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Inclusion of Social Workers in End-of-Life Discussions in Intensive Care Units

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This is to certify that the doctoral study by

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has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
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Abstract

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by

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MSW, Florida State University, 2000

BA, University of Florida, 1989

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Social Work

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Abstract

Clinical social workers have roles in providing end-of-life care in the United States. Although clinical social workers are present in the intensive care unit (ICU) setting and have expertise to address end-of-life care dynamics, social workers are not consistently included in end-of-life discussions in the ICU setting. The purpose of this action research study was to explore the barriers that prevent clinical social workers from being included in end-of-life discussions in the ICU and how clinical social workers perceive their roles in end-of-life discussions in the adult ICU setting. Open-ended questions were used to gather data by facilitating 4 focus groups with 17 clinical social workers employed at a Florida hospital. This study was guided by complexity theory, which is concerned with complex systems and how systems can produce order while simultaneously creating unpredictable system behavior. A thematic analysis coding technique was used to analyze the data collected. Three themes emerged from data analysis: the ICU setting as chaotic, complex, and unpredictable; role ambiguity; and lack of confidence of social workers to perform expected roles in end-of-life discussions. The implications of this study for social work practice and social change relate to closing the gap between the patient, family members, social workers, and the medical team by developing protocols that consistently include social workers in end-of-life discussions, including education for the multidisciplinary team in the ICU on the skill set and role of clinical social workers in end-of-life discussions and formal training and education for clinical social workers regarding end-of-life care.

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Dedication

First of all, I thank God who is the author and finisher of my faith (Hebrews 12:2). This entire project is dedicated to him, for with him, this dream of Dr. has now been realized. To my research participants who took out time and contributed their knowledge to this research project, you are greatly appreciated. Without your input this would all have been impossible. This project is also dedicated to my late maternal grandmother: Eldra Mae Wooten-Hanna (December 29, 1915-January 7, 2004). Things are not the same without you.

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Table of Contents

Table of Contents i

List of Tables iv

Section 1: Foundation of the Study and Literature Review 1

  - Problem Statement 6
  - Purpose of the Study 8
  - Research Questions 11
  - Key Terms 11
  - Nature of the Doctoral Project 14
  - Significance of the Study 17
  - Theoretical/Conceptual Framework 21
  - Review of the Professional and Academic Literature 23
  - Current Literature on End-of-Life Care 25
    - Barriers to Inclusion 25
    - ICU Stressors 26
    - Collaborative Care 27
    - Role Ambiguity in the ICU 29
    - Varying Goals of Care in ICU 30
    - Health Care Workforce 31
    - Weakness in Literature to Date 31
    - Strengths in Literature to Date 32
  - Concepts 32

Context 50

Summary 60

Section 2: Research Design and Data Collection 64

Research Design 65

Key Concepts 67

Methodology 68

Participants 68

Instrumentation 71

Existing Data 73

Data Collection Procedures 73

Data Analysis 75

Ethical Procedures 77

Summary 81

Section 3: Analysis of the Findings 82

Data Analysis Techniques 84

Validation and Legitimation Process 90

Field Testing 91

Peer Debriefing 91

Findings 95

Common Themes 96

Barriers to Consistent Social Work Inclusion 97

Theme 1: The ICU Setting 97

Perceived Role of Social Workers 118

Theme 2: Role Ambiguity 119

Theme 3: Lack of Confidence to Perform Expected Roles 122

Social Work Practice Implications..130

Section 4: Recommended Solutions 134

Key Findings..136

Applicable Solutions..137

Application for Professional Practice 138

Solutions for the Clinical Social Work Setting..140

Implications for Social Change..144

Contribution to Knowledge..145

Summary..146

Dissemination 147

Conclusion 148

References..149

Appendix: Focus Group Interview Questions..177

List of Tables

Table 1. Study Participants and Focus Groups 95

Table 2. ICU Setting 108

Section 1: Foundation of the Study and Literature Review

Social workers play a role in assisting people as they adjust to various changes in life, including end-of-life. End-of-life care is concerned with patient quality and advocacy of care at the patient's time of death (Boucher, 2016; Novelli & Banerjee, 2017). According to Curtis and Rubenfeld (2014) and Mark, Rayner, Lee, and Curtis (2015), the intensive care unit (ICU) is a setting where many decisions are made to stop the escalation of care or to withhold or withdraw treatments that are necessary to keep the patient from dying. Patients who are admitted to the neurological and neurosurgical ICU have a high risk of death and diagnoses that prevent them from making their own health care decisions (Creutzfeldt et al., 2015).

The ICU is also an environment that, due to its complexity, has been recognized as a setting that unintentionally creates barriers between patients, their families, and the medical team (Efstathiou & Walker, 2014). During the last stages of the patient's life, the medical staff may be more focused on meeting the medical needs of the patient in a technical environment that involves equipment that limits the physical space of the visiting family, while the patient's family may be more concerned with maintaining privacy, providing physical contact to their loved one, and providing some sort of comfort by holding a dying patient's hand (Efstathiou & Walker, 2014). Various disciplines provide care for patients, and each discipline is focused on their area of specialty and its professional roles and tasks; therefore, teamwork in ICU settings may be disjointed throughout a typical workday (Reeves et al., 2015).

Scholars (Boelen & Prigerson, 2007; McAdam & Erickson, 2016; Pochard et al., 2005) assessed bereavement follow-up care in ICU settings across the United States and suggested that family members of patients who died in the ICU had an increased risk for anxiety. In addition, scholars stated that family members had an increased risk for major depressive disorder (Boelen & Prigerson, 2007; Wright et al., 2008), sleep disorders (Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008; Wright et al., 2010), posttraumatic stress disorder (Azoulay et al., 2007; Gries et al., 2010; Schmidt & Azoulay, 2012; Siegel et al., 2008; Wright et al., 2010), and prolonged grief (Boelen & Prigerson, 2007; Downar, Barua, & Sinuff, 2014; Prigerson et al., 1997). This resulted in the loved one having worse outcomes when the patient died in the ICU rather than outside the ICU (McAdam & Erikson, 2016). In addition, family members whose loved one died in the ICU reported feeling distressed, which was accompanied by depression and anxiety (Carlson, Spain, Muhtadie, McDade-Montez, & Macia, 2015). These symptoms impact family members for a long time and contribute to reporting dissatisfaction with the level of emotional support they receive from the staff members who work in the ICU (Carlson et al., 2015). Although bereavement support is encouraged, it is not consistently offered in practice (Carlet et al., 2004; Davidson et al., 2007*;* Medina & Puntillo, 2006; Truog et al., 2008; Truog et al., 2001).

Families who have meetings regarding end-of-life decisions that include the hospital social worker report being more satisfied with care being provided in a hospital ICU (Sundarajan, Sullivan, & Chapman, 2012; Weisenfluh & Csikai, 2013). Rajamani et al. (2015) found that although families in ICU settings were overall pleased with the quality of end-of-life medical care provided for their family members, social workers should have been involved to assist in determining goals of care and transition of care discussions in addition to providing emotional support.

The role of the medical social worker is becoming more complex (Fusenig, 2012). However, Scanlan (2016) noted, social workers have the expertise to work with vulnerable populations, agencies, and communities and are able to communicate effectively about difficult and painful subject. Despite claims regarding the role that social workers have and should have in providing end-of-life care, the empirical documentation of their responsibilities and roles in end-of-life care in ICU settings is unclear; this contributes to role ambiguity and confusion among other members of multidisciplinary teams regarding what the duties and responsibilities of the social worker entail (Kramer, 2013). The current literature to date in pediatric ICU (Doorenbos, Lindhorst, Starks, & Aisenberg, 2012; Curtis & Hays, 2012; Michelson, Patel, Haber-Barker, Emanuel, & Frader, 2013; Thieleman, Wallace, Cimino, & Rueda, 2016) and palliative and hospice (Adshead & Dechamps, 2016; Silverman, 2016) care settings supports the consistent inclusion of social workers as a part of multidisciplinary teams and end-of-life discussions. However, although there has been discussion regarding social worker involvement in end-of-life discussions in ICU settings in the past, there is a gap in the documentation in the last 5 years that addresses the social worker’s role in the adult ICU setting. There seems to be a shift in practice changes, with more focus and discussion being on social worker involvement and end-of-life care in palliative care settings and the omission of ICU departments (Kelley & Morrison, 2015; Russell, 2015).

The ICU environment is not always collaborative. Although social workers are present and have the expertise to address end-of-life care dynamics that cannot be met by other members of the multidisciplinary team, the use of social workers is not consistent in this setting when it comes to end-of-life discussions. Social workers should be included in all stages of end-of-life care. In this study, I explored perceived barriers that prevent consistent social worker inclusion and the perceived role social workers feel they play when having end-of-life discussions. Using action research methodology with a qualitative component to collect data using focus groups, the goal of this study was to identify barriers as to why social workers are not consistently included in end-of-life discussions in the ICU setting. Another goal of this study was to explore how clinical social workers perceive their roles in end-of-life discussions.

The data from this study will be used to propose a process that will consistently include social workers in end-of-life discussions in ICU settings that will also close the gap between dying patients, their family members, social workers, and the members of the multidisciplinary team. The contribution of social work practice skills to end-of-life discussions and care is worthy of further development. There is a need to enable social workers to collaborate consistently with the medical team, patients, and families in the provision of end-of-life care. Proposing a protocol that consults social worker as part of end-of-life discussions provides an opportunity for social workers to play a role in improving family experiences of decision making, as well as other aspects of end-of-life care.

This research presents an opportunity to build trust and respect amongst members of the medical team in a manner that puts social workers on an even playing field with other members of the multidisciplinary team in the ICU, which is also beneficial to patients at the end-of-life and their family members who want the best for them. Building rapport amongst other multidisciplinary team members further allows other medical professionals to see social workers as being just as important as other members of the multidisciplinary team by highlighting the role of social workers as part of the multidisciplinary team in end-of-life discussions. This action research project contributes to positive social change because it gives validity to the field of social work and demonstrates the ability of social workers to work in this complex field. In developing a process that consistently includes social workers in end-of-life settings, this qualitative action research project has the potential to contribute to the delivery of high-quality, dignity-based care in clinical social work practice.

In Section 1, I introduce the social work practice problem that was the focus of this doctoral study followed by purpose for the study. I explain the phenomenon that this doctoral study addressed and the practice-focused research questions. Subsequent subsections include an explanation of the nature of the doctoral project and the significance of the study. In these subsections, the design of the study and the sources of data is explained as well as the potential contributions the project will make to advance social work practice knowledge. In the theoretical and conceptual framework, I identify the rationale for using this framework and how it aligns with the problem statement, research question(s), and purpose of the study.

Problem Statement

The roles of social workers are often multifaceted and intersect multiple systems of practice (Beder, 2013). Social workers in the ICU settings often meet, interact with, establish therapeutic rapport with, and demonstrate empathy towards patients and family members throughout the patients' entire hospital stay. The National Association of Social Workers' Code of Ethics (2008), addressed the needs of patients who lack capacity to make their own decisions and requires that social workers take steps to protect the interests and rights of those clients. Russell (2015) noted that as part of palliative care teams, social workers are in a position to facilitate dialogue between patients, their family members, and the medical professionals who provide care to the dying patient. However, social workers have not consistently been included in psychosocial discussions related to end-of-life care in the ICU setting.

According to Beder (2013) and Peres (2016), social workers have training to interact with and observe individuals in a manner that is holistic, including the context of their environments; therefore, it is a benefit to have social workers involved in all stages of end-of-life care planning. The ICU is a specialized unit in the hospital or health care facility that cares for critically ill patients with severe and life-threatening illnesses (Modrykamien, 2012; Yang, Fry, & Scurlock, 2015). In ICU settings, patients have a higher risk of and occurrence of death (Modrykamien, 2012). Statistically, 20% of all deaths in the United States occur in the hospital ICU setting (Curtis, 2005; Gries et al., 2010). Between 11.5 and 30% of U.S. hospital costs are in the ICU, and roughly half of the patients who have a length of stay longer than 14 days in the ICU eventually die

(Rose & Shelton, 2006). In the ICU setting, as many as 95% of the patients are incapacitated due to illness or sedation (Curtis & Vincent, 2010; McCormick et al., 2007; Truog et al., 2008). This results in the patients' family members having discussions, making difficult treatment decisions, and participating in goals of care discussions with members of the multidisciplinary team on behalf of the patient (Curtis & Vincent, 2010; McAdam, Fontaine, White, Dracup, & Puntillo, 2012; McCormick et al., 2007; Rose & Shelton, 2006).

According to Stein and Fineberg (2013), social workers are qualified to take the lead in addressing and guiding patients and families through effective end-of-life discussions; however, they are not consistently used in ICU settings. Bunting and Cagle (2016) noted that for patients faced with life-threatening illness, hospital social workers are often the point of communication between the medical team, patients, and families. However, in ICU settings, social workers are not consistently included in these discussions. In this research, I addressed this social work practice problem by exploring the barriers that prevent social workers' consistent inclusion in end-of-life discussions that occur in the ICU setting. Additionally, I explored social workers' perspectives on their inclusion and how they perceived their role in end-of-life discussions in the ICU setting.

The work done by social workers practicing in the ICU setting is different from those who practice in other hospital units. Social workers do not focus solely on patients throughout their admission and discharge planning, but rather work to reduce family strain and help to facilitate communication between the patient, family, and the medical team. Social workers provide interventions in the ICU that enable patients, families, and staff to deal with the uncertainty that accompanies the stress of critical illness and making end-of-life decisions.

Purpose of the Study

The purpose of this action research study was to explore social workers' perspective on how they perceive their roles in adult ICU settings and to identify barriers that may impede social workers from consistently being included in end-of-life discussions. Although many patients in ICU settings in North American and European regions receive some form of life-sustaining treatment prior to death, practices in end-of-life care vary (Mark et al., 2015). The National Association of Social Worker's (2008) emphasized the right of the patient to determine his/her level of care. Although there are claims regarding the role that social workers have and should have in providing end-of-life care in a range of contexts, there is a lack of documentation of their responsibilities and roles in end-of-life care (Kramer, 2013). Despite the literature in pediatric ICU (Doorenbos et al., 2012; Michelson et al., 2013; Thieleman et al., 2016) and palliative and hospice care settings (Adshead & Dechamps, 2016; Silverman, 2016) that supports the consistent inclusion of social workers as part of multidisciplinary teams and end-of-life discussions, scholars have not addressed the social worker's role in end-of-life discussions in adult ICU settings (Kramer, 2013). Epperson (1997); Hartman-Shea, Hahn, Fritz Kraus, Cordts, and Sevransky (2011); and Rose and Shelton (2006) posited that insufficient literature exists about the role of the social worker in critical care. This ambiguity leads to confusion among other multidisciplinary team members as it relates to the ICU social worker role (Kramer, 2013).

The ICU setting is made up of work areas that are characterized as being chaotic (Rashid, Boyle, & Crosser, 2014). These areas include numerous sensory stimuli (i.e., complicated life-support and monitoring systems that patients cannot survive without), noisy machines, noxious smells, bright lights, regular paging, telephone conversations and conversations between medical professionals on the floor, slamming doors, rolling carts, and many other disruptive and nondisruptive clinical and nonclinical events that are necessary in providing care for patients (Rashid et al., 2014). Patients and the family members of patients in the ICU face many challenges due to the patient’s diagnosis of a critical illness and the ICU environment itself (Brown et al., 2015). The process of having to make decisions on behalf of the patient may be burdensome for families because of high levels of acute stress and the risk for death (Brown et al., 2015). Family members of patients in the ICU environment experience stress, anxiety, and posttraumatic stress disorder (Davidson, Jones, & Bienvenu 2012; Paul & Finney, 2015; Schmidt & Azoulay, 2012). This experience can be overwhelming for the patient, as well as their family members. Complex situations, such as an ICU setting, require timely problem solving that may have negative consequences for both the patient and for the health care system (Grant & Toh, 2017).

When patients are diagnosed with an illness that is terminal or determined to be an end-stage condition, the aggressive care provided in an ICU setting may prolong the patient’s suffering and may not be the best option for the patient (Mark et al., 2015).

Managing the emotional distress of dying patients and their family members results in a family's satisfaction with care in the ICU (Carlson et al., 2015). Social workers can use the skills of the profession, which calls on their basic values that encourages them to promote an individual's right to self-determination and support towards people they serve (Conlon & Aldredge, 2013; Findley, 2014). Social workers show empathy towards the patients and families while also helping them overcome barriers and advocating on different levels (Findley, 2014). In situations where patients and family members are faced with making decisions related to in the end-of-life care, social workers can advocate for the rights of patients and families that will consider their quality of life.

Social workers provide interventions in the ICU that enable patients, families, and staff to deal with the uncertainty that accompanies the stress of critical illness and making end-of-life decisions. When working with patients and their family members, social workers will start with a value orientation in providing end-of-life care that promotes an individual's self-determination, dignity, and worth as well as interact in a manner that demonstrates respect for cultural sensitivity and competence (Conlon & Aldredge, 2013; National Association of Social Worker's, 2008). Social workers are in a position to identify social, cultural, and other factors that should be taken into consideration as patients and families make end-of-life decisions and communicate this information to the medical team (Findley, 2014). Some of the potential barriers that contribute to the exclusion of social workers in end-of-life discussions are related to a lack of communication with the other members of the multidisciplinary team (Kissane et al., 2012; Nørgaard, Ammentorp, Ohm-Kyvik, & Kofoed, 2012), a lack of processes to consistently include social workers, a lack of education or knowledge related to end-of-life discussions by social workers (Kramer, 2013), discomfort of the social worker having end-of-life discussions (Kramer, 2013), members of the multidisciplinary team having ambiguity related to the role of the social worker (Kramer, 2013), the chaotic ICU environment (Flannery, Ramjan, & Peters, 2016; Kramer, 2013) that does not allow for inclusion of social workers in end-of-life discussions, and the unavailability of social workers to participate in end-of-life discussions due to workload (Blom, Gustavsson, & Sundler, 2013).

Research Questions

The following research questions guided this action research study:

1. What are the barriers that impede social workers from inclusion in end-of-life discussions on a consistent basis in ICUs settings?
2. How do social workers in ICUs perceive their roles as social workers when having end-of-life discussions with patients and their families?

Key Terms

Action research: Research initiated to solve an immediate problem or a reflective process of progressive problem solving led by individuals working with others in teams or as part of a community of practice to improve the way they address issues and solve problems (Paul, 2016; Thiollent, 2011).

Barriers: Obstacles, actions, or factors that block or impede social workers from being included (Blom et al., 2013; Flannery et al., 2016; Kissane et al., 2012; Kramer, 2013; Nørgaard et al., 2012).

Communication: An exchange of verbal and nonverbal information (Kissane et al., 2012; Nørgaard et al., 2012).

End-of-life care: Care occurring in the last part of an individual's life, usually in the last few months, depending on the diagnosis, prognosis, and clinical course (Guo & Jacelon, 2014).

Intensive care unit (ICU): A specialized and technical unit in a hospital that provides a high level of care to severely and critically ill or injured patients (Modrykamien, 2012; Yang et al., 2015).

Multidisciplinary team: A group of health care professionals who work as a team to care for patients in an effort to address their physical, emotional, and psychological needs (Daly & Matzel, 2013).

Life support: Technical intervention that can artificially sustain or prolong an individual's life (Mark et al., 2015).

Mechanical ventilation: A common life support measure involving a machine that breathes for a patient who is unable to breathe adequately alone (Reade & Finfer, 2014).

Palliative care: Care that focuses on improving the quality of life and quality of care for individuals who have been diagnosed with life-limiting or life-threatening illness and their families by providing relief and prevention of suffering and discussions about goals of care that includes early identification and assessment and treatment (Cook & Rocker, 2014).

Social worker: A professional who uses social theories to understand human problems to improve individuals' lives and society as a whole and is available to assist with psychological, health, financial, relationship, and other problems as defined by their setting (Beder, 2013).

Withdrawal of care/treatment: The discontinuation of life sustaining treatment or therapies (i.e., mechanical ventilator, medications, vasoactive drips) from a patient who is expected to die without this treatment or support (Faigen, Hourwitz, & Niederman, 2013; Hayes, Checkley, Oakjones-Burgess, Subhas, & Brower, 2015; Mark et al., 2015).

Social workers can act as an educator to the patient and health care professionals, a mediator during meetings and discussions about possible treatment options, and support for the patient and family. The exploration of perceived barriers to the consistent inclusion of social workers in end-of-life discussions in adult ICU settings helps define the role of the social workers in that they can identify, and address family needs related to end-of-life decisions that need to be made. The social worker can also provide emotional support for the dying patient and their family members. The social worker can ensure the integrity of the patient and the role of the family is honored and assist in resolving struggles that may arise as end-of-life decisions are made that may conflict with what the medical team wants to do.

The findings of this study can highlight the perceived roles and barriers of social workers' inclusion in the ICU setting. The findings can also be used to educate the ICU staff and multidisciplinary team members on the role of the ICU social worker. The results may include a process that will consistently include social workers in end-of-life discussions in ICU settings. This study may provide an educational component to the ICU staff, so they are aware of how best to use social workers when patients are being treated in the ICU, primarily when having end-of-life discussions. Another benefit to conducting this study is establishing the social work profession as an integral component of the multidisciplinary team in the ICU setting and demonstrating social workers as key players in end-of-life discussions.

