as professionals to recognize what our value system is and to be able to own and name those feelings – to recognize how they might conflict with other families/other beliefs but then step aside – our role as social workers is to be advocates for these patients. Their decisions are not our decisions to make."

Discussion

Previous qualitative studies and literature review support the findings and strengths of this study in regard to patient and family dynamics, education on end of life, advance directives and the main role social workers play in supporting autonomy. This discussion will compare and contrast the present study to that of existing literature on medical social workers' best practices in supporting autonomy at end of life.

Patient and Family Dynamics

Findings from the present study are consistent with existing literature when discussing patient and family dynamics in end of life. Existing literature reported that patients at end of life often put their family before themselves. Their wishes reflect their effort to aid or assist in their families in the dying process (Broom and Kirby, 2013). Often, patients think that in making these choices, they are making it easier on the family. This thought process in existing literature was parallel to that of participant responses. Specifically, participants spoke to how fear, protection and barriers in communication impede patient and family discussions regarding end of life. According to participants, patients are often inhibited by family when discussing end of life with medical professionals because they alter their wishes based on factors that will lessen their family's pain and provide them comfort. This attempt of protection increases difficulty in patient ability to verbalize wishes and results in a barrier of communication because instead of an open dialogue, the purpose is intended to seek permission from family.

Therefore, despite patient effort to lessen the pain for families during end of life discussions, confusion often occurs as to what exactly patient wishes are. This is because patients are trying to make choices to ease the burden on the family while the family tries to ease the burden on the patient (Broom and Kirby, 2013). Thus, resulting in behavior that is

counterproductive. As difficult as dying is, it is complicated by the expectations of both the patient at end of life and their families. So, one thing that participants ask of both patients and families is to be both loving and brave.

Education on End of Life

Findings from the present study are consistent with existing literature when discussing education on end of life, or lack thereof, for all social workers, medical, and otherwise. Existing literature indicated that currently, a single course, if any, on death and dying is offered within most accredited social work programs (Murty, 2015), thus presenting a gap within knowledge and expectations of medical social workers when working with patients at end of life. Likewise, of the total of eight participants, all but two reported that they did not receive nor have the option to elect courses regarding death and dying. Therefore, the problem lies within the expectation of medical social workers to meet patient and families expectations during end of life without having received proper education on end of life or having an opportunity to be equipped with such skillset to do so. Thus, this lack of education on end of life resulted in participants to seek knowledge through self-study and learning on the job. However, while these efforts are honorable, they are not, or should they be, enough or satisfactory in terms of medical social workers role in upholding best practices in supporting autonomy at end of life.

Advance Directive

Notable similarities arose between present and existing literature on advance directives, specifically relating to the document's benefit and the potential it has in initiating conversation among patients and families while aiding them in expressing their end of life wishes. The Minnesota Health Care Directive Statute of 2017 defines a healthcare directive and provides necessary guidelines in selecting a power of attorney to make decisions for the patient when the

patient is unable to make those decisions (Health Care Directives, 145C.02, 2017). Both present and existing literature confirmed the benefit of completing the document resulted in mutual understanding among patients, families and medical professionals when caring for and carrying out someone's wishes at end of life. Furthermore, participants of this study noted that in order to best honor end of life wishes, they must be written down.

However, despite Minnesota law providing patients and family's access to an advance directive document, it does not require, nor is it mandatory, for the document to be completed. Thus, hindering it's potential in initiating the necessary and needed conversation around end of life. Creating time for conversation around end of life wishes must involve both the patient and their power of attorney for the purpose of creating a comfortable connection that results in understanding. That connection and understanding is key to carrying out end of life wishes because power of attorneys cannot, nor should guess, the individual's wishes (Fagerlin, 2002). Participants echoed this idea of importance in creating a comfortable connection with family regarding end-of-life wishes. Without open and honest dialogue, the potential of completing an advance directive becomes of little value.

Social Work Role in Supporting Autonomy

Both existing and present literature identify medical social workers as the main advocate in supporting patient autonomy as they factor in the patient's emotional, physical, and environmental needs when discussing patient wishes at end of life. Their lens differs from that of a medical provider. The medical lens focusses on saving lives, whereas, a social workers lens tends to focus on the quality at end of life. Multiple findings in this study support the already existing literature revolving around the importance of medical social workers role in supporting patient autonomy.

Highlighted within the Social Work for Social Justice 10 Principles, the human dignity principle illustrates the importance of individual worth and promotes empowerment for one's ability of choice. This framework coincides with participant responses regarding the significance in practicing with a mindset that emphasizes meeting the client where they are at. Participants identified redefining hope and providing education as key qualities embedded in best practice when supporting autonomy at end of life. Furthermore, they acknowledged the importance of remaining both emotionally sound and physically present in moments when patients and families are overwhelmed. This philosophy mimics that of Brené Brown's work on empathy and its four qualities: perspective taking, staying out of judgement, recognizing emotion in other people and then communication that emotion (Brown, 2013). Thus, further indicating the necessity of medical social workers during discussions with patients at end of life and their families.

Implications for Social Work Practice

Medical social workers are worthy of being recognized for more than handing out bus tokens. Their skillset, specifically in a hospital setting, provides a lens that focuses on the biopsychosocial needs of patients. Instead of focusing on the status quo of quantity and the mindset of implementing measures to go above and beyond to save every, and all, patients, their focus and practice is geared toward self-determination and quality of life. Medical social workers wear multiple hats when supporting patient autonomy. They are the advocate, the communicator, the active listener, the encourager, the realist and the one who practices with empathy. They assess based on biopsychosocial needs and practice with a framework composed of person-in-environment and strengths based perspectives with patients and their families. Yet, despite these efforts, findings indicate gaps in research regarding lack of methodology and end of life core curriculum for best practices in supporting autonomy at end of life.

Implications for Future Research

The findings of this study acknowledge and corroborate existing literature in recognizing the importance of the role medical social workers play in supporting autonomy. Thus, medical social workers remain at the forefront of advocating for, and supporting patient autonomy at end of life in a hospital setting. However, despite this recognition, further research of specifics relating to best practice used in supporting autonomy at end of life is needed. Specifically techniques and methodology used to navigate end of life discussions with patients and families and reasoning behind lack of coursework offered to aid in providing the skillset necessary when leading those discussions. Medical social workers often are present with patients during end of life yet they are offered little to no core education on death and dying and end of life throughout their undergraduate and graduate careers. Death does not come with a do over. Therefore, in order to best equip medical social workers with the ability to aid patients and families in being comfortable in one of life's most uncomfortable phases, they need more. More training, more funding, more support. Only with more, will patients at end of life and families be better served.

Furthermore, gaps in research continue to exist in determining the cause behind lack of effort made by patients to complete an advance directive in an effort to express their end of life wishes. Despite the findings in this study indicating family dynamics influence factors of fear, protection and barriers in communication when discussing end of life wishes, more research needs to be done in order to determine social workers best practices in overcoming these obstacles with patients and families. Therefore, advocacy needs to be done on a macro – level because in order for medical social workers to provide best practice and service to patients in end of life, additional educational opportunities and resources need to be offered.

Conclusion

Death, despite its inevitability, whether due to terminal illness, old age or natural causes, is unexpected. It is unexpected, yes, but it should also be expected. As a society, the topic of death and the dying process is taboo. We must do better. We must embrace that death is a part of life and medical social workers must be at the forefront of this task in order to best support patient autonomy.