Nature of the Doctoral Project

According to Aslakson, Curtis, and Nelson (2014), regardless of a diagnosis or prognosis, patients facing critical illness in the ICU have comfort care needs. Although there have been decreases in overall hospital mortality from critical illnesses, the needs for comfort care in the ICU setting has not diminished. Social workers can emphasize the importance of providing care and support to individuals who survive, as well as the family members of those who die in the ICU (Needham et al., 2012). In challenging environments such as the ICU, social workers can support, empower, and engage patients and their systems in their care and mediate between systems (Findley, 2014). Active communication between chronically ill patients and the medical team is essential to the patient's overall care (Findley, 2014). Social workers are trained in crisis intervention, cognitive restructuring, strengths perspective, and individual as well as family therapy (Hartman-Shea et al., 2011). McCormick, Engelberg, and Curtis (2007) stated, "Because social workers have specialized training for working with families of seriously ill or injured patients, the ICU represents a potential opportunity for social worker involvement in improving palliative care delivered to these patients and their families" (p. 930).

I used action research using focus groups to collect data for this research study to explore the inclusion of social workers in end-of-life care in the ICU. Action research refers to a community-based approach that consists of a variety of evaluative, investigative, and analytical research methods designed to diagnose problems or weaknesses and help to develop practical solutions to address them quickly and efficiently (Stringer, 2007). Action researchers study social situations and in a systematic inquiry by individuals with a common purpose with a goal of bringing about change (Whitelaw, Beattie, Balogh, & Watson, 2003). Through this cooperative inquiry, the researcher can work with, as well as study, people who enhance working environments for all participants, as well as stakeholders (Stringer, 2007).

Clinical social workers registered with the Florida Department of Health were targeted to recruit participants. For the purposes of this action research study, only clinical social workers were included. I invited 63 clinical social workers who worked primarily in the hospital setting by letter to participate in one of four focus groups. The participants were purposefully selected because of their expertise in their respective fields. Prior to the focus groups, the participants were asked to sign a consent form and complete a demographic and information worksheet of relevant background data. According to Palinkas et al. (2016), the purposive sampling method allows for an in-depth analysis of a small sample size and for the researcher to understand complex social phenomena. This method also allows the researcher to make discoveries and identify patterns and causal mechanisms that do not draw time and contest-free assumption (Palinkas et al., 2016). Although I focused on adult ICU settings, social workers from both the neonatal and pediatric settings were included in the sample because social workers are often called upon to fulfill duties in both adult and pediatric settings when needed on weekends, holidays, and after hours on-call.

According to Holloway and Galvin (2016), emotions, perceptions, and actions are qualitative experiences, and qualitative health research is in tune with the nature of the phenomena explored. A qualitative method using focus groups was appropriate for this action research project because using this approach allowed for the development of understanding human experiences, which is important for medical providers whose focus is on caring, communications, and interaction (Holloway & Galvin, 2016). Through this gained perspective, practitioners in this setting can advance knowledge and insight about human beings whether they are patients, colleagues, or other professionals (Holloway & Galvin, 2016). I did not focus solely on clinical conditions or professional and educational tasks, but also considered clinical social worker's experiences within their social and cultural context to generate detailed explanations that presented a lively picture of the participants' reality (Holloway & Galvin, 2016).

For this action research project, the social workers providing services in an ICU setting were asked open-ended questions that allowed them to share their experiences as clinical social workers as it relates to end-of-life discussions in ICU settings. The questions also included the participants' perceptions of barriers (if any) they saw or experienced to their inclusion in these discussions on a consistent basis. The data were reviewed, and significant features and elements were identified as well as coded. The verbatim principle was used to capture what was being said by the participants. The main features of the experiences as well as the elements that composed each of the participants' experiences was audio recorded and transcribed. The experiences of each of the participants was compared and common experiences were documented. The data were collected and coded, organized, and categorized so that key or common themes could be noted. The goal of this research was to propose a process that consistently includes social workers in end-of-life discussions in ICU settings.

Significance of the Study

Although there are claims regarding the role that social workers have and should have in providing end-of-life care in a range of contexts, there is a lack of empirical documentation of their responsibilities and roles in end-of-life care Social workers who work in a medical setting do well in this environment because they can use the skills of the profession that encourages them to promote an individual's right to self-determination and support towards people they serve (Findley, 2014). Social workers have training that enables them to interact with and observe individuals in a manner that is holistic. According to Peres (2016), it is a benefit to have social workers involved in all stages of end-of-life care planning.

Due to an increasing number of aging adults in the population in the United States in the last 20 years, there has been an increase in focus related to end-of-life and palliative care practice in social work (Murty, Sanders, & Stensland, 2015). On some multidisciplinary teams, the social worker may be the only individual who is trained to address cultural issues (Murty et al., 2015). According to Murty et al. (2015), cultural competence is important in end-of-life care because the patient's cultural beliefs and attitudes impact how the patient and the family respond and cope during the last stages of life and during post death grieving. The greater demand for patients who need emotional support and guidance during end-of-life care justified the need for this. Administrators are guided on what should be emphasized by multidisciplinary teams in the ICU setting to improve patient experiences. Social workers play a role in improving family experiences of decision making as well as other aspects of end-of-life care.

Working in the ICU allows professional social workers an opportunity to demonstrate empathy towards the critically ill patient and family members of the patient and assist them as they overcome barriers while also advocating for them on various levels (Findley, 2014). The social worker acts as an educator to the patient and health care professionals, a mediator during meetings and discussions about possible treatment options, and support for the patient and family. Social workers advocate for the rights of patients and families faced with making decisions related to in the end-of-life care in a manner that will consider their quality of life. Virbalienė (2015) stated that in end-of-life discussions, the social worker can be the main instrument and can offer their professional perspective without depreciating the patient’s dignity.

This research encourages medical providers in the hospital, namely the ICU setting, to consider the wishes of their patients and what family members have about what their loved ones want regarding end-of-life care. Positive experiences and satisfaction with ICU care are achieved when more focus is placed on helping family members manage their distress (Carlson et al., 2015). Communication with the medical team is the best way to get the information needed to make decisions. However, in the ICU, physicians can be hard to contact. An ICU social worker can facilitate family meetings with the medical team and meet with family members prior to the meeting to assist with preparation of questions. In addition, social workers are trained to provide counseling services, grief support, and to address religious and spiritual needs. Downar et al. (2014) noted that, although there are barriers, an ICU-based bereavement screening and support program for family members of patients who die in the ICU is both needed and desirable. According to Hupcey, Kitko, and Alonso (2016), discussion of religion and/or spirituality is important to patients and their families known to be beneficial. However, it happens infrequently in the ICU (Hupcey et al., 2016).

Both nurses and physicians feel unprepared to have conversations with families regarding end-of-life issues (Boss, Hutton, Donohue, & Arnold, 2009; Rider, Volkan, & Halfer, 2008). When a person is admitted to an ICU, this situation creates a crisis for the patient’s family, and they may experience shock, anger, guilt, denial, despair, and depression within the family because they are not mentally prepared for such a stressful situation (Sadeghi, 2012). The family members may be fearful of the patient’s death or permanent disability, may have uncertainty about the patient's condition and prognosis, role changes, unfamiliarity of the intensive care environment, and financial concerns. Although nurses in the ICU are in constant contact with patients, nurses are trained to focus on the nursing needs of the patient; therefore, the needs of the family members are not addressed (Buckley & Andrews, 2011; Fox-Wasylyshyn, El-Masri, & Williamson, 2005). There are times when the nurses and doctors do not recognize the needs of patients' family members (Omari, 2009; Söderström, Benzein, & Saveman, 2003). Both families and nurses prioritize the needs differently, and most health care professionals are not adequately aware of the particular needs of patients' families.

Social workers are in a position to facilitate dialogue between patients, their family members, and the medical professionals who provide care to the dying patient. It is advantageous to patients, families, and the medical providers to have social workers involved in all stages of end-of-life care planning (Peres, 2016). Social workers are in a position to identify social, cultural, and other factors that should be taken into consideration as patients and families make end-of-life decisions and communicate this information to the medical team (Findley, 2014).

This action research study provides information on the role of the ICU social worker and identifies barriers to inclusion of social workers being used on a consistent basis in the ICU, just as they are in palliative care and hospice care settings. The stakeholders identified for this action research study included the ICU administrators (nurse manager, clinic leaders, and medical director), members of the multidisciplinary team (physicians, nurses, pharmacist, dietician, and chaplain), the patient, the family members of the patient, and the ICU social worker. The findings of this study may lead to a proposal of an alternative or improved approach to social workers working collaboratively with the multidisciplinary team and other social workers to consistently include social workers in end-of-life discussions in the ICU setting.

This action research project creates an opportunity to advocate for and communicate these factors to the physicians to allow them to gain further understanding of the benefits of the inclusion of social workers in these discussions. The potential implications for positive social change for this action research project are to close the gap between the social worker, the patient, and their family members and the multidisciplinary team while determining solutions that will enable social workers to consistently collaborate with the medical team, patients, and families in the provision of end-of-life care in the ICU.

Theoretical/Conceptual Framework

The role of the medical social worker is becoming more complex (Fusenig, 2012). There are also many complexities in providing appropriate care at the end of life across unique circumstances and contexts (Zaman, Inbadas, Whitelaw, & Clark, 2017). Complexity theory was used to ground this action research study. Complexity theory is a multidisciplinary theory that grew out of systems theory in the 1960s; this theory is used to examine uncertainty and nonlinearity (Grobman, 2005). Complexity theorists suggest that rather than troubleshoot problems, organizations should solve problems by trusting workers to self-organize and function by bringing their organizations to the edge of chaos as a solution to solving problems (Grobman, 2005). According to Grobman (2005), rather than follow a script, staff members should go with the flow in order to create a healthy level of tension and anxiety in the organization to promote creativity and to maximize the effectiveness within the organization. Complexity theory is used to examine complex systems involving various parts and how the interactions of those parts often bring about unexpected order. According to complexity theory, small actions may have a large impact on overall systems while large actions have the potential to result in little overall effect (Cilliers, 2005; Haynes, 2015; Klein, 1984). Complex systems such as the ICU are open and interactive with their environment through the exchange of matter, information, or energy (Capra 1996; Heylighen, Cilliers, & Gershenson 2007). Therefore, interconnections between the environment and the system parts are taken into consideration in addition to their context (Capra 1996).

The hospital ICU is viewed as an open complex adaptive system that is prone to abrupt changes. These changes result in a shift in the equilibrium of the unit that may be sudden or unexpected. Complexity theorists stress interactions that are highlighted by constantly changing systems that are unpredictable but are also constrained by order-generating rules (Burnes, 2005). Through complexity theory, systems do have elements, but it is the interconnectedness and interactions among the elements that create the whole. Therefore, studying the interactions among the elements, as well as the unity of the system itself, provides insights for understanding an organization and its system properties (McDaniel, 2004; Price, 1997; Urquhart, Jackson, Sargeant, Porter, & Grunfeld, 2015). Complexity theory can be used to understand simple systems that may change in a sudden, unexpected, or irregular ways.

Complexity theory was used as a theoretical lens for understanding and exploring the exclusion of social workers from end-of-life care in the ICU setting. This approach was also based on the interrelatedness of system components and how ICU social workers are excluded from those systems, namely end-of-life care in that setting. I used the ideas of interconnectedness among the components or disciplines in the ICU as a measure of complexity and functional breakdown as a mechanism for studying meaningful subcomponents of a complex system as a framework for understanding the complex ICU and how a clinical social worker in an ICU fits into end-of-life discussions. Complexity theory was relevant to this study because it has a theoretical explanation of the dynamics of the large hospital system, its hierarchical structure, and interconnectedness to hospital social workers when having end-of-life discussions and how they may or may not be impacted by its stability. Complexity theory is concerned with complex systems and how these systems can produce order while simultaneously creating unpredictable system behavior. Complexity theory was appropriate in examining unpredictability in the ICU because it "addresses fundamental questions on the nature of systems and their changes" (Walby, 2007, p. 449). Additionally, interactions within complex social systems such as the ICU entails engaging with uncertainty (Montuori 2003; Montuori & Purser 1996). Complexity theory was a good fit for this action research because it is concerned with the composition of complex systems and how they relate to one another and the whole system (Walsh, 2014). Likewise, the social work profession is concerned with the whole person, including the context of their environment (Beder, 2013; Peres, 2016). I used this theory to examine the role and relationship social workers have with the multidisciplinary team in the implementation and facilitation of a process that will be consistently inclusive of social workers in end-of-life discussions.

Review of the Professional and Academic Literature

This section provides a context for exploring barriers that impede social workers from inclusion in end-of-life discussions on a consistent basis in the ICU setting and how social workers perceive their roles as social workers when having end-of-life discussions with patients and their families in the ICU setting. I also review the literature on the phenomenon and offer a rationale for conducting the study. The content in this section includes literature search strategies and philosophical, theoretical, and experiential explorations of barriers and roles.

An Internet search was conducted using search databases in the areas of social work, psychology, nursing, and health sciences that included SocIndex, PsychInfo, Cumulative Index and Allied Health Literature (CINAHL), Proquest, MEDLINE, PUBMED, and Google Scholar databases. Research articles and systematic reviews of end-of-life discussions in ICU settings and social workers role in those discussions and environments were searched using various combinations of key words as follows: *acute-care settings, advanced care planning, advanced directives, barriers, collaboration, communication, critical condition, critical-care unit, critically ill, death, discussions, dying, emergency room, end-of-life, end-of-life care, end-of-life decisions, end-of-life discussions, ethical issues, experiences, factors, treatment, goals of care, health care, health care practitioners, health care providers, hospice, hospital, ICU, inclusion, intensive care, intensive care unit, interdisciplinary teams, interprofessionals, interventions, issues, life support, life, life-sustaining treatment, mechanical ventilation, multidisciplinary teams, palliative care, patient-centered care, perceptions, physicians, physicians order for life-sustaining treatment, practitioners, quality of life, roles, social workers, stakeholders, stressors, support, teamwork, trauma, treatment*, and *withdrawal of care.*

I located thousands of publications on the topic of social workers and end-of-life discussions in the ICU and social work roles in end-of-life discussions. However, when the inclusion criteria of the last 5 years (January 2012 through 2017) was applied to obtain a more current status of the problem, the results were significantly minimized. Articles were chosen if they (a) addressed end-of-life discussions, (b) included social workers, (c) occurred in the ICU setting, (d) focused on the adult (versus pediatric) populations, and (e) were published in English.

Current Literature on End-of-Life Care

The current literature on end-of-life care in the last 5 years has been focused on providing collaborative care in palliative and hospice care settings, but not in ICU settings. Social workers' knowledge base and communication skill sets allow them to address and guide patients and families through effective end-of-life discussions (Black, 2005; Stein & Fineberg, 2013). Social workers should be involved in all aspects of end-of-life care. According to Beder and Peres (2016), social workers possess skills that qualify them to interact with and observe individuals in a way that is holistic, including the context of their environments; therefore, it is a benefit to have social workers involved in all stages of end-of-life care planning (Albrithen & Yalli, 2015; Chaddock, 2016; Chow, Chow, & Chow, 2015).

Barriers to Inclusion

The existing literature regarding barriers to the consistent inclusion of social workers in end-of-life discussions and how social workers perceive their role in adult ICU settings is minimal from 2010 to present. Some of the barriers identified in the recent literature as to why social workers are not included in end-of-life discussions consistently are related to lack of confidence on the part of the social worker (Albrithen

& Yali, 2015; Chow et al., 2015; Kirby, Broom, Good, Wootton, & Adams, 2014; Kwon, Kolomer, & Alper, 2014; Wilmont, 2015) and clinicians feeling ill-prepared to have end-of-life discussions (Boss et al., 2009); Rider et al., 2008). Additional barriers identified included social workers' lack of knowledge regarding end-of-life care (Albrithen & Yalli, 2015), a lack of communication amongst team members and with family (Anderson et al., 2015; Curtis et al., 2016; Howell, Nielsen, Turner, Curtis, & Engelberg, 2014, McAndrew & Leske, 2015; Steinhauser, Voils, Bosworth, & Tulsky, 2014; Wilmont, 2015), and a lack of clarity regarding the role of the social workers on the multidisciplinary team (Kramer, 2013). Other barriers identified are related to the complexity of the ICU and the hospital system as a whole (Flannery et al., 2016; Kramer, 2013).

ICU Stressors

The ICU contains technology needed to support critically ill patients is a potentially hostile and complex environment for the vulnerable critically ill patient (Abuatiqu, 2015; Rodriquez, 2015; Wenham & Pittard, 2009). It is beneficial for patients and family members to have increased emotional support in an ICU setting (Albrithen & Yalli, 2015; Bathgate, 2016; Carlson et al., 2015; Daly & Matzel, 2013). In addition, social workers can provide emotional support in end-of-life discussions on all levels (Browning, 2008; Csikai, 2006; McAdam & Puntillo, 2009). The ICU differs from hospice and palliative care settings in that it is more chaotic and unpredictable and not all patients in this setting are facing end-of-life issues and not all patients in the ICU die (Abuatiqu, 2015; Rodriquez, 2015; Wenham & Pittard, 2009).

Patients are admitted to the ICU with conditions and illnesses that are life threatening and with little to no warning (Bandari, Heravi-Karimooi, Rejeh, Mirmohammadkhani, Vaismoradi, & Snelgrove, 2015). Both the situation of having a critically ill family member and the environment of an ICU are stressful for the patient and their family members (Blom et al., 2013). Family members who have little understanding about the critical nature of an ICU admission have minimal time to prepare emotionally for what is going on. According to Abuatiq (2015) and Blom et al. (2013), family members experience acute distress and emotional disturbances. However, patients who were intubated during their hospitalization in the ICU setting reported being unable to recall any stressors during their hospital stay (Abuatiq, 2015).

Collaborative Care

An ICU does provide end-of-life care; however, collaboration with social workers or social work involvement does not occur on a consistent basis. Scholars who have studied pediatric ICU (Doorenbos et al., 2012; Michelson et al., 2013; Thieleman et al., 2016) and palliative and hospice (Adshead & Dechamps, 2016; Silverman, 2016) care settings support the consistent inclusion of social workers as part of multidisciplinary teams and end-of-life discussions.

According to Albrithen and Yalli (2015), Bathgate (2016), and Daly and Matzel (2013), the multidisciplinary team is an essential component of end-of-life care. When providing treatment for complex patients who are admitted to an ICU, there are benefits to having collaboration between social workers and other disciplines (Albrithen & Yalli, 2015; Bathgate, 2016; Daly & Matzel, 2013). Hospital social workers enjoy being part of a multidisciplinary team and have an opportunity to positively impact the life of patients or their family members when facing end-of-life care and decisions (Kwon et al., 2014). As the key member of the hospice and palliative care team concerned with psychosocial care, social workers can assume roles, including patient and family education; promoting meaningful communication among patients, family members, and health care providers; assisting patients facing illness in documenting their preferences; and advocating for patients' wishes (Stein & Fineberg, 2013).

As advocates, communicators, and counsellors, social workers can be leaders in encouraging and facilitating advance care planning (Stein & Fineberg, 2013). Hospital social workers experience personal satisfaction from being a member of health care teams that offer the "person-in-environment" perspective that incorporates all of the factors that influence a patient's health care experience. However, there is a disconnect between disciplines and the multidisciplinary team members involved in end-of-life care in the ICU setting. Medical social workers can clarify the health care system for the patient and family and explain the family system for the multidisciplinary team and advocate on behalf of patients and families, even when that advocacy challenges an agency's health care system (Craig & Muskat, 2013; Grant & Toh, 2017; Stein & Fineberg, 2013).

Improving collaboration with social work. The Institute of Medicine (IOM) was founded in 1970 to address end-of-life care issues (IOM, 2014). However, 18 years after the increase of activity generated by the IOM's (1997) report, gaps in end-of-life care remain and challenges to improvement persist (Peres, 2016). The IOM (year) suggested providing training, accrediting, licensing, and regulating the health care professions to do more to strengthen the palliative care knowledge and skills of all clinicians who care for patients with advanced illness near the end of life. The discipline of social work was already offering training in skills that enables social workers to operate effectively in bridging multidisciplinary care that is important at the end of life. To improve end-of-life care, social work efforts included increasing training in palliative care, particularly in academic institutions that offer certifications and continuing education in palliative care (Peres, 2016). The Social Work Hospice and Palliative Care Network also worked to provide the most up-to-date resources, policy updates, and best practices while working towards advancing education for social workers in the fields of palliative care and hospice (Peres, 2016). Although these recommendations did not address the ICU setting and the omission of social workers in end-of-life discussions, according to Peres (2016), focus has been placed on educating social workers in end-of-life care in the ICU setting.

Role Ambiguity in the ICU

Health care providers, patients, families, and social workers have perceptions that are sometimes inaccurate regarding the role of the social worker when it comes to end-of-life discussions (Bathgate, 2016; Brown & Walter, 2014; Kramer, 2013). The ambiguity that exists regarding social work roles in the ICU setting and a lack of clarity in these roles leads to uncertainty as to what a social worker actually does in end-of-life care in the ICU setting. This vagueness leads to confusion among other multidisciplinary team members as it relates to the ICU social worker role (Kramer, 2013). With the exception of conducting a mental health or psychosocial crisis, the services provided by social workers in the ICU do not usually take precedence over meeting the physical health needs of the patients (Bathgate, 2016).

Unlike ICUs and hospitals, hospice services receiving federal funding are mandated to provide care through an interdisciplinary team (IDT) and document regular meetings (Hospice Care, 2009). However, this is not a mandate for the ICU setting, and this may contribute to social workers not being included consistently in end-of-life discussions in this setting. Social workers are expected to be a catalyst to promote interactions among various professionals at IDT meetings (Albrithen & Yalli, 2015; Bathgate, 2016; Bomba, Morrissey, & Leven (2011); Daly & Matzel, 2013; Gwyther et al., 2005; Stein & Fineberg, 2013).

Varying Goals of Care in ICU

There is a shift in practice changes, with more focus on social worker involvement and end-of-life care in palliative care and hospice settings and the omission of research in ICU environments (Kelley & Morrison, 2015; Russell, 2015). Although hospice, palliative care, and ICU settings are similar in that they all provide care that addresses the medical needs of critically ill patients and assist patients and families in defining their goals of care and choices related to end-of-life in dying patients, the ICU environment is different (Abuatiq, 2015). The medical team in the ICU is more focused on the medical problems of the patient, and hospice and palliative care is focused primarily on chronic medical conditions and end-of-life care.

Members of the ICU team each have objectives and goals regarding patient care. During the last stages of the patient’s life where the medical staff may be more focused on meeting the medical needs of the patient, the social work profession is concerned with the whole person, including the context of his or her environment (Beder, 2013; Peres, 2016). There are times when the nurses and physicians in the ICU do not recognize the needs of patients' family members (Omari, 2009; Söderström et al., 2003). Nurses and other medical professionals in the ICU setting are trained to focus on the medical needs of the patient; therefore, the needs of the family members sometimes go unaddressed (Buckley & Andrews, 2011; Fox-Wasylyshyn et al., 2005).

Health Care Workforce

Health care workforce growth has not kept pace with the demand for end-of-life care. Because of the large increase in the number of older adults, the numbers of specialists in hospice and palliative care remains inadequate for the booming need for their services (Peres, 2016). Training is also limited for primary care doctors and nurses and medical and nursing students on how to care for individuals at the end of life (Anderson et al., 2015; IOM, 2014; Wilmont, 2015).

Weakness in Literature to Date

Although there is a demonstrated and identified need and benefit to having social workers included in ICU settings where end-of-life discussions happen, there is little to no current research on the barriers to why social workers are not included in ICU settings and end-of-life discussions on a consistent basis. There are also no actions identified towards implementing processes that address this gap in current practice nor strategic plans in place for the future. Other weaknesses include small sample sizes and research conducted that is specific to an area, region, or facility that cannot necessarily be generalized to other populations.

Strengths in Literature to Date

Social workers in ICU settings can play a role as a part of the multidisciplinary care team. By meeting with dying patients and their families who are often overwhelmed and in crisis, social work involvement allows the patients and their family members to feel understood and to feel that the medical team cares about them as individuals. Social workers assess for barriers and impediments to decision making, family values, and implement methods of appropriate intervention, often preventing and resolving conflict in decision-making (Hopeck & Harrison, 2016). Social workers can also empower families by identifying family strengths that may be overlooked in a medical setting oriented toward identifying pathology.

Concepts

Roles of Medical Social Workers

The role of the medical social worker has transformed over time to meet the fluctuating needs of patients and health care providers (Gehlert & Browne, 2012). As they deal with trauma, loss, disability, and illness, the acute care medical social worker provides support to the patient and his or her family members during difficult hospital admissions (Grant & Toh, 2017). A medical social worker offers resources and care to patients so that they can recover from illness or trauma as well as its emotional, psychological, and physical consequences (Findley, 2014). Medical social workers have opportunities to provide services in the community and in hospital settings in various capacities (Craig & Muskat, 2013; Daly & Matzel, 2013). Some of these duties could be as practical as arranging meals and transportation post discharge to more complex such as helping law enforcement in child abuse cases, giving psychosocial support to crime victims, or providing grief counseling.

Medical social workers are participants of hospitals interdisciplinary teams (Beder, 2013; Daly & Matzel, 2013). In some situations, their roles may be general, and other times the social worker role may be more specialized based on the needs of the individual (Beder, 2013). The medical social worker works with patients, families, and health care team members to address issues, emotional, and social issues that may impact their health and wellbeing (Daly & Matzel, 2013; Grant & Toh, 2017).

Internationally. Although empirical literature that addresses the role of the hospital social worker in the United States was limited, some quantitative and qualitative literature was found in other countries to illuminate an understanding of how medical social workers perceive their roles in various settings (Albrithen & Yalli, 2013; Bomba et al., 2011; Stein & Fineberg, 2013). Albrithen and Yalli (2013), Craig and Muskat (2013), and Kwon et al. (2014) characterized the role of hospital or medical social workers as being complex, challenging, and evolving to meet the changing needs of patients and families, regardless of the country or setting. Albrithen and Yalli, Kwon et al., and Craig and Muskat stated that the duties of the social worker vary based on the setting, and social workers fulfill various roles in an effort to meet the needs of patients as they prepare for end-of-life. However, according to Kwon et al. even with the uncertainty, complexity and challenges social workers maintain positive attitudes towards proving care to patients and end-of-life care and demonstrate that they remain committed to the field when it comes to providing care.

In Australia, scholars O'Malia, Hills, and Wagner (2014) conducted both qualitative and quantitative research surrounding routine social work team activity data for a 6-month period and found that the use of a social work assistant (SWA) allowed social workers the opportunity to focus on the core responsibilities in an increasingly complex work environment. Not only were social workers in the acute care setting seen as beneficial, O’Malia et al. (2014) found that having a social work assistant, benefited the social workers and the organization by reduced service cost. The social worker delegated tasks to the assistant which allowed the social worker more time to undertake complex tasks and interventions that correspond with their social work skills and training (O’Malia et al., 2014). According to Cleak and Turczynski, (2014) and O'Malia et al., 2014) in addressing the role of social workers and how they are able to operate effectively in the expanding responsibility for emerging client problems, such as patient complexity, legal, and other issues, the researchers acknowledge that despite the growth of the social work profession over the decades, and the predominance of health social workers in the field, similar to the United States, there has not been much investigation that examines the role of hospital social work in the Australian context. Emerging trends, such as chronic illness, care issues and the needs of some groups, is impacting social work activities within hospital settings (Cleak & Turczynski, 2014; Craig & Muskat, 2013; O'Malia et al., 2014). As the hospital system struggles with the increased demand for its services without any increase in resources, social work is increasingly called on to review its role and adapt to the changing practice environment (Cleak & Turczynski, 2014; O'Malia et al., 2014).

Resource and advocate. Hospital social worker advocate for the rights of patients in end-of-life care decisions in a manner that considers the patient's quality of life (Kwon et al., 2014; Stein & Fineberg, 2013). Hospital social workers also promote the well-being of a dying patient and their families to reduce conflicts in end-of-life situations (Kwon et al., 2014; Stein & Fineberg, 2013). National Association of Social Workers Standards for Social Work Practice in Health Care Settings (National Association of Social Workers Standards for Social Work Practice in Health Care Settings, 2005) and the National Association of Social Workers Standards for Palliative & End of Life Care (National Association of Social Workers Standards for Palliative & End of Life Care, 2004) practice standards require social workers to have skills in empowerment and advocacy and an ability to identify and resolve barriers to meet the needs of marginalized and vulnerable populations. As noted in the National Association of Social Workers Standards for Social Work Practice in Health Care Settings (National Association of Social Workers Standards for Social Work Practice in Health Care Settings, 2005) practice standards social workers must be competent in values and ethics, knowledge, assessment, empowerment, and advocacy to support implementation of changes that occur in practice while care is provided at a patient's end-of-life.

Medical social workers provide services to individuals during challenging medical situations. Medical social workers work to assemble available resources to help individuals recover from illness or live the remainder of their lives with the greatest level of dignity and independence (National Association of Social Workers, 2008). Medical social workers perform their professional duties in a public or private healthcare setting, in hospice or in the hospital. Medical social workers coordinate short and long-term healthcare services, counsel individual patients and their families and facilitate support groups (Beder, 2013).

Limitations and challenges. According to Albrithen and Yali (2013) social workers in hospital settings feel there were limitations that impacted their ability to effectively perform their roles as social workers. Some of the limitations these hospital social workers described included inadequate training that is necessary in keeping up their skills, lack of support from their superiors and, feeling of inadequacy that inhibit their ability to provide good practice (Albrithen & Yali, 2013). Craig and Muskat (2013) used interpretive description as the analytical framework for this study because this method is commonly used for small-scale qualitative studies of clinical phenomena. This framework also focuses on understanding individuals' experiences and grounds these experiences within the context of practice (Craig & Muskat, 2013). Scholars suggested that as funding changed, and resources deceased, social workers were focused on meeting the immediate needs of patients and had less time for counseling or treatment planning (Craig & Muskat, 2013). Participants felt their major roles were to support the interdisciplinary team while acting as therapist, resolving conflicts that may arise in the group, and managing these relationships amongst interdisciplinary team members, while advocating for the needs of vulnerable patients and their families (Craig & Muskat, 2013).

Barber, Coulourides Kogan, Riffenburgh, and Enguidanos (2015) presented a single-case, case study methodology to investigate the social work role in providing care transition support for an at-risk older adult. The researchers highlighted the fact that although social workers are qualified to improve care transitions they have not been used in these roles (Barber, Coulourides Kogan, Riffenburgh & Enguidanos, 2015). Additionally, scholars suggested that there is value in having social workers in transitional care roles from the patients' hospitalization to the patients' home.

According to Sharma, Astrow, Texeira, and Sulmasy (2012) many spiritual needs go unaddressed in health care settings. Hodge and Wolosin (2014) attempted to address the gap in literature in this area by demonstrating that frontline hospital personnel play an instrumental role in addressing patients' spiritual needs. These scholars further stated that it is important for social workers to collaborate with other providers in the hospital setting in order to optimize service provision to hospitalized adults (Hodge & Wolosin, 2014). The research of scholars Bathgate (2016), Daly and Matzel, (2013) and Hodge and Wolosin (2014) suggested that social workers were key members of the multidisciplinary health care team.

Findley (2013) indicated because social workers are not specifically mentioned in most chronic care models the complicated health and social care processes created barriers to social workers collaborating with other health care professionals and suggested the role of the social worker needs to be more clearly defined. Social workers in the health care setting are a natural fit because basic values of social work are called upon that included the promotion of the individual's rights to self-determination, having an attitude of empathy for the individual while negotiating barriers, or advocating for people on multiple levels (Findley, 2014).

According to Sharma et al., (2012), unmet spiritual needs of patients are associated with decreased quality of care (Astrow, Wexler, Texeira, He & Sulmasy, 2007), patient satisfaction (Astrow et al., 2007; Clark, Drain & Malone, 2003) and a patients' quality of life (Balboni et al., 2009). Hodge and Wolosin (2014) addressed the gap in literature in this area by demonstrating that frontline hospital personnel played a role in addressing patients' spiritual needs and the importance of social workers collaborating with other providers in the hospital setting in order to optimize service provision to hospitalized adults.

Education and readiness as collaborators. Social worker involvement is key to end-of-life care and planning (Albrithen & Yalli, 2015; Black, 2005; Chaddock, 2016; Chow et al., 2015; Peres, 2016 & Stein & Fineberg, 2013). The delivery of high quality end-of-life care depended on the involvement and contributions made by social workers (Chow et al., 2015). This is relevant for when addressing the psychosocial needs of both patients and families (National Association of Social Workers, 2008). The field of end-of-life care is changing and evolving due to the aging population (Gardner, Doherty, Gerbino, Walls & Chachkes, 2015; Chow et al., 2015). With the expected increase in demands for end-of-life services, the profession of social work needs to keep up with both the demand and skills necessary to meet these demographic changes (Gardner et al., 2015; Chow et al., 2015). However, there is a serious shortage of social workers prepared to provide quality palliative and end-of-life care (Gardner et al., 2015).

The attitudes of social work professionals regarding end-of-life decision-making are related to their knowledge and perceived role in assisting with the formalization of advance directives, educational needs pertaining to the psychological, and social needs of patients and families, and psychosocial interventions (Baker, 2000; Chow et al., 2015; Werner, Carmel, & Ziedenberg, 2004; Weisenfluh & Csikai, 2013). When social workers were asked to describe their experiences of integration and collaboration on health care teams, they indicated the need to encourage and support health care providers to more fully understand the foundation, role, and efficacy of social workers on multidisciplinary teams (Glasser & Suter, 2016; Kwon et al., 2014). Clinical social workers also felt it was important to develop comprehensive treatment plans, facilitate communication between patients their family members and the multidisciplinary team, address advance directives, crisis intervention, bereavement counseling, and link patients and families to needed resources. (Glasser & Suter, 2016; Kwon et al., 2014). Social workers consistently reported that they did not feel adequately prepared or supported to work in palliative and end-of-life care settings (Blacker & Christ, 2011; Csikai & Raymer, 2005; Christ & Sormanti, 2000). It was suggested by scholars that strategies be developed to prepare and sustain the next generation of social workers who are skilled in providing end-of-life care (Gwyther et al., 2005; Whitaker, Weismiller, & Clark, 2006).

As a member of the hospice and palliative care team, concerned with psychosocial care, social workers assume roles to address advanced care planning related to end-of-life care (Stein & Fineberg, 2013). Scholars Arthur (2015) as well as Conlon and Aldredge (2013) noted specifically that social workers also advocated for expanded policy that reached marginalized groups, namely lesbian, gay, bisexual, and transgender patients in nursing facilities, home health, hospices, and other health care arenas (Conlon & Aldredge, 2013). Open, and timely communication, which is sensitive to diversity and cultural difference, lies at the heart of good end of life care and is a constant theme in training initiatives related to end-of-life care (Adshead & Dechamps, 2016; Wilmont, 2015). To achieve cultural competence in these areas it is recommended that adequate education and training be provided so that social workers are able to develop knowledge of how factors in vulnerable populations intersect with the health care environment (Adshead & Dechamps, 2016; Conlon & Aldredge, 2013; Gardneret al., 2015). Course work should strive to prepare students for the complex, challenging roles required for social worker in health care settings, especially end-of-life care, through focused attention on developing skills such as enhanced crisis intervention, problem solving, and communication skills (Craig & Muskat, 2013).

Value and benefit. Social workers help the medical team remember the big picture and that each patient and family exist in a social context (Beder, 2013; Bomba et al., 2011; Peres, 2016). According to Kwon et al. (2014) social work students tended to have positive attitudes toward end-of-life care planning and higher levels of comfort when discussing death, more emphasis on self-determination, and an increased commitment of social workers' to maintaining the ethical principle of the client's right to self-determination in end-of-life planning (Glasser & Suter, 2016; Kwon et al., 2014). Hospital social workers are highly valued for their responsiveness, emotional support and practical help during the process of a patient's hospitalization (Bomba et al., 2011).

Additionally, findings by Barber, Coulourides Kogan, Riffenburgh and Enguidanos (2015) suggest there is value in having social workers in transitional care roles from the hospital to home. These findings could be generalized to end-of-life care roles for social workers in the ICU setting.

Beder, Postiglione and Strolin-Goltzman (2012) found that social workers in this setting face many challenges as they work to address the ongoing health and mental health needs of those who serve in the military. However, they are very important to the multidisciplinary medical teams at the VA and the VA hospital environment and most social workers report feeling positive about work and their contributions to the care of the military (Beder et al., 2012). Likewise, in other hospital settings social workers are seen as important to end-of-life patient care (Albrithen & Yalli, 2015; Black, 2005; Chaddock, 2016; Craig & Muskat, 2013; Chow et al., 2015; Peres, 2016; Stein & Fineberg, 2013). However, O'Malia et al., 2014) notes many social work tasks assigned in the hospital setting are low-level or routine, and do not necessarily warrant social work intervention.

Barriers to Social Worker Inclusion

Social workers are often the health care professionals who deal with family members who are in denial about the prognosis of a loved, resistance from the medical team regarding patients transition to palliative and/or hospice care, and administrative pressure regarding the flow of patients (Craig & Muskat, 2013; Grant & Toh, 2017; Hopeck & Harrison, 2016; Silverman, 2015; Stein & Fineberg, 2013). Members of the healthcare teams’ lack of knowledge or insensitivity to cultural differences may impinge on productive end-of-life decision-making, or the healthcare social worker may face psychological issues that often presents as bioethical or end-of-life and communication and a patient distrust in the health care system (Adshead & Dechamps, 2016; Bomba et al., 2011; Silverman, 2015; Stein & Fineberg, 2013). Just as McAndrew and Leske (2015) noted the physicians and nurse's difficulty with balancing emotional responsiveness, professional role and responsibilities, and communicative or collaborative behaviors during end-of-life decision making that created moral distress, Silverman (2015) noted that social workers must also find a balance as they work through barriers and must balance the conflicting needs of the patient and the hospital system.

According to Bomba et al. (2011), Stein and Fineberg (2013) and Sullivan et al. (2012) a key to social worker involvement in end-of-life scenarios is their ability to identify and negotiate existing barriers between patient systems and providers. Multidisciplinary care is an integrative approach between groups of professionals, including the patient and family (Beder, 2013). However, scholars identified several barriers that prevented social workers from being included on multidisciplinary teams. Some of those barriers included, lack of confidence on the part of the social worker (Albrithen & Yali, 2015; Chow et al., 2015; Kirby et al., 2014; Kwon et al., 2014; Wilmont, 2015) and clinicians feeling ill-prepared to have end-of-life discussions (Boss et al., 2009; Rider et al., 2008). Additional barriers identified included, social workers lack of knowledge regarding end-of-life care (Albrithen & Yalli, 2015), lack of communication amongst multidisciplinary team members and family, (Anderson et al., 2015; Curtis et al, 2016; Howell et al., 2014; McAndrew & Leske, 2015; Steinhauser et al., 2014; Wilmont, 2015) and lack of clarity regarding the role of the social worker on the multidisciplinary team (Kramer (2013). Other barriers identified were related to the complexity of the hospital ICU setting, and the hospital system as a whole (Flannery et al., 2016; Kramer, 2013). Likewise, Seaman, Arnold, Nilsen, Argenas, Shields, and White (2016) found that the barriers to having timely family meetings regarding end-of-life discussions included clinicians being uncomfortable with conducting meetings concerning end-of life conversations, the practice of having meetings only when decisions need to be made, the lack of a clear processes to schedule family meetings, and having a responsible party for setting up meetings (Seaman et al., 2016). Furthermore, although social workers reported feeling comfortable in dealing with issues related to specific psychological issues, grief and bereavement, funeral planning, and spiritual issues of dying patients, they also reported feeling ill-prepared to meet the multidimensional needs that arise when having discussions at the end of life (Kramer, 2013).

One of the barriers to social worker’s inclusion in end-of-life discussions is that hospital social workers may not be familiar with end-of-life care, they lack professional experiences with death and dying issues in the field, and many social workers lack confidence in their ability to engage with patients in end-of-life discussions (Albrithen & Yali, 2015; Chow et al., 2015; Kirby et al., 2014; Kwon et al., 2014; Wilmont, 2015). Symbolic interactionism (SI) and applied general systems theory (GST) are theories that provided insight into current challenges in end-of-life care and identified areas where research and interventions were needed to address them and as a practice model that suggested change among multiple levels of systems (Wallace, 2016).

Other barriers identified included insufficient understanding among other professional groups regarding the role of the social worker, negative attitudes of medical care professionals toward social work, and medical professionals in the hospital displaying negative attitudes toward social workers (Albrithen & Yalli, 2015). Other barriers cited include team members seeing social workers as competition rather than cooperation, lack of a strong common value base, and lack of organizational support for effective linkages between the various professional groups Albrithen and Yalli (2015). Scholars Stein and Fineberg (2013) as well as Wallace (2016) contradicted the belief that social workers are not prepared by suggesting that social workers are prepared and that their knowledge base and communication skill sets make them appropriate to take the lead in addressing and guiding patients and families through effective end-of-life discussions. It was posited that whether in palliative or end of life care, social workers are leaders in introducing and encouraging dialogue about advance care planning (Peres, 2016; Stein & Fineberg, 2013). The presence of a social worker was important because they are often involved with helping patients and their families during critical times like end-of-life. Social workers in the ICU provide interventions that allow patients, families, and medical providers to cope with the uncertainty that accompanies the stress of critical illness (Bomba et al., 2011; McLaughlin, 2016; Stein & Fineberg, 2013).