References

- Advocacy Practice for Social Justice . (2016). In R. Hoefler, *Advocacy Practice for Social Justice* (pp. 62-85). Chicago : Lyceum Books, Inc.
- Aging, M. B. (2017, February 27). *Minnesota Board on Aging* . Retrieved from Health Care Directive : <http://www.mnaging.org/advisor/healthcaredirective.aspx>.
- Benson, W. F. (2012). Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself. *Advance Care Planning Critical Issue Brief*, 1-24.
- Broom, A., & Kirby, E. (2013). The end of life and family: hospice patients' views on dying as relational . *Sociology of Health & Illness Vol. 35(4)*, 499-513.
- Brown, B. (2013, December 10). *Brené Brown on Empathy*. Retrieved from YouTube: <https://www.youtube.com/watch?v=1Ewvuw369Jw>.
- Center, P. R. (2013, November 11). *Pew Research Center - Religous and Public Life* . Retrieved from Views on End of Life Medical Treatments: A Growing Minority of Americans Say Doctors Should do Everything Possible to Keep Patients Alive: <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/>.
- Fagerlin, A., Ditto, P., Hawkins, N., Schneider, C., & Smucker, W. (2002). The Use of Advance Directives in End-of-life Decision Making. *American Behavioral Scientist*, 46(2), 268-283.
- Galambos, Colleen M. (1998). Preserving end-of-life autonomy: The Patient Self-Determination Act and the Uniform Health Care Decisions Act. *Health and Social Work*, 23(4), 275-81.
- Grinnell, J. R., Williams, M., & Unrau, Y. (2016). *Research Methods for Social Workers: An Introduction*. Kalamazoo: Pair Bond Publications.
- Health Care Directive Statute of 2017, § 145C.02, MN Stat. (2017).
- Lee, H. (1960). *To Kill A Mockingbird*. HarperCollins Publishers Inc.
- McMililan, S C., & Small, B J. (2007). Using the COPE Intervention for Family Caregivers to Improve Symptoms of Hospice Homecare Patients: A Clinical Trial . *Oncology Nursing Forum Vol. 34 (2)*, 313-321.
- Mitchell, M. (2015). Assessing Patient Decision-Making Capacity: It's About The Thought Process . *Emergency Nurses Association*, 41(4), 307-312.
- Murty, S., Sanders, S., & Stensland, M. (2015). End-of-Life Care as a Field of Practice in the Social Work Curriculum. *Journal of Social Work in End-of-Life & Palliative Care*, 11(1), 1-26.

- National Association of Social Workers (2008) *Code of Ethics*. National Association of Social Workers.
- Ordille, J. (2016). Phenomenology in End-of-Life Care: Implications for Philosophy and Clinical Practice. *Clinical Social Work Journal*, 44(2), 170-178.
- Pevey, C. (2005). Patient Speaking: Hospice patients discuss their care. *American Journal of Hospice & Palliative Medicine Vol. 22(2)*, 129-133.
- Peterson, K. (2012). Shared Decision Making in Health Care Settings: A Role for Social Work. *Social Work in Health Care*, 51(10), 894-908.
- Sandman, Lars, Granger, Bradi, Ekman, Inger, & Munthe, Christian. (2012). Adherence, shared Decision-making and patient autonomy. *Medicine, Health Care and Philosophy*, 15(2), 115-127.
- Silberman, S. L. (2003). 2003 Minnesota Advance Directives Survey. *AARP*, 4-8.
- Southall, D. (2012). The patient's use of metaphor within a palliative care setting: Theory, function and efficacy. A narrative literature review. *Palliative Medicine Vol. 27(4)*, 304-313.
- St. Catherine University. (2010, August). *Social Work for Social Justice: Ten Principles*. Retrieved from School of Social Work: <https://www.stthomas.edu/media/schoolofsocialwork/pdfdocs/SWSJ-COLOR9-15-11.pdf>.
- Thomas, Dylan (1952).
Do Not Go Gentle Into That Good Night. Retrieved from poets.org:
<https://www.poets.org/poetsorg/poem/do-not-go-gentle-good-night>.
- Winzelberg, G., Hanson, L., & Tulsky, J. (2005). Beyond Autonomy: Diversifying End-of-Life Decision-Making Approaches to Serve Patients and Families. *Journal of the American Geriatrics Society*, 53(6), 1046-1050.

Appendix A – Consent Form

ST CATHERINE UNIVERSITY Informed Consent for a Research Study

Study Title: Medical Social Workers' Best Practices in Supporting Autonomy at End of Life.

Researcher(s): Morgan Hanley, LSW, C-SWCM

You are invited to participate in a research study. This study is called Medical Social Workers' Best Practices in Supporting Autonomy at End of Life. The study is being done by Morgan Hanley, an MSW student in the Graduate School of Social Work program at St. Catherine University in St. Paul, MN. The faculty advisor for this study is Rajean P. Moone, PHD, Graduate School of Social Work at St. Catherine University.

The purpose of this study is to describe medical social workers best practices in supporting autonomy at end of life, specifically within a hospital setting. This study is designed to further explore the role of medical social workers in supporting patient autonomy at end of life. This study is important because it is designed to further explore the topic of how medical social workers work to support patient autonomy at end of life in regards to the importance of autonomy and decision-making capacity, autonomy at end of life, advance directive, open communication, patient and family expectations, patient centered care and social work role in supporting autonomy at end of life. The benefits of this study illustrate the significance of the patient autonomy at end of life and the decisions associated with the death and dying process. Approximately eight people are expected to participate in this research. Below, you will find answers to the most commonly asked questions about participating in a research study. Please read this entire document and ask questions you have before you agree to be in the study.