Communication in the ICU. Information regarding a patient’s prognosis allows physicians and patients to make decisions regarding plans of care. Hospital social workers are often the facilitators of communication between physicians, patients, and families, especially when patients are facing life-threatening illness (Bunting & Cagle, 2016). However, communication is a barrier to social workers being included in end-of-life discussion in the ICU setting (Anderson et al., 2015; Howell et al., 2014; Steinhauser et al., 2014; Wilmont, 2015). Despite the importance of open discussions about end-of-life decisions, poor communication among physicians, family decision makers, nurses created conflict about treatment decisions (Bandari, et al., 2015; Bunting & Cagle, 2016; McAndrew & Leske, 2015). In many instances, communication with the family of critically ill patients was often poor, and this contributed to family distress and increased the intensity of care at the end of life (Anderson et al., 2015; Bandari et al., 2015; Curtis et al., 2016; Howell et al., 2014). There was an imbalance among emotional responsiveness, professional roles and responsibilities, and communicative or collaborative behaviors during end-of-life decision making that created moral distress (Anderson et al., 2015; McAndrew & Leske, 2015). Scholars suggested a need to have training developed for physicians and nurses involved in end-of-life decisions making and further research to test interventions aimed at improving communication and collaboration (Anderson et al., 2015; Bunting & Cagle, 2016; Han, Dieckmann, Holt, Gutheil, & Peters, 2016; McAndrew & Leske, 2015).

Communication intervention was associated with a reduction in intensity of end-of-life care and improved family distress (Curtis et al, 2016; Steinhauser et al., 2014). When a patient was aware of the facts at the end-of-life they were able to come to terms with impending death and determine whether or when to pursue or forgo curative or end-of-life treatment interventions (Han et al., 2016). However, for various reasons cited physicians were reluctant to communicate a patients’ prognosis to them (Bunting &

Cagle, 2016; Han et al., 2016). Improved communications involving social workers improved communication and self-efficacy and lessened fears of death and dying (Bunting & Cagle, 2016). Additionally, clinicians in the intensive care unit suggested that facilitator interventions acted as an enhancement to communication and as a support to both patients' families and clinicians (Howell et al., 2014). They also identified the importance of the facilitator within the interdisciplinary team (Howell et al., 2014).

While family members expressed high satisfaction with the care provided in the hospital ICU, lower ratings were given for communication, information, and emotional support (Carlson et al., 2015). The most important need identified in end-of-life discussions was for family members of ICU patients to have their questions answered honestly when discussing prognosis' in end-of-life care (Bandari, et al., 2015; Chatzaki et al., 2012; Prachar et al., 2010; Steinhauser et al., 2014). Although the need 'To know about the patient's condition' was stated to be the most important need in the ICU when having end-of-life discussions, family members also preferred to communicate with nurses rather than physicians (Prachar et al., 2010).

The quality of the communication of the medical professionals providing care related to end-of-life care remained poor, including discussions about prognosis, advanced care planning, and shared decision making (Anderson et al., 2015; Bishop, Perry & Hine, 2014; Han et al., 2016). In addition to stress on the patient and family, according to Anderson et al., (2015), Bishop et al., (2014), and Han et al., (2016)., the ICU environment produced emotional exhaustion, stress, burnout, and sadness for the medical professional, especially for new doctors who were in their residency. Scholars

Flannery et al. (2016) found that communication challenges with social workers in the ICU involved, role ambiguity, communication issues, indecisions on futility of treatment and the timing of the initiation of end-of-life discussions. Physicians and nursing in the ICU setting have cited end-of-life decision making as one of the most common sources of ethical conflicts encountered in clinical practice (McAndrew & Leske, 2015). Their different perspectives were viewed as a source of potential conflict and a barrier to communication and concerted processes. End-of-life decision making is a balancing act of emotional responsiveness, professional roles and responsibilities, and intentionally communicating and collaborating (McAndrew & Leske, 2015). Implications from research are a need for a more comprehensive, standardized approaches that support medical staff in end-of-life decision making in the ICU which could be addressed by the inclusion of social workers (Flannery et al., 2016; Manias, 2015).

Multidisciplinary teams and social work. Social workers are key members of the multidisciplinary health care team and the multidisciplinary team is an essential component of end-of-life care (Bathgate, 2016; Daly & Matzel, 2013; Hodge & Wolosin, 2014). When treating complex patients that are admitted to an ICU, researchers identified the benefits of collaboration between social workers and other disciplines (Albrithen & Yalli, 2015; Stein & Fineberg, 2013). The social workers perceptions regarding the inter-professional work issues influenced their ability to maintain an effective contribution to the multidisciplinary team (Albrithen & Yalli, 2015).

Scholars supported the notion that good medical treatment was dependent on the interdisciplinary team’s continual awareness of the social situations of patients and their feelings about these circumstances and this is where the social worker can lend expertise (Albrithen & Yalli, 2015; Stein & Fineberg, 2013). However, researcher, Manias (2015) contradicted this and instead suggested that hospital professionals did not demonstrate traditional forms of teamwork and instead coordinated and networked on an as needed basis. Collaboration, that involved active decision making about specific issues, typically occurred among medical staff only or with all health professionals during crisis situations (Manias, 2015). In addition, the medical team dominated the unit and impacted the way other members of the team interacted (Anderson et al., 2015; Manias, 2015).

Due to social workers and other members of the team not being present consistently it resulted in miscommunications with information sharing (Anderson et al., 2015; Manias, 2015). Scholar Manias (2015), indicated the need for developing and evaluating quality improvement initiatives and according to Anderson et al., (2015), when it comes to informing patients and families with information related to a poor prognosis, that information should initially come from the physician. However, social workers and other members of the medical team should have a role responsibility of reinforcing physicians’ prognostications and help families emotionally process a poor prognosis (Anderson et al., 2015). Similarly, Rodriguez (2015) stated that most ICU care work is done in isolation, punctuated by bursts of activity involving multiple staff members working to complete a task. Combining observational methods with interviews showed how teamwork varied over time within an organization, an offered insight that had not been shown in the existing literature (Rodriguez, 2015).

The perceptions of social worker’s in relation to inter-professional work issues and their work on an interdisciplinary team create barriers to the social workers contributing to multidisciplinary teams (Albrithen and Yalli, 2015). Some of the barriers identified included multidisciplinary team members lack of understanding regarding the role of the social worker, negative attitudes of medical staff toward the social work profession, competitiveness between team members (i.e. case managers, discharge planners), and lack of support from administrators (Albrithen & Yalli, 2015; Kramer, 2013). Scholars stated that teamwork between social workers and medical care staff contributed to the successful identification and resolution of health and social problems, that led to stronger partnerships and better continuity of care for patients, especially those with complex needs (Albrithen & Yalli, 2015). Social workers have access to people at an early stage of their difficulties and are equipped with the skills required to adeptly introduce the subject of end-of-life (Chaddock, 2016). In a society, reluctant to address end-of-life issues, health and social work professionals pulling together can effectively support individuals to define and realize their end-of-life wishes.

Patients, families, and health care providers used communication to explore options and decision making related to serious and life-threatening illnesses (Aelbrecht et al., 2015; Dervin & Foreman-Wernet, 2012; Warnock, 2014). When patients are dealing with serious, life-threatening illness communication between the patient, their family members and the medical team is imperative (Ford, Catt, Chalmers, & Fallowfield, 2012; Ventres & Frankel, 2015). A lack of communication skills to discuss information about serious or life-threatening illnesses, including the ineffectiveness of treatment, poor prognosis, or other types of information that can adversely impact a patient’s treatment plan, contributed to misunderstandings about patient preferences for treatment and goals of care (Curtis et al., 2013; Ptacek & Eberhardt, 1996). Although social workers are generally trained to handle complex situations, scholars examined the effectiveness of communication training and found that it usually focused on the physicians and nurses (Kissane et al., 2012; Nørgaard et al., 2012). Scholars suggested the need for continued education for social workers on more advanced techniques being critical for developing effective communication skills such as conflict mediation, preservation of hope, and assessment of how a patient’s illness influences family dynamics (Cagle & Williams, 2016).

Context

History of Medical Social Workers

Hospital social worker in the Unites States began at Massachusetts General Hospital (MGH) in the 1900’s (Beder, 2013). Due to the increase of patients experiencing different medical conditions including, tuberculosis, syphilis, polio, coupled with pregnancies of unmarried women and poor living conditions this impacted how clinicians were able to provide care and treatments for their patient’s (Beder, 2013). According to Beder (2013), treatment began moving away from the patient’s home and to the acute care setting. Dr. Richard C. Cabot saw the necessity of having a non-medical staff presence in the hospital and created the position of social worker (Beder, 2013). Dr. Cabot brought in social workers to work with physicians to assist with helping patients adjust to their illnesses and social problems that impacted treatment (Beder, 2013).

According to Gehlert and Browne (2012), Dr. Cabot felt that by both social workers and physicians working together with the patients they could gain, by associating with one another.

As noted in the literature, Dr. Cabot appointed Garnet Pelton, a nurse, to act as the first social worker for MGH (Bartlett, 1975; Beder, 2013). Garnet Pelton acted in this role for six months and subsequently resigned due to medical problems (Bartlett, 1975; Beder, 2013). In 1906 Ida Cannon was appointed as the next social worker (Bartlett, 1975; Beder, 2013). Although Ida Cannon was initially trained as a nurse, she later received a degree in social work from what is now called Simmons College, (Bartlett, 1975; Beder, 2013). Beder (2013) noted, Ida Cannon focused on bridging the gap between the hospital environment and the social environment of the patient to remove barriers that might impact the patient’s treatment.

The ICU Environment

The specialty of intensive care medicine was developed in the 1950s, due to the poliomyelitis epidemic and the need to have many patients mechanically ventilated (Wenham & Pittard, 2009). Since that time, the technology in the ICU setting that is available to support critically ill patients in the ICU has become more sophisticated and complex but is important in providing care to patients (Abuatiq, 2015; Wenham & Pittard, 2009). Both the situation and the environment in an ICU are stressful for the patient and their family members (Blom et al., 2013; Flannery et al., 2016; Kramer, 2013). Patients are admitted to an ICU with life threatening conditions and with little warning (Bandari, et al., 2015). There is also the likelihood that family members have very little understanding about the critical nature of an ICU admission. This leaves patients' families minimal time to prepare emotionally for what is going on and leads to family members experiencing acute distress and emotional disturbances (Blom et al., 2013; Brown et al., 2015; Carlson et al., 2015; Davidson et al., 2012; Grant & Toh, 2017; McAdam, 2016; Paul & Finney, 2015; Schmidt & Azoulay, 2012).

According to Blom et al. (2013), in recent decades, family-centered care has been highlighted, and families are being offered more active roles in the care in ICU settings. One of the main responsibilities of healthcare teams in an ICU setting is to identify the needs of patients and patients' families (Chatzaki et al., 2012). However, the high stress of the ICU is worsened by the vast complexity of technological interventions designed to maintain physiological functioning, while the patient is being cared for medically, as well as the constant concerns related to cost, effectiveness, and efficiency (Bishop et al., 2014; Rashid et al., 2014). This can be taxing and overwhelming to the patient, their family members, and the medical professionals involved in the patients care.

There is a need to improve communication and emotional support of family members of ICU patients (Carlson et al., 2015). It is suggested that the experiences and satisfaction with ICU care is achieved when more focus is place on helping family members manage their distress (Carlson et al., 2015; Steinhauser et al., 2014). The literature is conflicting regarding the support patients and family member's needs in the ICU setting and who should be providing the support. Family members of patients being treated in the ICU were more likely to report dissatisfaction if they reported zero involvement in formal family meetings (Hwang et al., 2014). Implications from this research support the need to evaluate strategies to provide better decision-making support and the implementation family meetings on a consistent basis (Hwang et al., 2014).

Overall, family members have confidence in the ICU medical team and reported feeling supported when family members were permitted to participate in the patients care (Blom et al., 2013). On the other hand, family members reported it to be distressing when they were excluded from participation (Blom et al., 2013; Sullivan et al., 2012). Most family members of patients in the ICU experienced learned helplessness and that can have negative implications in the collaborative decision-making process for the patient (Sullivan et al, 2012).

Scholars McAdam et al. (2012), reported that the patient's family members' symptoms of anxiety, depression, and posttraumatic stress disorder decreased considerably 3 months after the intensive care experience, and did not differ based on the patients' final disposition (McAdam et al., 2012). However, many family members still had significant risk for posttraumatic stress disorder and borderline anxiety and depression at the 3-month mark (McAdam et al., 2012). As it relates to the complex care needs of family members of ICU patients, leading up to and following patient deaths and organizational constraints, social workers' ICU training was inadequate in equipping them to address the complex care needs (Blom et al., 2013). Also, lack of access to social works after hours contributed to concerns about family care (Blom et al., 2013; Bloomer, Morphet, O'Connor, Lee & Griffiths, 2013).

According to Benbenishty (2015), employing a family support group as a tool for the delivery of instruction, guidance, education and support in an ICU setting, that is nonthreatening and non-hospital' looking, (i.e. a lounge area, and arranging the furniture in a circle) provided participants and opportunity to see one another in a safe atmosphere and to share and discuss information. The needs of family members of patients hospitalized in the ICU suggested the need for providers to identify and understand the significance and priority of the needs within sociocultural contexts with the need for social support being identified as the least important (Bandari, et al., 2015). This suggested that there is no need for support from ICU social workers in this environment. However, it is suggested by scholars that there is a benefit to having increased emotional support in an ICU setting (Carlson et al., 2015).

Ethical Issues and ICU Social Work

The National Association of Social Workers' Code of Ethics (2008) states that social workers should demonstrate a working knowledge of the theoretical models essential to effectively practice with patients and professionals in end-of-life care. Also needed is training for other professional providers, such as nurses and doctors (Arthur, 2015). Ethical issues can arise in the ICU settings when dealing with end-of-life situations. Some of those issue deal with making decisions on behalf of incapacitated patients and withdrawal of life-sustaining support (Modra & Hilton, 2016). nurses who cared for patients having experiences where life sustaining treatment is withheld or withdrawn, reported having significant personal and professional dilemmas (Mcleod, 2014). Scholars McCormick et al. (2014), used case studies to demonstrate ethical conflicts and the role of social workers in resolving them. A continuing education training was developed to educate social workers in bioethics related to determining decisional capacity and understanding standards of ethical decision making. Other ethical challenges seen in the ICU involved the management of the noncommunicative patient symptoms and medical futility, medical providers providing an accurate prognosis, ensuring healthcare surrogates made decisions that respected the patient's preference, and avoiding conflicts in organ donation (Bernat, 2015; Chow, 2014). While members of the medical team agreed on a patients' goals of care, other members reported their voices and concerns were not heard when it came to the patients care, and this led to them feeling ethically challenged (Chow, 2014).

Action Research

Action research is a methodology that aims to increase knowledge, experience and understanding of a current situation and engage in a process of change (Paul, 2016). Action research within a community seeks to change social as well as personal dynamics in a manner that positively impacts the lives of all participants (Thiollent, 2011). Action research is operational field research that deals with everyday issues of practice to increase effectiveness, and involves a spiral of steps composed of planning, action, and evaluation and critical reflection of the action, in order to plan subsequent events (Paul, 2016). Action research sits within participatory research paradigm and involves connecting people, subjects, objects and their environments (Paul, 2016). Action research is a developmental process where participants resolve the issues in question. Theory in action research thus attempts to 'bridge theory and practice" but also generate new ways of understanding practice (Paul, 2016).

Action research is an approach that is community-based and allows a researcher an opportunity to study social situations (Stringer, 2007). Action research involves systematic inquiry by individuals with a common purpose, with a goal of bringing about change in specific contexts (Whitelaw et al., 2003). Through this cooperative inquiry, the researcher works with as well as study people that in turn leads to enhanced working environments for all participants, and stakeholders (Stringer, 2007). Meyer (2000), proposed a strength of using action research is that it focuses on generating solutions to real-world problems. Another strength of using action research is that it empowers participants by allowing them an opportunity to engage with the researcher in the development or implementation of solutions (Meyer, 2000).

According to Gray, Sharland, Heinsch, and Schubert (2014), action research is an appropriate methodology because it allows a researcher to focus on knowledge, mobilization, implementation, and innovation, with a shared emphasis on the role of organizations in bridging the gap between research and action. Participatory planning brings together various practices where stakeholders can collectively, define the purpose, identify objectives and targets they would like to reach, and evaluate criteria for a planned activity (Thiollent, 2011). The decisions regarding the direction of research and the possible outcomes should be collective. Behaviors a researcher could employ that may aid in fostering trust include, consulting with all individuals relevant to the research, being receptive to inquiries from participants regarding purpose and progress, ensuring that all participants are in acceptance of the guiding principles of the work in advance, and keeping the developments visible and open to suggestions from the participants.

Summary

Social workers play a role in assisting people as they adjust to various changes in life, including end-of-life. End-of-life care is concerned with patient quality, and advocacy of care at the patient's time of death. The ICU is a specialized unit in the hospital or healthcare facility that cares for critically ill patients with severe, and life-threatening illnesses (Modrykamien, 2012; Yang et al., 2015). In the ICU setting as many as 95% of the patients are incapacitated due to illness or sedation (Curtis & Vincent, 2010; McCormick et al., 2007; Truog et al., 2008). This results in the patient's family members making treatment decisions and participating in goals of care, and discussions with members of the multidisciplinary team on behalf of the patient (Curtis & Vincent, 2010; McAdam et al., 2012; McCormick et al., 2007; Rose & Shelton, 2006).

In ICU settings patients have a higher risk of and occurrence of death (Modrykamien, 2012). Statistically, 20% of all deaths in the United States (US) occur in the hospital ICU setting (Curtis, 2005; Gries et al., 2010). Patients and the family members of patients in the ICU face many unique challenges due to the patient's diagnosis of a critical illness, and the ICU environment itself (Brown, et al., 2015). The process of having to make decisions on behalf of the patient is particularly taxing for families because of high levels of acute stress and the risk for the patients' death (Brown et al., 2015). This experience can be very overwhelming for the patient as well as their family members. Complex environments, such as an ICU setting, require timely problem solving that may have devastating consequences for both the patient and for the health care system (Grant & Toh, 2017).

During the last stages of the patient’s life, the medical staff may be more focused on meeting the medical needs of the patient (Buckley & Andrews, 2011; Fox-Wasylyshyn et al., 2005; Omari, 2009; Söderström et al., 2003). The social work profession is concerned with the whole person, including the context of their environment (Beder, 2013; Peres, 2016). According to Beder (2013) and Peres (2016), because of the social workers’ training that enables them to interact with and observe individuals holistically, it is a benefit to have social workers involved in all stages of end-of-life care planning. Social workers also, educate the medical team on the patient’s cultural and religious background, and advocate for the wishes of the patient and families in cases when conflict arises.

The literature review included an examination of both theoretical and empirical literature relevant to the perceived barriers to the consistent inclusion of social workers in end-of-life discussions and how social workers view their role in the adult ICU. First, the origin of social workers and the evolution of their changing roles was reviewed. The notion of medical social work roles in ICU settings and a part of multidisciplinary teams was then examined in advancing a conceptual rationale for conducting this action research study. Complexity theory and its core construct of an organization, such as an ICU, being on the edge of chaos as a solution to solving problems was described. Using complexity theory, an explanation was offered to explain the ICU and this environment as a complex system of the hospital that involves various parts that interact to bring about unexpected order that can be overwhelming to families and non-inclusive of social workers. A review of the literature which explored the ICU environment, hospital social workers and social worker role on multidisciplinary teams was presented and the antecedents to barriers to inclusion including changing needs of social workers, communication, role ambiguity, lack of resources and education, were discussed.

Using action research methodology with a qualitative component to collect data using focus groups, the goal of this study was to identify barriers as to why social workers are not consistently included in these end-of-life discussions. This action research project also contributes to positive social change because it gives validity to the field of social work and demonstrates the ability of social workers to work in this very complex field. The potential implications for positive social change for this action research project were to close the gap between the social worker, the patient and their family members and the multidisciplinary team while determining solutions that will enable social workers to consistently collaborate with the medical team, patients, and families in the provision of end-of-life care in the ICU. This research expands knowledge within this specific practice area and benefits the patient, the hospital and the social work profession. The data will be used to propose a process that will consistently include social workers in end-of-life discussions in ICU settings.

This section of the Action Research Project serves as a literary exploration of barriers to the consistent inclusion of social workers in end-of-life discussions and how social workers perceive their role in adult (ICU) settings in order to identify barriers and develop a process for consistent inclusion in end-of-life discussions. The research review supports the notion that social workers are vital to end-of-life discussions and care and this warrants exploration of why this does not occur consistently in the ICU setting like it does in palliative and hospice care settings.

Section One Summary

A review on physician communication with patients and family members in palliative care settings found that physicians tend to focus on medical and technical issues and avoid discussing quality of life and emotional issues. Social workers have the expertise to work with vulnerable populations, agencies and communities and can communicate effectively about difficult and painful subjects (Scanlan, 2016). However, social workers are not consistently included when end-of-life discussion occur in ICU settings. Despite claims regarding the important role that social workers have and should have in providing end-of-life care in a broad range of contexts, the empirical documentation of their responsibilities and roles in end-of-life care in ICU settings is limited (Kramer, 2013). Social workers bridge the gap that exists between the members of the medical team, the patient and the patient's family because of miscommunication (Hartman-Shea et al., 2011; McCormick et al., 2010). Bomba et al. (2011), Bunting and Cagle (2016) and McCormick et al., (2010) emphasized the significant impact social workers have on improved communication between patients, families and members of the multidisciplinary team. Family meetings are effective in the ICU for multidisciplinary team members to discuss end-of-life care and deliver poor prognosis and have been linked to the reduction of the family's symptoms of posttraumatic stress disorder (PTSD), anxiety, and depression (Browning, 2008; McAdam & Puntillo, 2009).

Both social workers and physicians were found to be the most involved health care professionals in end-of-life communications and decision making (Csikai, 2006). According to Werner et al. (2004), social workers are more likely than nurses to interact with family members in decisions regarding life sustaining treatment, request additional information from the medical providers when needed, spend time with the patients and families to process their emotions, and guide decisions made throughout the ICU admission. Social workers also, educate the medical team on the patient's cultural and religious background, and advocate for the wishes of the patient and families in cases when conflict arises. Social workers spend time interacting with the patient and their families directly, discussing the family's outlook on the patient's condition and plan of care, clarifying information, addressing questions and concerns, organizing and attending family meetings, and providing relevant psychosocial information to the ICU multidisciplinary team (Rose & Shelton, 2006; Young & Iverson, 1984).

The current literature in pediatric ICU (Doorenbos et al., 2012; Michelson et al., 2013; Thieleman et al., 2016), palliative and hospice (Adshead & Dechamps, 2016; Silverman, 2016) care settings support the consistent inclusion of social workers as part of multidisciplinary teams and end-of-life discussions. Also, there has been a great deal of research regarding social worker involvement in end-of-life discussions in ICU settings in the past, as noted in the literature. However, there is a gap in the documentation in the last 5 years that addresses the social worker's role in the adult ICU setting. Social workers are trained to provide counseling services, grief support and to address religious and spiritual needs. According to Hupcey et al. (2016) discussion of religion and/or spirituality is important to patients and their families known to be beneficial. However, it happens infrequently in the ICU (Hupcey et al., 2016).

Section one of this research project related to the exploration of barriers to the consistent inclusion of social workers in end-of-life discussions and the perceived role of social workers in the adult ICU settings, introduced the social work problem and provided a purpose for this action research project. Practice-focused research question(s) were stated in this section and the significance of the study regarding barriers to social work inclusion and the perceived roles of social workers in the ICU setting was noted. Section one includes identification and definitions of key terms, concepts, and constraints related to barriers and perceptions in the ICU. The nature of the doctoral project was explained and includes information about participants and methods of data collection. The theoretical framework and basic tenets for complexity theory were identified, and its applicability to the presenting social work problem explained. The first section includes a comprehensive review of the professional and academic literature related to barriers to the consistent inclusion of social workers in end-of-life discussions and the perceived role of social workers in the adult ICU settings and the methods utilized to obtain supportive and relevant documentation.

The quantitative and qualitative research literature examined within social work and end-of-life care suggests that there is lack of understanding of the barriers to social work inclusion on a consistent basis in end-of-life discussions in the ICU. Also, perceptions of how social workers view their role in end-of-life discussions in the ICU setting is not always clearly defined. This review of the professional and academic literature suggested that the social work profession should examine how social workers describe the phenomenon of barriers and perceived roles in end-of-life discussions. Little to no research in the current literature is available that explains why social workers are not consistently included in end-of-life discussions in ICU settings. Further research into the phenomenon of barriers and perceived roles of social workers in the ICU setting was explored to move forward towards positive social change and the methods of data collection will be discussed in section two of this action research project.

Section 2: Research Design and Data Collection

Patients and the family members of patients in the ICU face many challenges due to the patient's diagnosis of a critical illness and the ICU environment itself (Brown et al., 2015). The process of having to make decisions on behalf of the patient is taxing for families because of high levels of acute stress and the risk for death (Brown et al., 2015). Family members of patients in the ICU environment experience stress, anxiety, and posttraumatic stress disorder (Davidson et al., 2012; Paul & Finney, 2015; Schmidt & Azoulay, 2012). This experience can be overwhelming for the patient as well as their family members. Complex situations, such as an ICU setting, require timely problem solving for both the patient and for the healthcare system (Grant & Toh, 2017). Social workers in ICU settings often meet, interact, establish therapeutic rapport with, and demonstrate empathy towards patients and family members throughout the patients' entire hospital stay. However, social workers have not consistently been included in essential psychosocial discussions related to end-of-life.

In this action research project, I used qualitative methods with focus groups to explore the barriers that prevent social workers' consistent inclusion in end-of-life discussion in the ICU setting. Additionally, I explored social workers' perspectives on inclusion and how they perceive their role in end-of-life discussions in the ICU setting. Section 2 covers the action research design and data collection. In this section, the research design, methodology, data analysis, and ethical procedures were addressed.

Research Design

In this action research project, I used qualitative research methods with focus groups to gain an in-depth understanding of how social workers perceive their role in end-of-life care in an ICU setting and what the barriers and factors are that may impede them from being involved in providing care. To create consistency in the profession for how end-of-life care is delivered in the ICU setting, it was important to conduct this study to gain an understanding of how social workers approach their work when administering end-of-life care, their various roles and responsibilities, and their interactions with the multidisciplinary team, patients, and family members of the ICU.

Action research is a research paradigm that allows for flexibility, involves the stakeholders in the organization being researched, and provides an opportunity to bring about change at the same time (Paul, 2016; Thiollent, 2011). According to Berg, Lune, and Lune (2012), “action research can be defined as a kind of collective self-reflective enquiry undertaken by participants in social relationship with one another in order to improve some condition or situation with which they are involved” (p. 259). This action research study was important to conduct because there are barriers to social worker consistent inclusion in end-of-life discussions in ICU settings that need to be addressed.

Focus groups are used to gather opinions to gain a better understanding of how people feel or think about an issue, idea, or service (Krueger & Casey, 2014). Focus groups provide a social context for research and offer an opportunity to explore how participants think or speak about a topic (Ritchie, Lewis, Nicholls, & Ormston, 2013). Focus groups are valuable when in-depth information is needed about how people think about an issue, their reasoning about why things are as they are, and why they hold the views they do (Laws, Harper, Jones & Marcus, 2013). Focus groups also allow participants to hear from others, and according to Ritchie et al. (2013), provide an opportunity for reflection and refinement that can deepen participants' insights into their own circumstances, attitudes, or behaviors. A focus group is a unique type of group in terms of size, purpose, procedures, and composition (Krueger & Casey, 2014). They can be formal or informal gatherings of a varied group of people who may not know each other, but who might be thought to have a shared interest, concern, or experience in issues (Bell, 2014).

Although surveys are an effective tool to use when conducting research, they have close-ended or multiple-choice questions, offering little opportunity for elaboration. This would not be appropriate for this exploratory action research project. Conducting focus groups for this action research project was more appropriate than any other method because the focus groups offer the flexibility to dive deeper into issues that came up during the discussion (Ritchie et al., 2013). Focus groups allow the collection and analysis of three complementary forms of data: individual and group level data and data generated based on participant interaction (Onwuegbuzie, Dickson, Leech, & Zoran, 2009). This feature allowed me an opportunity to explore multiple units of analysis to understand the research questions. Ritchie et al. (2013) also noted that the use of focus groups offers an opportunity to uncover ideas and issues that may not have been previously considered but are important to the study and allows for spontaneous discussion of topics that may otherwise go unaddressed in other methods of data collections, such as individual interviews. Focus groups provide data more quickly and at a lower cost than if participants are interviewed separately and groups can be assembled on shorter notice than for a more systematic survey (Bell, 2014). Lastly, the use of focus groups for this action research project allowed participants to provide feedback in their own words and voices.

A qualitative study permitted an in-depth exploration of this topic, drew attention to barriers social workers face when providing end-of-life care in the ICU setting, and allowed an opportunity to highlight what social workers should be doing and what they actually are doing. Action research and the use of qualitative methods with focus groups was appropriate for this research because I wished to improve understanding, uncover problems, and identify solutions to why social workers are not consistently included in end-of-life discussions.

Key Concepts

Barriers: Obstacles or actions that block or impede social workers from being included (Blom et al., 2013; Flannery et al., 2016; Kissane et al., 2012; Kramer, 2013; Nørgaard et al., 2012).

Interconnectedness: The interconnectedness and interactions among elements of the large hospital system, its hierarchical structure, and interconnectedness to hospital social workers when having end-of-life discussions impacts the stability of the system (Capra 1996; Cilliers, 2005; Haynes, 2015; Klein, 1984; Okpala, ,2014; Urquhart et al., 2015).

Social worker role: A professional who uses social theories to understand human problems to help improve individuals lives and society as a whole and is available to assist with a broad range of issues, including psychological, health, financial, relationship, and other problems as defined by their setting (Bathgate, 2016; Beder, 2013).

Self-organizing: According to the concepts of complexity theory, rather than troubleshoot problems, organizations solve problems by trusting workers to self-organize and function by bringing their organizations to the edge of chaos as a solution to solving problems (Grobman, 2005).

Methodology

Participants

The Florida Department of Health, Florida Board of Clinical Social Work, Marriage & Family Therapy and Mental Health Counseling website was accessed on April 2, 2018. Using the tab for license lookup, a search was conducted to identify all social workers in the State of Florida. This list was further sorted to identify social workers in a specific county. Social workers on the list noted to be deceased, retired, or having a license that was null/void were eliminated from the list. Social workers who listed a practice location that was the focus of this study were then identified as potential participants for this action research project. An invitation letter was mailed to 63 social workers employed at this particular hospital, requesting their participation in the action research project focus group.

The social workers were given a deadline to respond by phone call and/or e-mail informing of their intention to participate or not. In all, 22 potential participants responded. The participants' e-mail address was collected at the time they responded to the letter. All of the participants who respond were then e-mailed a demographic and information worksheet, informed consent documents that also contained information regarding the nature of the study, and the time commitment requested from the participants. Each of the participants were preassigned a participant number, which was noted on the top of each form so that each participant could be identified. The demographic and information worksheet included a request for information regarding the number of years the participant had been a social worker and their years of experience in an ICU setting. The participants were asked to return these documents by April 20, 2018. From the social workers who returned the demographic and information worksheet and signed informed consent form, using purposive sampling, I chose 17 participants who the criteria to participate in this action research study. Purposive sampling is commonly used in qualitative research, and it involves selecting research participants according to the needs of the study (Glaser, Strauss, & Strutzel, 1968). Using this method, researchers select participants who provide information that is appropriate for detailed research (Patton, 2005). This method also allows the researcher to make discoveries and identify patterns and causal mechanisms that do not draw time and contest-free assumption (Palinkas et al., 2016).

Once social workers returned their demographic and information worksheets and signed informed consent forms, the selected participants documents were reviewed and placed in numerical order based on the number of years they had worked as a social worker. Because all social workers in this hospital were presumed to have hospital and/or ICU experience, the initial selection of participants was based on the number of years the clinical social worker had worked in the hospital setting. Approximately 1 week after the established deadline to respond, the minimum number of participants was met. Therefore, snowball sampling was not used for this study.

Morrow (2005) stated that there is not an exact number of participants to fit a qualitative study; rather, data should be collected until saturation is reached. However, an average of eight to 10 participants per group is ideal (Morrow, 2005). Once the designated predetermined deadline for participants to respond had passed, 22 participants had responded as potential participants. Two of the participants who initially responded to the invitation letter did not meet the inclusion criteria to participate in this action research project due to the number of years they had worked as a clinical social worker. In addition, three other potential participants who initially expressed an interest in participating by responding to the invitation letter did not respond to the demographic and information worksheet and informed consent. Ultimately, 17 participants were purposely selected to participate in this action research project.

The 17 participants were then assigned to one of four focus groups, where the same questions were asked in each group (See Appendix). An attempt was made to ensure the size of the groups had equal numbers with the first criteria being based on the participant’s availability. However, the size of the groups had to be adjusted with some groups having more participants than others based on the group size. The next criteria for sorting participants into groups was based on the unit where the social worker primarily worked. Sorting based on assigned work unit was important in order to understand how the social worker had integrated end-of-life care into practice and his or her understanding and balance of the different responsibilities as a medical social worker.

Although I focused on adult ICU settings, social workers from both the neonatal and pediatric settings were included in the sample. Although social workers work primarily in assigned settings, social workers are often called upon and are expected to fulfill duties in both adult and pediatric settings when needed on weekends, holidays, and after hours on-call. Social workers who worked on similar units were not placed in the same group, as to create diversity in each group. This inclusion criteria were clarified by the participant’s answers on the demographic and information worksheet that asked about how much of the social workers daily work involved working in the ICU setting and other related questions contained on the demographic and information worksheet.

Instrumentation

Self-designed, open-ended questions that were designed to be used in a focus group setting were used to explore how the social workers perceived their role in providing end-of-life care in the ICU setting and the factors that hindered their ability to provide that care. In addition, complexity theory was used as a guide in the development of the focus group interview questions as noted in the Appendix. The questionnaire that consisted of 36 questions was developed out of the existing literature using concepts and themes based on the known barriers and roles identified in social work practice for end-of-life care and complexity theory. The questions were organized to address the social worker as an individual, then the social worker as part of a multidisciplinary team, and a as part of the department in this hospital.

The topics covered within the sections included the social workers' perception of end-of-life care in the ICU, their perceived roles in the ICU setting, factors or barriers that impede their consistent inclusion in end-of-life care in the ICU setting, the social workers' interactions with the multidisciplinary team, how the hospital influences the social worker role in this setting, potential ethical dilemmas that arise in the ICU, and the social workers' satisfaction with their role in the ICU. The focus groups were semistructured in that key questions were asked that helped the social workers discuss the areas to be explored but allowed an opportunity to diverge in order to pursue an idea or response in more detail. Additional questions were posed during the focus group in order to explore context and meaning of reflections, experiences, or comments that were verbalized. Social workers experiences from ICU settings outside of their current employment were not considered for this study, and this was clarified at the beginning of each of the focus group sessions. The participants were not given a copy of the questions prior to the focus group session. As the facilitator, I asked the same questions in each group.

Validity or the ability of an instrument to measure what it is intended to measure is important to qualitative research (Heale & Twycross, 2015). To test the credibility and dependability of the self-designed questionnaire, the questions from the questionnaire that were asked in the focus groups were initially field tested prior to the first scheduled focus group, by using sample questions with two social workers who were employed as medical social workers at the facility that was the focus of this study. These two social workers selected were the two clinical social workers who were not selected for the study and were identified at the time the demographic and information worksheet were returned. I wished to ensure that the questions were clear and understandable and capable of answering the research questions. Other purposes for the field test were to assess the need for changes to the questions or the need for additional questions to be added for use throughout the study and to ensure that the data from the questions were valid and reliable. Some of the questions were asked in more than one way to assess internal consistency. Acceptability was determined by asking the two field testers how they found answering the questionnaire during the validity testing. This process helped identify main issues and form the basis of the type of questions to be used in the action research project.

Existing Data

No existing data were used for this action research project exploring the barriers to the consistent inclusion of social workers in end-of-life discussions and how social workers perceive their role in adult ICU settings.

Data Collection Procedures

To make participation convenient, the focus groups took place using conference call software and were scheduled at a date/time outside of each of the social workers' scheduled work hours. Prior to the focus group, the participants were provided with a phone number to call at the designated date and time of their assigned focus group. The participants were also provided with the pin number to use when they called in so that they could join the conference call. The focus groups were scheduled to last for approximately 2 hours. However, the average time of each focus group was 1 ½ hours, depending on the amount of information the participants wished to share regarding their experiences with end-of-life care. The same questions were asked in each of the focus groups. When necessary, additional questions were posed during the focus group in order to explore context and meaning of reflections, experiences, or comments that were verbalized. Upon receipt and review of the completed demographic and information worksheet, and prior to scheduling the first focus groups, the participants were organized and assigned to one of four focus groups based on the information obtained on the demographic and information worksheet and the participants' availability. The participants who were selected for the study were preassigned numbers, which were noted at the top of each demographic and information worksheet. Before the start of each focus group, the participants were e-mailed their assigned number as a reminder and asked to announce their number prior to answering questions during the focus group. This method assisted in identifying which participant provided particular information during the transcription process and to maintain anonymity. The focus groups were audio recorded, and the questions were asked based on the format of how they were noted on the self-designed questionnaire (See Appendix). During the focus groups, participants were asked to discuss and explain how they perceived their role as social worker in end-of-life discussions and barriers that may impede social work inclusion on a consistent basis. Open-ended, semistructured questions that allowed the participants the opportunity to share their individual perceptions about social worker role were used (See Appendix). Additionally, a more directive style of questioning was used as needed when more clarification of information that the participants was providing needed further explanation. Additional subquestions noted as probes were also used as needed.

The participants were then asked to describe the role they play with patients and family members at end-of-life, and their interactions with the other multidisciplinary team members in the ICU setting. The participants were also asked to share how they felt their practice could be improved. The participants were not asked to discuss specific details or disclose identifying information on any patient, family members or members of the multidisciplinary team. Nor were they sked to share any personal experiences with death or end-of-life care.

Data Analysis

Thematic analysis was employed to analyze the data. According to Aronson (1994, p.1), this method focuses on distinguishable themes and patterns of living and/or behavior, beginning with the collection of data, writing memos, connecting the memos to the data, coding the interviews into themes and sub-themes, using deductive and inductive coding, and connecting the data to the existing literature. In relation to the research question regarding why social workers are not consistently included in end-of-life discussions in the ICU and their perceived roles in those settings, relevant information was captured from the participants about the barriers social workers identified during their current employment. The information collected on the demographic and information worksheet was used solely for the purpose of organizing the focus groups based on experience and specific ICU assignment, so that the groups were equally distributed and representative of the sample group. The focus group sessions were transcribed by a third-party transcription service, and then an inductive approach was used to identify “patterns in the data by means of thematic codes” and the categories and themes emerged from the data (Bowen, 2005, p. 217). The transcriptions were checked against the audio recordings for accuracy. The patterns across data sets that provided important passages of text linked by common themes, was relevant to the specific research questions and offered a description of this phenomena was coded and indexed into categories. Coding of the data was conducted using qualitative data analysis software.

To ensure the credibility and rigor of this research various methods such as an audit trail, member checking, and engagement in reflexivity was used to ensure the trustworthiness and dependability of the results. To begin, the data was triangulated. Triangulation is a method of validation that allows the researcher to be more confident of the study findings (Bowen, 2005). Two colleagues who were not selected for the study independently reviewed one transcript using the same level of thematic analysis of the transcriptions and then codes were reviewed for similarities. The results were then compared to determine themes that were agreed and disagreed on and then a consensus was reached. Notes of the research process were kept, including how the participants were recruited, and the codes and memos developed, as the data was coded and analyzed. The latest version of NVIVO 12 Pro qualitative software was then used to organize and manage the codes developed.

Member checking was another important element used to ensure the credibility of the research. Member checking is significant when the researcher is an ‘insider’ with respect to the culture being investigated or is familiar with the phenomenon of inquiry (Morrow, 2005). A clear audit trail and member checking support the process of reflexivity, through ‘monitoring of self’ and being ‘rigorously subjective.’ (Morrow, 2005). Throughout the focus groups, the participants were asked for clarification and the participants were engaged in providing a deeper meaning and explanation from the questions asked while I maintained a neutral stance on the topic (Morrow, 2005). Notes and codes were taken surrounding the evaluative process of the findings, to identify any personal biases I had. These strategies for managing subjectivity assisted in achieving the goal of fairness and identifying personal biases. These strategies also allowed me to limit the degree of skewed or lopsided interpretations based on those biases.

Ethical Procedures

According to Walden University Center for Research Support (n.d.), no part of the research process involving participants may take place before IRB approval. I did not engage in research activities with the participants before obtaining IRB approval. The proposal for this action research study was submitted and approved by the Institutional Review Board before any participants were contacted or data collected. I obtained approval from the Walden University Internal Review Board (IRB) on March 29, 2018 (approval number 03-29-18-0278860). The participants gave written consent had full disclosure about the project before any commitment to participate took place. I also ensured that I reviewed informed consent and disclosed participant’s rights and any risks of harm of the study at the start of each focus group.

As part of a focus group, the participants were asked open ended questions that allowed them an opportunity to describe the role they played with patients and family members at end-of-life and their interactions with the other multidisciplinary team members in the ICU setting. The questions also allowed the participants an opportunity to share how they felt their practice could be improved. To provide research participants the safest environment possible, the researcher must have an understanding and ability to apply ethical theories to their situations (Smith, 1995). Researchers should always remember their ethical responsibility to participants. Smith (1995) stated that researchers are obligated to ensure that participants in studies are not harmed physically or psychologically by research (Smith, 1995).

One ethical consideration as a researcher using focus groups was the potential of over disclosure by the participants particularly if the research topic is sensitive. Participants were asked to reveal things that could possibly impact them later. In the event that participants experienced any psychological distress or discomfort while participating in this action research study, I provided resources for free mental health providers in their area, included on the informed consent document. Another ethical consideration was to protect participants privacy in final reporting. I removed personal identifiable information from quotes, if there was a possibility the participant could be identified by the information they shared. Participants were made aware they were part of a research process in advance and, what exactly what was being studied, and agreed to participate by signing informed consents (via e-mail) prior to the start of the study.

At the start of each focus group participants were informed of the ethical principles including anonymity and confidentiality. A copy of the informed consent form was e-mailed to each participant prior to the first focus group meeting. The participants were reminded that they could leave the study at any time for any reason and should simply notify the researcher if they wish to do so. The focus group information and transcription has been and will continue to be stored in a locked cabinet in my secure home office. Data from this action research project will be kept for a period of at least 5 years, as required by the Walden University's IRB.