Why have I been asked to be in this study?

You have been selected to be in this study because of your field of practice and job title of licensed medical social worker.

If I decide to participate, what will I be asked to do?

If you meet the criteria and agree to be in this study, you will be asked to do these things:

- Read over, discuss, sign and turn in consent form
- Determine date, time and place to meet with researcher for interview
- Participate in a one-time, recorded, semi-structured 60-75 minute interview
- Answer 11 questions during interview

In total, this study will take approximately 60-75 minutes over one session.

What if I decide I don't want to be in this study?

Participation in this study is completely voluntary. If you decide you do not want to participate in this study, please feel free to say so, and do not sign this form. If you decide to participate in this study, but later change your mind and want to withdraw, simply notify me and you will be

removed immediately. You may withdraw until March, 19, 2017 after which time withdrawal will no longer be possible. Your decision of whether or not to participate will have no negative or positive impact on your relationship with St. Catherine University, nor with any of the students or faculty involved in the research.

What are the risks (dangers or harms) to me if I am in this study?

There are no identified direct risks to participating in this study.

What are the benefits (good things) that may happen if I am in this study?

There are no direct benefits to you participating in this research. The societal benefit to you participating in this study is identified by adding knowledge to the field of social work. Specifically, focusing on medical social workers best practices in supporting autonomy at end-of-life, specifically within a hospital setting.

Will I receive any compensation for participating in this study?

You will not be compensated for participating in this study.

What will you do with the information you get from me and how will you protect my privacy?

The information that you provide in this study will be audio recorded on my password protected cellular device. Recordings will be individually transcribed and shared with research advisor. Identifying information will be removed from transcriptions and any final papers. I will keep the research results separate on my password protected computer and only I and the research advisor will have access to the records while I work on this project. I will finish analyzing by April 16, 2018. I will then destroy all original reports and identifying information that can be linked back to you. Audio recordings will be destroyed on June 30, 2018.

Any information that you provide will be kept confidential, which means that you will not be identified or identifiable in the any written reports or publications. If it becomes useful to disclose any of your information, I will seek your permission and tell you the persons or agencies to whom the information will be furnished, the nature of the information to be furnished, and the purpose of the disclosure; you will have the right to grant or deny permission for this to happen. If you do not grant permission, the information will remain confidential and will not be released.

Are there possible changes to the study once it gets started?

If during the course of this research study I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings

How can I get more information?

If you have any questions, you can ask them before you sign this form. You can also feel free to contact me at hanl2344@stthomas.edu. If you have any additional questions later and would like

to talk to the faculty advisor, please contact Dr. Rajean P. Moone at rpmoone@stkates.edu. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:

I consent to participate in the study and agree to be videotaped/audiotaped.

My signature indicates that I have read this information and my questions have been answered. I also know that even after signing this form, I may withdraw from the study by informing the researcher(s).

Signature of _____ Participant _____ Date _____

Signature of Parent, Legal Guardian, or _____ Witness _____ Date _____
(if applicable, otherwise delete this line)

Signature of _____ Researcher _____ Date _____

Appendix B – Interview Questions

Research Question: What are Medical Social Workers' Best Practices in Supporting Autonomy at End Of Life?

1. What behaviors do patients demonstrate during conversations regarding end-of-life care?
 - a. Be specific: both verbal and nonverbal?
 - b. Are conversations different when in the presence of family? Explain.
2. Provide an example of a time when you provided patients with strategies of healthy coping skills when discussing their end of life goals with family.
3. How do family dynamics influence end of life care decisions?
4. In your experience, how often do medical social workers assist patients and families in filling out advance directives?
 - a. Do you receive referrals?
 - b. Who is the notary on-site?
5. During your educational career, how much education did you receive, or elect to take, regarding end of life?
6. Provide an example of a time when family had to act as primary agent due to patient not having an advance directive.
7. In your experience in working in a hospital setting, what would you determine as differences in regards to quantity versus quality of life?
8. Provide an example of a case when an ethical dilemma resulted in the process of caring for a patient at their end of life.
9. In your experience, what are ways for patients to best articulate their end of life wishes?
10. In what ways do you advocate to honor patients end of life wishes?
11. In your experience, what are the benefits of having an advance directive?