To address specific concerns that could be uncomfortable related to the discussion of how a social worker feels about providing end-of-life care in the ICU, participants were educated from the beginning of the focus group. Participants were informed that this research is an exploration into how ICU social workers in general perceive their roles in providing end-of-life care and not an evaluation or judgment of their skills as an ICU social worker. In addition to the participant signing a consent form prior to the recorded interview, they were asked to provide contact information in case clarification was needed or the participant needed support services at the conclusion of the focus group, in the event that involvement in this action research project created discomfort or emotional responses related to the subject matter dealing with end-of-life discussion and recalling distressing events. At the conclusion of the study and after all focus groups had been held, all participants selected for the focus groups were compensated with a $20 Visa gift card for their participation.

As a researcher, I am biased towards the consistent inclusion of social work intervention and them being crucial to providing end-of-life care. My professional experiences as a clinical social worker have allowed me to see the importance of having an ICU social worker work with the ICU multidisciplinary team to provide the best possible patient care. The benefits of such teamwork are profound for the patient and their family. In particular with the work of the social worker, the team provides consistent information, time to process the information, and support throughout the patient's stay in the ICU. Patients and families need an advocate on the medical team who understands the factors guiding their decision making, which are typically cultural, religious, and environmental. As the social worker on the multidisciplinary ICU team, I challenge the other physicians and nurses to understand and respect the cultural, religious and ethnic differences of patients, and to provide care sensitive to the patient's wishes.

Summary

Qualitative research methods using focus groups to collect data using a semi-structured self-designed questionnaire was used for this action research project. Data was collected from audio recordings of four focus groups that included a total of seventeen participants with four to five participants in each group. Self-designed, open-ended questions were asked. The data was then coded, organized and categorized so that key or common themes could be noted. Two clinical social workers not selected for this study was asked to independently review one transcript using the same level of thematic analysis of the transcriptions and then codes were reviewed for similarities. The results were then compared to determine themes that were agreed and disagreed on and then a consensus was reached. Notes of the research process were kept, including how the participants were recruited, and the codes and memos developed, as the data was coded and analyzed. Qualitative data analysis software was used to organize and manage the codes developed.

Section Two Summary

Section two of the capstone research project related to the exploration of barriers to the consistent inclusion of social workers in end-of-life discussions and the perceived role of social workers in the adult ICU settings, provided an explanation of the research design and the rationale for how this research aligned with the approach used in this study. Operational definitions of key aspects of the doctoral project were clarified and the methodology related to the participants and the strategies for identifying and recruiting discussed. The instrumentation, tools and techniques used to collect the data, and data analysis were covered in this section, and concluded by explaining ethical procedures employed to ensure ethical protection of participants.

Section three provides a bridge to connect it to section two by offering an analysis of the data techniques and the presentation of the findings. Once the data was collected, barriers and perceptions were defined, with a goal of this action research project leading to positive social change by the proposal of a process that will consistently include social workers in end-of-life discussions in ICU settings. Ultimately, the hope is that this discovery will close the gap between, dying patients, their family members, social workers and the members of the multidisciplinary team.

Section 3: Analysis of the Findings

The purpose of this qualitative, action research study was to explore the barriers that prevent clinical social workers from being consistently included in end-of-life discussions in a hospital ICU setting and to explore how clinical social workers perceive their roles in end-of-life discussions in the hospital ICU setting. The two foundational research questions guiding this project were

1. What are the barriers that impede social workers from inclusion in end-of-life discussions on a consistent basis in ICU settings?
2. How do social workers in ICUs perceive their roles as social workers when having end-of-life discussions with patients and their families?

These research questions provided an opportunity to gather information provided by clinical social workers related to barriers that exclude them from consistently being included in end-of-life discussions in the ICU setting and their perspective on how they perceived their roles in adult ICU settings in end-of-life discussions. An action research design was used with focus groups employing a self-designed questionnaire to gather information relevant to the study's research questions. The data were collected by facilitating a total of 4 semistructured focus group sessions with 17 purposively selected clinical social workers in the state of Florida who were all employed at a hospital in Florida. The goal of the focus groups was to explore perceived barriers that prevented consistent social worker inclusion and the perceived role social workers feel they play when having end-of-life discussions.

Each focus group was asked the exact 36 questions noted on the self-designed questionnaire (See Appendix). Responses to questions asked in each focus group were open ended, and when additional clarification of information was required, a more directive style of questioning was used as needed, including subquestions noted as probes. The first focus group was held on May 6, 2018, consisted of 5 participants, and lasted for 1 hour and 20 minutes. The second focus group was held on May 7, 2018, consisted of 4 participants, and lasted for 1 hour and 22 minutes. Focus Group 3 was held on May 8, 2018, consisted of 4 participants, and lasted for 1 hour and 35 minutes. The fourth and final focus group was held on May 12, 2018, consisted of 4 participants, and lasted for 1 hour and 30 minutes. Participants in each of the o focus groups described their experiences and presented their perspectives on the clinical social work issue.

The focus group sessions were documented using digital audio-recording on freeconferencecall.com. Using a reflexive journal, I documented my personal thoughts regarding the research process and information presented in each of the focus groups. The information collected from the participants, exclusively by me, revealed common themes across study participants and groups, which were sorted and organized using qualitative data analysis software. The use of a reflexive journal improved the data collection process, data analysis, identification of codes, and rigor of the study as this technique allowed me to make my experiences, feelings, and opinions visible and an acknowledged part of the research process.

The following section includes a brief introduction, a description of the data analysis techniques used in this research project, and an explanation of the validation and legitimation processes used throughout this action research project. The qualitative findings that were gathered from study participants and organized according to common themes will be summarized as well as how they answer the overarching research questions. Lastly, learning points, findings that impact social work practice, and recommended solutions to address the clinical social work practice problem will be presented.

Data Analysis Techniques

This action research project was conducted between April 02, 2018 and May 12, 2018. Prior to the first scheduled online focus group, 2 social workers who were not selected as participants for this study field tested the 36 questions on the self-designed questionnaire (See Appendix). I facilitated four focus group sessions with a total of 17 clinical social workers to explore barriers that impeded their consistent inclusion in end-of-life discussions and to gain an understanding of the perceptions that clinical social workers had of their roles in end-of-life discussions in the hospital ICU setting. The Florida Department of Health, Florida Board of Clinical Social Work, Marriage & Family Therapy and Mental Health Counseling website was accessed and narrowed down to the county and hospital location identified for the focus of this study. After deleting the names of social workers noted to be deceased, retired, or having a license that was null/void were eliminated, 63 clinical social workers were identified as potential participants for this action research study. Invitation letters were mailed out to the 63 potential participants on April 2, 2018 with a request that they respond by April 20, 2018 indicating their interest in participating in this qualitative action research study and to provide their e-mail address for future correspondence. Twenty-two of the 63 clinical social workers responded by the deadline and expressed an interest in participating in this qualitative action research study.

Between April 21 and April 24, 2018, 22 participants who responded to the invitation letter were then e-mailed a demographic and information worksheet and informed consent document. All of the documents sent out to participants included a preassigned focus group member number in the upper right-hand corner of the documents. The information requested on the demographic and information worksheet was used for the purposes of organizing the focus groups based on experience and ICU assignment, so that the groups were equally distributed and representative of the sample group. The information requested on this document pertained to the number of years the participant has been a clinical social worker, the assigned area the clinical social worker primarily worked in, and the number of years of experience in both the hospital and ICU settings. The informed consent contained information regarding the nature and purpose of the study and the time commitment each participant was asked to provide. Participants were asked to return the demographic and information worksheet and respond to me via e-mail “I consent” to indicate their consent to participate in this study within 2 weeks.

Two of the participants who returned their completed demographic and information worksheet and based on the information provided did not meet the criteria for inclusion in the study as they had worked as a clinical social worker for less than a year. These individuals were advised by e-mail of the same. However, these two clinical social workers who did not meet inclusion criteria for this study were contacted later and asked to independently review 1 transcript using thematic analysis to analyze and code the transcriptions so that they could be compared. Three other potential participants who had previously responded to the invitation letter and expressed an interest in participating did not respond to the demographic and information worksheet and informed consent. Ultimately, 17 of the 22 participants who initially responded to the letter of invitation met criteria and were purposefully selected to participate in this action research study resulting in seventeen participants. The 17 participants were divided into four online focus groups based on their experience and the date and time of their availability. The confidentiality agreement was signed and returned from a regional third party transcription company on April 27, 2018.

Qualitative online focus groups with clinical social workers who worked in the hospital and ICU setting revealed a variety of themes faced by clinical social workers related to barriers that prevented them from consistently being included in end-of-life discussion and perceptions of how clinical social workers viewed their roles in end-of-life discussions. Several themes emerged to explain the perceived barriers to social work inclusion and the perceived roles of social workers in end-of-life discussions in the ICU setting. Themes related to perceived barriers were the ICU setting being chaotic, complex, and unpredictable. Themes related to perceived social work roles in end-of-life discussions in adult ICU settings were related to role ambiguity and lack of social work confidence to perform expected roles.

Each of the 17 participants were sorted into one of four online focus groups for this qualitative action research project based on their experience and their date and time of availability. All study participants were clinical social workers who worked in a Florida hospital for a minimum of 1 year, and who had experience in the ICU setting, and had taken part in end-of-life discussions. Each study participant was identified, and data from their demographic and information worksheet were sorted numerically by their preassigned focus group member number based on the number they were assigned when the 63 participants were initially identified. The participants were then reassigned participant numbers beginning with P1 through P17. The participants were sorted based on information gathered from their demographic and information worksheets according to their years of experience and availability and were then assigned to one of four focus groups. Focus Group Number 1 included five participants, and Focus Groups Number 2, 3, and 4 all included four participants each for a total of 17 participants.

The focus group interview data were collected using an audio digital recorder on freeconferencecall.com. On the assigned date and time of the participants’ scheduled focus group, each participant dialed the online focus group number he or she had been provided with and entered the access code to join the group. Once all of the participants signed in, the online focus group began, and a script was read that provided an introduction of the study, purpose of the study, and reason why the participants were recruited. The participants were also reminded to use their preassigned focus group member number that was documented on all the documents mailed to them. The participants used their preassigned focus group member number to announce themselves when they signed in and each time they responded to questions asked during the duration of the focus group.

I facilitated four focus group sessions using a self-designed questionnaire (See Appendix) consisting of 36 questions. The same 36 questions were asked in each of the four online focus groups. The first online focus group was held on May 6, 2018, consisted of five participants, and lasted 1 hour, 23 minutes, and 33 seconds. The second online focus group was held on May 7, 2018, consisted of four participants, and lasted for 1 hour, 22 minutes, and 19 seconds (Table 1). Online Focus Group 3 was held on May 8, 2018, consisted of four participants, and lasted for 1 hour, 35 minutes, and 40 seconds, and the fourth online focus group was held on May 12, 2018, consisted of four participants, and lasted for 1 hour, 30 minutes, and 39 seconds.

Following each focus group, the audio digital recording was accessed and transcribed by a regional third party transcription service. Once the transcripts from the four focus groups were returned from the transcription company, I read over each of them while simultaneously listening to the audio recordings to ensure they had been transcribed accurately. Few corrections were needed but were made at that time. I read through the transcripts several times before the coding process began in order to become more familiar with all aspects of the data. After the focus group, data were transcribed and reviewed, the transcripts were uploaded to Nvivo 12 Pro Software where it was sorted and organized, and themes associated with the data of each participant and group were identified. The information collected from the demographic and information worksheets was uploaded as a Microsoft Excel document, and the participants' information was coded to note educational degrees, how long the participant had been a social worker, the number of years the participant had worked as a hospital social worker,

, license length, the ICU where the participant worked, and the percentage of work involving end-of-life care daily and weekly. The two clinical social workers not selected for this study were asked to independently review one transcript using thematic analysis to analyze and code the transcriptions so that they could be compared. One of the reviewers reviewed focus group Transcript 1 and the other reviewed focus group Transcript 4.

Thematic analysis coding technique was used to analyze the data collected for this action research project. Thematic analysis, which is one of the most common forms of data analysis in qualitative studies, identifies themes and patterns related to living and/or behavior (Aronson, 1994). According to Braun and Clarke (2006), this method of data analysis stresses pinpointing, examining, and recording patterns that are also known as themes. The data analysis procedures used in this qualitative action research study included the use of coding and word frequency queries using Nvivo 12 Pro qualitative data analysis software. Thematic analysis served as a useful method for examining the perspective of each of the various research participants, highlighting similarities and differences and generating unanticipated insights. An inductive approach was employed to identify “patterns in the data by means of thematic codes” with themes emerging from the data (Bowen, 2005, p. 217). Once the transcripts were checked for accuracy, the patterns across data sets that provided passages of text linked by common themes, relevant to the research questions and phrases that offered a description of this phenomena, was coded using Nvivo 12 Pro software and indexed into categories.

Validation and Legitimation Process

The latest version of Nvivo 12 Pro software was used to organize and manage the codes that came from the collection of the data. As the data were analyzed and coded, comprehensive notes of the research process were kept, including how the participants were recruited and how the codes and memos were developed. To ensure the credibility and rigor of this research, various methods were employed including an audit trail, peer debriefing, field testing, and member checking to ensure the trustworthiness and dependability of the results. Data triangulation was used across the four focus groups, and reflexivity was used throughout the data collection and analysis processes. Bowen (2005) stated, “Triangulation is a means of corroboration, which allows the researcher to be more confident of the study conclusions” (p. 215).

At the beginning of the research, notes were made on what was expected to be obtained from the research. Those notes were revisited at the conclusion of the data analysis, and any unexpected findings were documented at that time. After each of the four focus groups, a reflexive journal was used to jot down notes and document my personal thoughts and questions that I would later discuss with my chair. According to Stringer (2007), the purpose of reflexive journaling is to document the research process and generate self-awareness against possible biases of the researcher and to ensure transferability and confirmability of the research process. E-mail correspondence as needed and weekly phone conferences with my chair were also employed to make inquiries and address any questions or concerns that arose throughout the data collection and analysis processes. The most important themes and the most noteworthy quotes were noted. These processes improved the way the data were collected and analyzed by better informing and focusing questions and probes in subsequent focus groups.

Field Testing

Prior to the first scheduled online focus group, two social workers who were not selected as participants for this study, due to the length of time they have worked as a social worker in the ICU setting, reviewed or field tested the 36 questions on the self-designed questionnaire (See Appendix). Field testing was necessary to ensure the questions being asked in the online focus groups were clear and comprehensible and capable of answering the research questions for this action research study. The field testing also served as a means to assess the need for changes to the questions or the need for additional questions to be added for use throughout the study prior to the first group. Acceptability was determined by asking the two field testers how they found answering the questionnaire during the validity testing. This process helped in identifying main issues and formed the basis of the type of questions to be used in the action research project. Notes for this process were taken, and questions were arranged based on the feedback. However, based on the feedback, none of the wording contained in the questions was changed.

Peer Debriefing

The two colleagues who were not selected for this action research study independently reviewed one transcript using the same level of thematic analysis of the transcriptions, and then themes and codes were reviewed for similarities. The purpose of peer debriefing was for these two individuals to ensure the collection of valid information and to help me become more aware of views regarding the data. The results were compared to determine themes that were consistent or different. These two individuals also checked for under or over emphasized points, under emphasized points, vague descriptions, general errors in the data, and biases or assumptions that I made

Member Checking

Since misinterpreted or incorrect data could undermine the research, member checking was also used. Member checking is an important technique used to ensure the credibility of the research. According to Morrow (2005) when a researcher is an 'insider' regarding the phenomena being explored member checking is significant. Throughout the focus groups, the participants were routinely asked to clarify responses. Additional sub-questions noted as probes were also used to clarify the understanding of participant responses as needed. This process provided an opportunity for participants to offer additional information, correct errors and challenge what may be perceived as incorrect interpretations.

Audit Trail

Having an audit trail that is clear and utilizing member checking support the process of reflexivity, which causes a research to self-monitor remain subjective (Morrow, 2005). Notes and codes were taken surrounding the evaluative process of the findings, to identify any personal biases. A transparent description of the research steps taken from the beginning of this project to the development and reporting of the findings was employed. These strategies helped in maintaining fairness and identifying personal biases that would otherwise cause skewed or uneven interpretations based on those personal biases (Morrow, 2005).

The use of an online focus group was intended to generate knowledge grounded in the experiences of clinical social workers. The online focus group participants provided an opportunity to freely share and compare their experiences with each other, develop and generate ideas and explore issues of shared importance in their own words. There was no reason to believe that the participants were not being truthful in their responses. Through these methods I was able to make reliable comparisons between the focus group participants as well as the individual units where they work, to get an institution-wide perspective based on clinical social worker experiences and understand recent changes/developments that have occurred over time. Since I do not work directly with any of the focus group participants I do not feel that my professional relationship with the study participants had any influence on their responses.

To be accepted as trustworthy, qualitative researchers must demonstrate that the data analysis has been conducted in a precise, consistent, and exhaustive manner through recording, systematizing, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible. Limitations to trustworthiness and rigor for this study include me as the researcher coming to the analysis with some prior knowledge of the literature on this topic and possibly having some initial analytic interests or thoughts. However, reflexivity was used whereby there was an awareness of biases and those biases were set aside while the study was being conducted and while analyzing the data (Morrow, 2005). I was able to identify with some of the challenges and barriers other clinical social workers experienced while working in the ICU and participating in end-of-life discussions. As the researcher, I continued to reflect any bias, so I could maintain an awareness and maintain an objective position throughout the study.

Another limitation to trustworthiness and rigor of this study is the lack of diversity of the sample as the participants were purposefully selected. Although the participants for this study worked in varied units within the same hospital, they were all from one hospital setting. While the findings of this project may not specifically pertain to other hospital ICU settings, this presents as a limitation as other hospital ICUs may provide significant information concerning this social work problem. Therefore, the generalizability and transferability of the findings of this study may also be limited. It should be noted that, by personal observation and review of the names on the demographic and information worksheets, I determined that all participants who responded and participated in this action research study were female.

According to Rubin (2000), social desirability is a concern because participants may answer the questions in the online focus group the way they feel the research wants them to or based on how others in the group may have responded. However, attempts were made to minimize this by assigning the participants with pre-assigned numbers and advising the participants that they would be asked to share their experiences and perceptions. Participants were also advised that they would not be asked to discuss specific details or disclose identifying information on any patient, family members or members of the multidisciplinary team. Lastly, participants were assured they would not be asked to share any personal or specific experiences with death or end-of-life discussions.

Findings

The purpose for conducting this action research study was to contribute to positive social change by discovering barriers that may impede social workers from consistently being included in end-of-life discussions and exploring social workers perspective on how they perceive their roles in adult ICU settings in end-of-life discussions. Through data analysis, primary findings emerged to answer the two research questions. As part of an online focus group, the participants in this action research study discussed (a) the ICU environment in a hospital setting, (b) barriers to consistent social work inclusion in end-of-life discussions, (c) communication in the ICU setting, (d) varying structures and processes for each ICU the hospital, (e) undefined and varying roles in social work practice in the hospital and ICU setting, (f) social workers as part of a multidisciplinary team and, (g) education and training for social workers related to end-of-life discussions. The participant-inspired themes and subthemes that emerged are documented under the following two headings: (theme 1) the ICU setting, (theme 2) role ambiguity and (theme 3) lack of confidence to perform expected roles.

Table 1

Study Participants and Focus Groups

Participant #	Focus group assignment	Number of years as Clinical Social Worker	Licensed Clinical Social Worker
P1	1	18 years	No
P2	2	25 years	Yes

P3	4	8 years	Yes
P4	3	1 year 11 months	No
P5	1	2 years	No
P6	1	3 years 5 months	Yes
P7	3	11 years	Yes
P8	3	16 years 2 months	Yes
P9	4	32 years 3 months	Yes
P10	1	1 year 5 months	No
P11	1	18 years	Yes
P12	2	14 years 6 months	Yes
P13	2	28 years 9 months	Yes
P14	4	14 years 4 months	Yes
P15	3	8 years 4 months	Yes
P16	2	8 years	Yes
P17	4	4 years 2 months	Yes

Common Themes

Four online focus groups were conducted with a total of seventeen participants for this qualitative action research study. A self-designed questionnaire which consisted of 36 questions, was used for each of the four groups (See Appendix). The same 36 questions were asked in each of the four focus groups. The participants were asked open ended questions regarding known barriers to the consistent inclusion of social workers in end-of-life discussions and how social workers perceived their roles in end-of-life care.

In addition to the 36 focus group questions, the participants were provided with opportunities to further expound on their responses in the focus group discussion through the use of probing questions.

The questions for the online focus group were organized to address the social worker as an individual, the social worker as part of a multidisciplinary team and lastly as part of the ICU in the hospital where they currently work. The focus group process revealed emergent themes across groups and they will be discussed in the following sections. Upon completion of the action research project, the findings helped to answer the two research questions regarding barriers to social work inclusion and how social workers perceive their roles in end-of-life discussion in the adult ICU setting.

Barriers to Consistent Social Work Inclusion

Theme 1: The ICU Setting

When asked about the barriers social workers experienced or were aware of to the social worker being included consistently in end-of-life care, the primary theme was the ICU setting, as all participants noted the setting created barriers for social workers. The ICU is a setting in the hospital where many decisions are made to stop the escalation of care or to withhold or withdraw treatments that are necessary to keep the patient from dying (Curtis & Rubenfield, 2014; Mark et al., 2015). Patients who are admitted to the ICU have a high risk of death and diagnosis' that prevent them from making their own healthcare decisions (Creutzfeldt et al., 2015). As a specialized unit in the hospital, the patients in the ICU are critically ill with severe and life-threatening illnesses (Modrykamien, 2012; Yang et al., 2015). Also, in this setting, as many as 95% of the patients are incapacitated due to illness or sedation (Curtis & Vincent, 2010; McCormick et al., 2007; Truog et al., 2008).

The ICU setting creates many types of barriers to social worker inclusion. Participants shared that, the critical population of ICU patients, unpredictability of the ICU unit, communication in the ICU setting and inconsistent protocols are factors in the ICU setting that prevent social workers from being included in end-of-life discussions on a consistent basis. The ICU differs from hospice and palliative care settings in that it is more chaotic, complex and unpredictable and not all patients in this setting are facing end-of-life issues, not all patients in the ICU die and not all patients in the ICU die right away (Abuatiqu, 2015; Rodriquez, 2015; Wenham & Pittard, 2009). Both the environment and the situation in the ICU are stressful for the patient and their family members (Blom et al., 2013; Flannery et al., 2016; Kramer, 2013). The complex, chaotic and unpredictable nature of the ICU setting was a shared observation of participants across all four focus groups (Table 2) and was noted frequently as a characterization of the ICU setting and contributor of barriers to social work inclusion.

The ICU is a healthcare delivery system that is relatively an autonomous and unpredictable environment with new and unexpected behaviors that emerge routinely. The incidence of many threshold phenomena and other non-linear cause-effect relationships is another feature of the ICU environment. This description of the ICU setting, as noted by the participants in this study aligns with complexity theory which is the theory that grounds this research study. At several different levels, the ICU exhibits various features characteristic of complex systems. Complex theory offers a novel perspective to help understand the functioning of the hospital ICU. Based on the principles of this theory, complexity theory is a multidisciplinary theory that grew out of systems theory in the 1960’s and examines uncertainty and nonlinearity (Grobman, 2005). This theory is concerned with complex systems and how systems can produce order while simultaneously creating unpredictable system behavior. Complexity theory suggests that rather than troubleshoot problems, organizations solve problems by trusting workers to self-organize and function by bringing their organizations to the edge of chaos as a solution to solving problems (Grobman, 2005).

Unpredictable. While the ICU setting in and of itself was viewed as a barrier to consistent social work inclusion in end-of-life discussions, more specifically, the unpredictability of the adult ICU setting, on various levels, was identified as a common barrier (table 2). One shared barrier identified by all of the participants as to why social workers are not consistently part of end-of-life discussions in the adult ICU setting includes, inconsistent protocols and processes in the ICU for consulting social workers to participate in end-of-life discussions. Throughout the four focus groups all 17 of the participants for this action research study shared that they felt it important that social workers be consistently included in end-of-life discussions, for a variety of reasons. However, depending on the ICU the processes to include social workers in end-of-life discussions is unpredictable as it varies from unit to unit. P17 discussed experiences with learning of end-of-life situations and the end-of-life bundle, which is a protocol utilized by bedside nurses to indicate care has been withdrawn and a patient is at the end-of-life, in the following statement:

> I have covered several ICU's, especially when I worked PRN. There is no protocol. I make it a habit to go to the charge RN when I cover, to find out what is going on with the patients on the unit. Sometimes they will let me know there is an end-of-life situation going on in the unit and other times I will be walking through the unit and see the sign on the patient's door which indicates to me this is an end-of-life situation. At that point, the sign is on the door, which means things are already in progress and I wrestle with approaching the family or not. I think to myself, are they gonna wonder where I have been or why I was not present before and why am I showing up now? I hate not being consulted before these things are decided. That in and of itself makes it stressful. You do not know what to do based on each unit. Each unit varies. There is lots of confusion. No structure.

P1 adds to the unpredictability of processes when sharing lack of knowledge of the process involving the end-of-life bundle to indicate a patient is dying until recently in the following:

> I had no idea what the end-of-life bundle was until recently when I was discussing with a nurse on my unit that I would be taking part in this research and what it was about. I told her how excited I was to learn some things to bring back to my unit about end-of-life. When she mentioned it, the end-of-life bundle, I was like, the what? She then explained how the palliative care team implemented this a long time ago here at the hospital. The person who had this role before me and

> trained me, never told me anything about this. I feel, there are still so many things I do not know. There are so many components. Things are so random.

Having a protocol that consistently consults social worker as part of end-of-life discussions, provides an opportunity for social workers to consistently play an important role in improving family experiences of decision making as well as other aspects of end-of-life care. Each of the 17 participants shared that there is no consistent protocol or process in their specific ICU to include a clinical social worker in an end-of-life discussion. Each ICU has developed their own informal processes and P2 characterized this as follows:

> Depends on the floor. Depends on the unit. It is not consistent. It's hit or miss. The unit, depending on where you go, is different so you are kind of having to figure out what works here and what doesn't. The fact that the units are large and there are so many more patients, it gets more and more convoluted. Lots of confusion and disorder when it comes to this [ICU) setting. Random processes for how we're consulted.

The social worker is one of the only members of the team that has an opportunity to consistently interact with the patient and their family members. Participants suggested that having a protocol to consistently include social workers is beneficial. Participants also, discussed the constant weekly and monthly rotations of providers that occurs in the ICU settings that can shift the goals of patient care based on the provider. P3 suggested that since clinical social workers are constantly and consistently interacting with the patients and their family members throughout the patient's hospital course, there should be a process in place for social workers to be consulted by the physician each time an end-of-life discussion arises and stated:

> I feel like social work is uniquely equipped to sort of gently peel back those layers and kind of look at what all this means. Invite social workers to the table earlier. Put a process in place. They have protocols and order sets to trigger other things on a routine basis. They can do the same thing to always include us. The social worker is able to interact with the patient and their family throughout their entire hospital stay. Even most nurses only work an average of three shifts per week. You just cannot have too much social work in terms of hurting the family by talking to social work. Especially when it is an end-of-life situation. The families need this. The medical teams need this. This would surely cut down on some of the mystery that occurs.

Additionally, P1 went on further and stated:

> I agree. There is no set process that flows over to other units. Many times, the patients and family members are confused, and they don’t really understand. There is so much going on. Each unit is different. So just having a social worker to provide them with that level of clarity and preparing them, really helps a lot. Continuity to always have us there. A process is definitely needed so that we are there at every end-of-life discussion.

According to Beder (2013) and Peres (2016), social workers have training that enables them to interact with and observe individuals in a manner that considers the whole person and therefore, it is a benefit to have social workers involved in all stages of end-of-life planning. Social workers are in a significant position to identify social, cultural and other barriers that impact them from being consistently included in end-of-life decisions. P14 explained that the only way to have a full proof method of consistently including social workers is to have a process and stated:

> I would like to say as a clinical social worker when it comes to end-of-life I think we get to look at the whole person. The person and the environment. We get to include the different dynamics of the family. There should not be inconsistent processes that vary unit to unit. It should be uniform. Not having a process creates confusion when no one knows that is supposed to be happening and who does what.

While all 17 of the participants in this action research study confirmed that there is no formal method, protocol or process in place for them to be included in end-of-life discussions, 4 of the participants (P7, P11, P12 and 16) shared that when available, they are “almost always” included in end-of-life discussions on their primary units. These social workers work primarily in burn ICU, palliative care or pediatric ICU settings. For instance, P7 shared that the location of the social work office on the unit makes the social worker more accessible for inclusion and stated the following:

> My office is right on the unit, so I am easily accessible. That is why I feel I am always included. Sometimes when I am walking on the unit, the nurse or someone from the team will say, something about so and so being withdrawn from care or a meeting is about to take place. If I can I will drop what I am doing to be there. While I am not consulted I am at some point advised, most of the time.

P11 shares being a part of a consult team that always receives social work consults which provides an opportunity to always being informed, but not always included. This participant explains that when the consult team receives a formal consult, the consults are divided and any of the other members of the team, including the physician or ARNP may respond and that is when a social worker is not included and shares:

> I am usually always included. Being on consult team, we are usually consulted for that purpose, end-of-life discussions. The only time when I am not included, is when I am not here, or other members of the team respond. We divide the work amongst the team members so when a consult is received it could be one of a few team members. Not always a social worker. Then it is not a social worker being included. I am the only social worker on my team and the only one who does not rotate in and out. I am consistent. The others rotate so while there is a process for consults or our team, it does not mean a social worker will be included.

The social workers who were routinely included in end-of-life discussions reported that they work in smaller than average hospital units at the hospital, round with their teams regularly or have offices housed in a location that makes the social worker more accessible to the multidisciplinary team members. P16 confirms how rounding regularly with the medical teams is advantageous because it helps alert social work to what is going on and advised in the following:

> I happen to be lucky enough that I am in rounds every day and I can lead the discussion about are we going to discuss end-of-life or palliative care. That is

> when I usually find out about an end-of-life discussion but if it comes up later in the day, I may not know about it.

P12 shared similar sentiments of being consistently included when available because of the size of the unit. However, this participant goes on to further share how providing social work coverage for additional units creates a problem because it takes the social worker off of the unit and there is no formal protocol to alert the social worker of what is going on. P12 shares the following:

> I have a very small unit. I always know what is going on and I am always included when I am there. I have patients and they are with us for a very long time but sometimes when I am covering other units I may miss an end-of-life discussion even when I know about it. There is no process for me to know what is going on back on my unit when I am on another floor covering for another social worker. We do not have a defined process either.

The unpredictability of the social workers workloads and availability to participate in end-of-life discussion creates another barrier to being consistently included in end-of-life discussions. Likewise, in the literature, according to Blom et al. (2013) the workload of social workers assigned to work in the ICU setting creates a barrier to them being included as they are unavailable when the end-of-life discussions take place and they are providing coverage in other areas of the hospital. Many of the participants is this current study shared that they are often assigned to work other units in the hospital, in addition to the ICU they are routinely assigned to work. Participants shared that this leaves them very little time to be involved to extensively in end-of-life discussions, if at all. During discussions about unpredictable workloads contributing to the reasons as to why social workers are not consistently a part of end-of-life discussions, P4 shared staff shortages as a primary reason in the following:

> Not being staffed appropriately. That creates a huge problem. We have to cover for other units which limits the amount of time you can spend in the ICU. I miss end-of-life conversations all the time.

Due to the unpredictability of the social workers' workload, participants suggested from their experiences, there are no clear lines as to what is going on and what is expected. P16 weighed in and explained how excessive caseloads, job assignments and covering social workers out on leave, create a barrier to social work inclusion in end-of-life discussions and stated:

> I can tell you that our shared workload is also a part of it. It's hard to be present when you have no idea where you will be called to cover for someone else. You know when you work multiple floors and multiple units. You miss the opportunity to be a part of the conversation because you're not even in the unit. It seems there are never enough social workers to cover when someone is out or on vacation.

P3 elaborated on the demands a social worker has working in the ICU and the burdens it creates when called upon to cover other areas in the following:

> Very similar. Chronic staffing storages in the hospital often results in me having to carry another unit. At the ICU level we are already stretched very thin and when you add a whole other service that has a very adverse impact on the level of

> care that we can provide the patients and the families. I think that is probably if I could change anything about my role it would be an ability to have a reasonable case load that didn’t result in….sometimes to simply not being able to meet the needs of these patients and families.

P4 contributed to the discussion of staff shortages in the following statement:

> The inconsistencies of not being staffed appropriately all the time does present as a barrier when we are having those end of life discussions and working with those families.

Similarly, some study participants combined the availability of social workers, their working hours and the time of day when family members are available for end-of-life discussions to occur into a single narrative. These participants saw all three as conflicts and shared how these unpredictable dynamics can create a barrier to social worker involvement. P11 discussed social work availability in the following statement:

> I found that some of the barriers currently in my role when I work ICU areas is the patient’s inability to participate. The family’s availability or them being there at the bedside when I am there because I do float all over the hospital. Sometimes I cannot predict where I will be nor how long, I will be there. This causes me to…let’s just say, I miss out on a lot of end-of-life conversations.

According to P6 the working hours that social workers are available, and the time family members are able to come sometimes conflicts, which also creates a barrier and offered the following explanation:

> We work 8:30 in the morning to 4:30 or 5pm and sometimes the only time family is available is after they leave their 9 to 5 job also. The PRN or evening social workers, there are only two of them from 5 to 9pm and they are only here for emergencies that come up, which is not meeting with family members or attending end-of-life meetings. That is a real barrier to inclusion. Availability.

The varying and inconsistent protocols and processes to consult social workers regarding end-of-life discussions also contributes to the unpredictability of the ICU setting. While the literature documents the positive presence of and need for social workers in palliative and hospice care settings, there is a gap in the literature in the last five years that supports the presence of social worker inclusion in end-of-life discussions in ICU settings. When asked specifically about how the participants are notified or get involved in end-of-life discussions in the adult ICU, each participant explained a different process for how they become involved. Participants in this study shared that the way they get involved in end-of-life discussion varies day to day and it is based on the ICU they are working in and the particular medical team that is rotating that week.

Table 2

ICU Setting

Description	References	Word Frequency
complex unit	14 participants	42 references
chaotic unit	15 participants	37 references
unpredictable unit	11 participants	58 references

Complex. The second most frequent descriptor participants in this action research study used to describe the ICU environment was related to the complexity of the unit (Table2). Whether it was related to the complex nature of the patients in the ICU, or the setup of the unit, complexity was commonly discussed as an aspect that creates barriers to social work inclusion. During the focus groups, participants discussed the many components that contribute to making the ICU environment complex.

In ICU settings patients have a higher risk of and occurrence of death (Modrykamien, 2012). Approximately 20% of all deaths in the United States happen in the hospital ICU (Curtis, 2005; Gries et al., 2010). P11 weighed in and offered a description of issues faced by ICU patients and their inability to interact with their family members, the medical team and social worker as follows:

> The patients in the ICU are chronically ill or have a serious chronic illness or the prognosis is very poor and terminal. They [patients] are not able to participate in any aspect of their care. It's all so complex what is needed, and social workers are not always on the top of the list to consult with.

Across all of four focus groups, the participants described and recognized the critical and high acuity level of the patient population in the ICU setting as a contributing barrier to consistent social work inclusion. Due to the critical nature of the patient's unstable medical condition and need for frequent interventions, patients in the ICU setting require constant monitoring and observation. The patient's status fluctuates and necessitates continuous care from multiple medical teams. The medical team members are primarily concerned with providing medical interventions to critically ill patients and consulting the social worker when end-of-life situations arise is not always a principal concern. Whether participants of this action research study work mostly with patients in the pediatric ICU or adult ICU, similar comments expressed by all participants was related to the critical nature of the patients in the ICU setting and how complex the patients are. P5 explained how the patient population in the ICU is seriously ill and shared one of the reasons why the patients in the ICU require closer observation and monitoring and social workers are not consistently consulted in the following:

> The ICU, ratio of staff to patient is smaller because usually the patients are more critically ill than patients in other hospital units so there is usually a set of lenses that need to be on the patient at all times. Their status changes all of the time. The doctors and nurses are trying to save the patients not knowing what may come next. They are not thinking about consulting social workers when the patient declines and now they’re talking end-of-life.

Similarly, P7 shared sentiments regarding the serious nature of the critically ill patients who may be urgently admitted to the ICU and how many specially trained providers are needed to provide care that is oftentimes, complex based on the patients’ medical condition, in the following statement:

> Many patients in the ICU have tragic and sudden declines in health. Their hospitalization is usually unplanned. Because of everything going on, there is not much structure. There are a lot of teams and staff specifically trained to work in the ICU providing care. The medical teams are doing what they need to do to save the patient. While some things in their treatment are uniform, at other times the

> patients' medical condition is a mystery and they are trying to figure things out to help the patient. Nobody is thinking to consult the social worker. They have a different focus. Treating the patient or making them comfortable.

The ICU is a setting designed to care for patients who are seriously ill. Patients and the family members of patients in the ICU face many unique challenges due to the patient's diagnosis of a critical illness or progression of a chronic medical condition and the ICU environment itself (Brown, et al., 2015). Patients are admitted to an ICU with life-threatening conditions and with little warning (Bandari, et al., 2015). P13 discussed the difficulties faced by family members and the critical nature of the patients admitted to the ICU in the following:

> The patients in the ICU are really sick and usually end up there unexpectedly. They are facing critical illnesses and oftentimes the family members do not know if the patient is even going to survive. There are machines and tubes everywhere. The patient does not look like themselves due to the swelling or trauma they have endured from their medical condition. It can be very stress inducing for the family members who have not been through this before. They do not know what to do. There are a lot of emotions. Lots of hysterical crying at times. Sometimes the patient will seemingly make improvements and then take a turn for the worse. This complex setting can be so overwhelming.

Chaotic. As it pertains to interactions with social workers, **c**ommunication was noted to be the most common issue that contributes to chaos in the ICU environment when it comes to social workers being consistently included in end-of-life discussions.

According to Anderson et al., (2015), effective communication between medical providers, patients and their family members in the ICU can fosters feelings of trust with the healthcare providers and can improve family satisfaction in this setting. However, the literature also indicates that communication with medical providers in the ICU is often lacking (Anderson et al., 2015). The literature also documents a chief complaint of family members of families who had family member die in the ICU as communication with 30% of family members reporting feeling dissatisfied with communication in the ICU (Carlson et al., 2015). The same was noted to be true in this action research study.

Inconsistent communication amongst the various team members in the ICU, patients and family members was viewed by participants in this action research project as a contributor to the chaos witnessed in the adult ICU. The inconsistency amongst the various team members about the patient care and a decision to have an end-of-life discussion greatly impacts social workers being included in end-of-life discussions the ICU setting and was characterized as fragmented. P4 stated:

> Communication is a big barrier despite all of the different forms of communications that we have available to us. It is just no one reads, and no one talks. Everyone assumes someone else has told me something I should know about an end-of-life discussion. It's all over the place.

Prevalent contributing factors of chaotic communication included, limited interactions with the medical team members and family members and information coming from various team members which was described as varied and inconsistent amongst members of the medical team. P9 talked about the confusion amongst the team members as it relates to goals of care for patients and how conflicting information communicated to the patients and their family members creates problems in the following:

> Based on the team member interacting with the family, one will say the prognosis of the patient is poor and may or may not contact the social worker for involvement while another team member will come in at a different time and say there is hope the patient will have a full recovery "if we give it more time" and also may or may not consult the social worker. It is so overwhelming and confusing. I wish communication was better. They should all be on the same or similar page when they are speaking with the family or the patient and should communicate with the social worker about what is going on.

According to Finley (2014) active communication between chronically ill patients and the medical team is essential to the patient's overall care. Many social workers in this study spoke of interacting with different members of the medical team and getting varied accounts of what the plan is for the patient as well as what is going on. P3 shared experiences with conflicting information given by the critical medical team, who is concerned about the patient's ventilator and respiratory status and the Neurosurgeon who is concerned about the patient's neurological status in the following:

> You have to have that communication with the entire team when dealing with end-of-life issues. Everybody has to be on board with the communication. Again, it goes back to this is where confusion comes in when there is the lack of communication or the two individuals do not consult with each other and have

> individual conversations with the family members, with no social workers present. The social worker is someone who has the potential to always be present, but they have to know what is going on. You would think the medical team would communicate consistently with the social worker, but they don't. The social worker can at least gather everyone together for a family meeting, so everyone can speak the same language, especially when it comes to end-of-life, but they don't always call us.

Thoughts shared by P3 reflected what is documented in the previous literature regarding the importance of communication in the ICU. P16 echoed similar experiences and went on further to say:

> Communication is so inconsistent in the ICU I work on. With so many teams involved, sometimes I don't even know there is a withdrawal of care or end-of-life situation going on, on my unit until I go out there and see family crying or see a huge family gathered around a particular room and I ask the charge RN or someone else what is going on. Then I have to decide if it will help the family for me to approach say, after the fact. I really wish these things were always communicated to me before they happen. They make things so complicated.

P2 went on further to share the following example:

> I do not feel any of the teams are wrong when they communicate. It's just that inconsistent communication gives a mixed message. For instance, the patient could have strong lungs and heart and be doing well from a respiratory standpoint but neurologically, the patient's brain is so severely damaged from a stroke, brain

> tumor or aneurysm the patient may not make a meaningful recovery or will have a poor quality of life. This adds to the chaos of an already chaotic case and social workers being involved. Communication in the ICU is vital.

The ability to communicate well with professional colleagues, patients and their family members is a fundamental clinical skill in an ICU setting and is key to good medical practice. Poor communication with the members of the medical team, social workers, the patients and their family members, can hinder preparation for a patient who and end-of-life care. According to Gwyther et al. (2005), the social worker can help better prepare the family members of a patient by fostering effective communication between members of the multidisciplinary team, the patient, and their families.

Fourteen of the seventeen participants in this study agreed that the ICU is chaotic, and care being provided can fluctuate based on the needs of the particular patient and what is going on. P9 discussed the fast paced and chaotic nature of the ICU in the following:

> In the ICU there is so much going on. It seems chaotic, like no one knows what is going on, but they do. It just looks that way because of the nature of events going on in the unit. People running around everywhere. Since this is a level one trauma hospital, we get the sickest patients. It is not uncommon to have several medical codes going on at the same time and the medical teams working to save a patient's life. There are always alarms going off. You could be talking to a patient one minute and then the next an alarm goes off because the patient has declined,

> and they [medical team] are providing CPR. It is very chaotic. I sometimes have to just wait to try to figure out what is going on and where I fit in.

During focus group two, P13 recalls feeling bewildered, confused and shocked when discussing experiences of stepping into the hospital ICU setting as a clinical social worker for the first time:

> I can recall the first time I set foot in the ICU, I felt so overwhelmed. I was unsure what I was supposed to do and what everyone was doing. So many unexpected events. Over time, things got clearer, but it is indeed chaos and it appears disorderly. It took forever to understand the roles of the team members. There are many layers and it's hard to predict what a typical day will look like. One day I'm talking with a patient and the next, the patient is on life support. I could not keep all of the players of the medical teams straight.

P5 shared perspective when interacting with family members and the medical team members when they have differing views regarding the treatment of the patient in the following:

> I have had experience with both sides. The team has been on all the same page and has kind of a briefing before the actual family is involved and it runs very smoothly. I have also experience where the team may not want to proceed and not be aggressive with treatment and the family still wants to be aggressive in treatment. Therefore, it kind of creates some chaos. Not usually a large chaos, but usually some form of chaos between the team and when the family wants to

> go aggressively vs. withdrawal of care. Social workers are not thought of because the doctors are consumed with other things.

The information presented to the family members in the ICU about the patient's medical condition is very clinical and many times, family members have difficulty understanding and deciphering the information that has been given to them. P3 offered an overall assessment of the ICU and how the frequent rotation of medical teams can have a negative impact when interacting with patients and family members in the following:

> The ICU is a very, very fast paced environment with a very high death rate. The medical teams rotate so frequently, they do not have a rapport with the patient or family. As someone else stated, I agree, it's chaotic and complex. The NICU is such a fluid unit. I kinda call it controlled chaos, but I guess that's what makes it work.

Due to the complexity of the patient population and set up of the ICU an unpredictability of events that occur in the ICU setting, the ICU is historically known as an environment that, unintentionally creates barriers between patients, their families and the medical team (Efstathiou & Walker, 2014). The ICU setting is also seen as chaotic. In fact, because various disciplines provide care for patients and each discipline is focused on their area of specialty and its professional roles and tasks instead of having a holistic view, researchers have characterized teamwork in ICU settings as disjointed throughout a typical workday (Reeves et al., 2015). Overall, participants see the hospital ICU as one of the most critically functioning operational environments in the hospital. The patients in this environment are seriously ill and unstable and the complexity of this unit is considered high because of the level of care the patients require. The patients require constant monitoring from staff and specialized equipment and the staff to patient ratio is low to reflect this. Every ICU in the hospital has a different and unpredictable environment that is dictated by the specialist medical and surgical procedures for that patient population. However, staff who work in the ICU setting should possess skills and an innate ability to cope with stressful situations in a crisis.

Perceived Role of Social Workers

Participants in this study explained the role of social workers as an advocate, liaison, source of information and referral and support. However, the perceptions of how clinical social workers see their role in end-of-life discussions varies based on the unit the social worker primarily works in as well as the comfort level of the social worker. P11 explained:

> I think that it is very important for the social worker to be there to play the role as an advocate, provide emotional support, just be there. I feel it is a disservice to the patient and the family by not having us there or having a social worker included.

The participants in this action research study shared that some of the roles filled by social workers includes but is not limited to conducting psychosocial assessments, advocacy, and emotional support, education to the patient and patient’s family and discharge planning. When participants were asked specifically about how they perceive their roles in end-of-life discussions in the ICU setting, in addition to the roles listed above, they shared more specific responses including helping patients and their families understand a specific illness, assisting patients and their family members as they work through and process the emotions of a diagnosis and providing emotional support and counseling about decisions that need to be made regarding a patients plan of care.

While research documents the important role that social workers have and should have in participating in end-of-life care in a broad range of contexts, the empirical documentation of their responsibilities and roles in end-of-life care in ICU settings is weak (Kramer, 2013). According to Kramer (2013), the absence of specifically defined social work roles in end-of-life care contributes to role ambiguity and confusion among other members of multidisciplinary teams regarding what the duties and responsibilities of the social worker entail. This was further confirmed by participants in this action research study. When asked about their role as a social worker role in adult ICU settings as it pertains to end-of-life discussions, participants in this study, described the perceptions of their roles as being ambiguous, uncertain and vague. In addition, while all of the participants felt it important for social workers to always be present in end-of-life discussions, the predominant feelings of the participants were that their role is not very well defined, and they do not always feel confident or prepared in their social work role. In addition, there is no clear explanation of what role social workers should play from the ICU social workers, administrators or the multidisciplinary team. These perceptions will be discussed in the following sections.

Theme 2: Role Ambiguity

The ambiguity that exists regarding social work roles in the ICU setting and lack of clarity in the social worker role in end-of-life discussions leads to uncertainty as to what a social worker actually does as it pertains to end-of-life care in the ICU setting.

Specifically, lack of understanding by the medical team regarding the role of the social workers on the multidisciplinary team was also a shared perception of the social worker. P16 discussed how the frequent rotation of the medical team members and social workers themselves not having clearly defined roles further adds to the confusion regarding role ambiguity of the social worker as evidenced in the statement made by P16 in the following:

> I do not feel as though many of them even know what it is we do exactly. To be honest. I guess it doesn't help that social workers serve in different roles throughout the hospital, depending on the unit. Many of them [physicians] do not have a clear understanding and I have to admit that sometimes I do not know myself. I have sort of developed a role based on what I am called on to do and over time that has unofficially become my role. Whether is right or not, I don't know, it works for my unit. When I work with other social workers or cover the unit of other social workers that is when I learn that we're all doing something different.

P15 went on further to explain role ambiguity of the ICU social worker in the following:

> I have to agree with you on that. The physicians in the ICU I work in do not know my role as social worker from the case manager. Some of them rarely even know what we do. They think all we do is get rides for patients, help with discharge medicines and stuff like that because that's what social workers outside the ICU may do.

Many of the study participants also expressed role ambiguity and confusion among other members of multidisciplinary teams regarding what the duties and responsibilities of the social worker entail. They saw their roles as varied, based on where they worked and felt the other members of the multidisciplinary team were not knowledgeable of the skillset of the social worker and what they were capable of. P8 shared how being a social worker on a teaching service results in physicians themselves being unfamiliar with the role of social workers and discussed them being confused in the following:

> Some of the baby docs as I call them, they are so cute trying to be confident but not really knowing what to do. They will many times call me for anything they cannot answer otherwise or just are not sure of.

In addition, participants felt that being in an academic or teaching hospital and frequent rotation of the physicians on the teams contributes to role uncertainty of the ICU social worker. Take for example the statement made by P9 describing feelings and the impact the physicians rotating has on role confusion of the social worker:

> I do not think they know what we do and why we are there. Especially due to the type of facility and unit this is. The physicians rotate so frequently and by the time you feel that they get it, they rotate out and a new batch rotates in, and we have to start all over again, educating them about what it is we do. I can be very frustrating.

P5 discussed working in a unit that requires the social worker to serve in the role as a case manager when they are short and the confusion it causes in the following:

> I know sometimes in my unit when the case manager is out, and I am asked to fill in for the case manager but still work as the social worker, this really confuses the medical team. One day I am doing tasks solely done by a clinical social worker and the next day I am filling in as a case manager. Then we go back to our specific roles and the medical team still comes to me confused about what I am doing and why I don't help them with the same things I helped them with the day before. I'm like, the case manager is back today, and they will handle that.

The literature for the last 5 years notes that health care providers, patients, families and social workers have perceptions that are sometimes inaccurate regarding the role of the social worker when it comes to end-of-life discussions (Bathgate, 2016; Brown & Walter, 2014; Kramer, 2013). The lack of clarification or literature that explains the contribution of the social worker role in end-of-life discussions leads to confusion with the multidisciplinary team members (Kramer, 2013).

Theme 3: Lack of Confidence to Perform Expected Roles

When the topic of the perceptions of ICU social worker roles was discussed in the online focus groups, a common theme that emerged included, lack of confidence on the part of the social worker when called on to participate in discussions related to end-of-life care. 15 of the 17 participants shared feeling unprepared and uncomfortable in participating in end-of-life discussions even to the point of avoiding the discussions altogether. Hospital social workers may not be familiar with end-of-life care, because they may lack professional experiences with death and dying issues in the field and many social workers lack confidence in their ability to engage with patients in end-of-life discussions (Albrithen & Yali, 2015; Chow et al., 2015; Kirby et al., 2014; Kwon et al., 2014; Wilmont, 2015). These participants in this study stressed that they learned by watching others or just doing what they felt based on instinct or personal experiences and developed confidence through repeated experiences in the ICU. The participants in this study who shared lack of confidence, discussed how they would shy away from end-of-life discussions because they were uncertain and uncomfortable. P10 discussed initially avoiding situations involving end-of-life cases in the following statement:

> I would avoid those conversations and if I did show up, I would not know what to say so at first, I would just kind of awkwardly stand there asking the family members if they needed anything. I felt useless. So, you know it is very…it's on the ground training. I was not prepared at all and felt very intimidated.

This statement was echoed by P1 who shared similar experiences that highlighted not being prepared to take part in end-of-life discussions in the following statement:

> I had no idea what I was doing. I remember acting like I did not know there were dying patients on the unit. I stayed in my office or remained involved with the less serious things I felt confident doing. I was not confident at all. I was actually terrified in the beginning. I eventually got more comfortable but not in the beginning.

Social workers play an important role in end-of-life care but according to participants in this action research study when they initially began working in the ICU setting, they often struggled to perform due to lack of confidence when called to participate in end-of-life discussions. The participants who have been a social worker longer shared that they eventually gained more confidence the more they continued the job. However, some of the newer social workers who have worked for only a couple of year still struggle. P10 has only been a social worker in the hospital ICU for 1 ½ years and stated:

> I still struggle with knowing what to do. The nurses in my unit are amazing and most times I just follow their lead. I take cues from them on how to interact with the family members but sometimes I do not take the initiative to become involved because I do always feel confident in what I am doing. When a family member or physician thanks me for being there, I think to myself, I have no idea what I did but ok. I get so anxious. I wish I felt more confident.

Contrary to the perceptions of the 15 participants regarding their confidence level being low, 2 participants in the focus groups, shared that while they did not receive training in the hospital regarding end-of-life, their former employment allowed them to hone their skills and prepared them for end-of-life discussions in the ICU setting. P11 shared how former employment within a hospice was setting allowed an opportunity to participate in end-of-life discussions because these patients already had an understanding that they were in an end-of-life situation, in the following:

> I used to work for hospice so coming here, I was already comfortable having those discussions. I did not get any training but when it comes to that I did not need any. I just needed to know how things were done here in the hospital but the overall concept of end-of-life, I was comfortable with that.

Similarly, P9 discussed sharpening skills related to end-of-life while employed with a crisis center prior to obtaining employment in the hospital ICU in the following:

> Through the crisis center I worked with clients who were survivors of homicides, rape and survivors of suicide. I was so comfortable talking about death and end-of-life because I dealt with some family members who were deep in crisis, having lost a loved one due to a traumatic death. Coming to this setting [hospital] was something I felt I was prepared to do after having worked there. I was very confident.

Not Properly Trained and Educated. Overall, participants felt curriculums do not prepare students for end-of-life care. P4 shared feelings of being unprepared after graduating and suggests the need for more education in the area of end-of-life care, especially in the ICU setting in the following:

> As students we learn about the stages of grief and how to work with families who are grieving but if we are going to be providing grief counseling and participating in end-of life discussions, that should be something that is offered maybe at the bachelor’s level of social work. It’s like we do not even hear about the ICU. We hear about trauma and the emergency department but not the ICU. At least I didn’t.

In addition, participants reportedly received no training in the workplace related to social work in the ICU as P14 shared the following:

> When I graduated and decided I wanted to go into medical social work, I did not know much about the ICU either. Especially from school. When I began working

> in the ICU, it was boots on the ground for me. Going through and watching a few cases with some mentors helped but we could definitely use more training.

Although according to Stein and Fineberg (2013) social workers are uniquely qualified to take the lead in addressing and guiding patients and families through effective end-of-life discussions, they are not consistently utilized in ICU settings. Social workers are skilled in listening, helping individuals adjust to changing circumstances and when working with the whole family who are faced with end-of-life decisions on behalf of dying patients, should display a level of confidence. In challenging environments, such as the ICU, social workers have knowledge and training and are in essential roles that would allow them to support and empower patients and engage patients and their systems in their care and mediate between systems (Findley, 2014). Although participants felt the role of the social worker takes on many forms in end-of-life discussions, they all agreed with what is documented in the literature, that social workers should always be present when these discussions take place in the ICU setting.

Regardless of the circumstances that brought the patient to the ICU, it is important for social workers to be able to attend to the emotional needs of a patient and a patient's family members.

Important Learning Points

As the facilitator of 4 online focus groups, I endeavored to create an opportunity for clinical social workers to share their experiences regarding barriers to inclusion in end-of-life discussions and discuss how they perceive their roles in end-of-life discussions in an ICU setting. From this study, I came to the realization that the ICU is a unique setting in the hospital and not all ICU settings operate the same. However, the ICU is a setting that is set up in a way that is chaotic, complex and unpredictable. Also, the ICU setting is such that it unintentionally creates barriers to social workers being consistently included in end-of-life discussions. Communication in the ICU is inconsistent and processes to include social workers in end-of-life discussions vary across units within the same hospital and imposes challenges to consistent inclusion. While there are various barriers that prevent consistent social worker inclusion, social workers have a desire to always be included in end-of-life discussions. The clinical social workers who work in the ICU, have a passion for this work and want to be included in all aspects of end-of-life care, namely end-of-life discussions. However, there is a need for more formal education, training and the development of protocols to ensure they are included on a consistent basis. An important learning point of this study was the complexity of the ICU environment in the hospital system and how this impacts consistent social work inclusion in end-of-life discussions. The primary theme regarding barriers to social work inclusion includes the ICU setting with the critical patient population, the complex chaotic and unpredictability of the ICU, communication, varying and inconsistent protocols and processes and social worker workloads and availability.

An additional learning point from this qualitative action research project includes how the consistent inclusion of clinical social workers in end-of-life discussions in the ICU setting could be beneficial to the medical team, and the patients and their family members. There is a benefit to having social workers involved sooner rather than later during a patient’s hospital stay. Social workers interact with the patients and their family members throughout their hospital stay and are in a position that allows them the ability to facilitate dialogue between patients, their family members and the medical professionals who provide care to the dying patient. The social workers’ knowledge base and communication skill sets make them beneficial in taking the lead in addressing and guiding patients and families through effective end-of-life discussions. Just as social workers are consistently used in hospice, palliative care and pediatric settings, participants felt the same should occur in the hospital ICU setting as well.

Another important learning point from this action research study is the need for the development of a process in the ICU that consistently includes social workers in end-of-life discussions. Based on the unit, the social worker serves in various capacities and roles. There is a benefit to having a prescribed process or set structure as far as social work when it comes to being involved in end-of-life discussions. The social work profession is concerned with the whole person, including the context of their environment (Beder, 2013; Peres, 2016). The physicians do not have significant time available to spend developing relationships with patients in the ICU and reaching out to families to provide ongoing support. The social worker is well-versed in cultural competence which allows them to address current and future needs of patients impacted by end-of-life care and being a part of a multidisciplinary approach allows them to address dying patients care from all facets including physical, psychosocial, emotional, and spiritual wishes.

The perception of how social workers view their roles in end-of-life discussions is ambiguous, void of confidence and absent of formal education and training pertaining to end-of-life care. The participants reported consistently that hospital wide, regardless of the ICU setting they work in, there is no protocol or process that calls for the social worker to be included in end-of-life discussion on a consistent basis. The final learning point from this action research project is the significance of education to new social workers and medical providers on the role social workers are able to play in end-of-life discussions. There is a need for further education for not only the social work students but the members of the ICU multidisciplinary team to teach the staff the skill set of the social worker and what they can bring to a case dealing with end-of-life. Clinical social workers feel that MSW programs lack adequate end-of-life care training, education that prepares social workers for their role in the ICU setting and preparation for end-of-life discussions in the ICU setting. The clinical social workers who participated in this study were keenly aware of their limitations when participating in end-of-life discussions. According to Grady et al., (2008) the education in MSW programs should include working with patients and families at end-of-life, how to work on an interdisciplinary team, how to facilitate family meetings and medical social work as a whole (Fineberg, 2005; Grady et al., 2008). While there are various barriers that prevent consistent social worker inclusion, social workers have a desire to always be included. The clinical social workers who work in the ICU, have a passion for this work and want to be included in all aspects of end-of-life care, namely end-of-life discussions. However, there is a need for more formal education, training and the development of protocols to ensure they are included on a consistent basis

Social Work Practice Implications

The participants of this action research study identified various challenges regarding barriers that prevent the clinical social worker from being consistently included in end-of-life discussions and the perceptions social workers have regarding their roles in those discussions. Specific findings from this action research project that will impact the clinical social work practice was the identification of the barriers that prevent social workers from consistently being included in end-of-life settings in several of the ICU settings. The identification of these barriers as noted in this action research study demonstrated that this is an issue prevalent across many of the ICU settings. The data identified challenges on various levels and the lack of knowledge about the benefit of having the clinical social worker present in all end-of-life discussions. I consider the development of a specific protocol to consistently include clinical social workers in all end-of-life discussions in the ICU to be a proactive step towards addressing concerns regarding social work inclusion.

Some participants shared limitations to services they are able to provide to dying patients due to heavy caseloads, which impedes their ability to provide adequate attention to patients and patient’s family members during the end-of-life. Participants also expressed concerns that many members of the multidisciplinary team are oblivious to the role of the social worker in the ICU setting and felt social workers should be consulted sooner rather than later in a patient’s hospital stay. Agency administrators and members of the multidisciplinary teams need to recognize underutilized skillsets clinical social workers possess that could be a benefit to both the patient and the team members.

Members of the multidisciplinary team should be oriented on the role of the clinical social worker and how their presence could be beneficial during end-of-life discussions. Order sets and/or processes should be implemented that includes protocol to include a clinical social worker once end-of-life discussions occur. Specialized training should be offered to clinical social workers who are assigned to work in the ICU setting as this is a unique setting with unique sets of circumstances.

Unexpected Findings

I had no prior interaction with any of the participants, nor was I familiar with the specific units they worked on. One unexpected finding was related to the desire of clinical social workers to be included in all phases of end-of-life care, regardless of their level of experience or training. It was also unexpected to hear that many of the participants experience similar barriers to consistent inclusion in end-of-life discussions, working in the ICU setting and that none of the ICU’s have a formal protocol, process nor order set that calls for the consistent inclusion of a social worker in an end-of-life discussion. There is a unique variation in many of the roles that some of the participants filled depending on the unit they worked, the population they served and the size of their unit.

I had a preconception that all social workers were not consistently included in end-of-life discussions in the ICU setting. The last unexpected finding was related to social workers who are consistently included in end-of-life discussions. Previous literature documents the consistent inclusion of a social worker in pediatric ICU (Doorenbos et al., 2012; Michelson et al., 2013; Thieleman et al., 2016), palliative and hospice (Adshead & Dechamps, 2016; Silverman, 2016) as part of multidisciplinary teams and end-of-life discussions. This was an unexpected finding for this study as the participants in this study who work in those settings also confirm consistent inclusion as documented. Participants who worked in pediatric, palliative or smaller settings shared that in some ICU settings, social workers who round with their medical team daily, work in an environment that makes them more accessible and have smaller units are always included in end-of-life discussions when they are available. Some participants who exercise these practices or are in these settings even shared that members of the medical team have their personal phone numbers and communicate after hours if necessary, which was also an unexpected finding.

Summary

The two research questions for this qualitative action research study sought to explore the barriers to the consistent inclusion of social workers, and how social workers perceive their role in adult ICU settings in end-of-life discussions. Through the use of social workers serving as participants for this study, they were able to share their experiences as social workers as it relates to end-of-life discussions in ICU settings. The findings of this study resulted in the identification of barriers that prevent social workers from being included consistently in end-of-life discussions in the ICU setting and knowledge about the way clinical social workers perceive their roles in those discussions. Through data analysis, including coding and word frequency queries, results were organized to determine ways the research questions were answered. To add validity to this action research project, validation procedures were used. There were limitations to this study in that the participants were all from the same hospital setting and the study only explored the perceptions of clinical social workers.

Participants contributed to this qualitative study by providing insight into the barriers that prevent them from being consistently included in end-of-life discussions and the perceptions of how clinical social workers view their roles in end-of-life discussions in the adult ICU setting. There were findings in this study that could contribute to a positive impact from changes within the social work field. While many social workers in this study expressed feeling ill-prepared when it comes to end-of-life discussions, the overall feeling was that social workers should always be included when end-of-life discussions take place. The participants were passionate about contributing to positive change by developing protocols or processes to ensure consistent inclusion of social workers and policy changes that address the need for formal education and training to better prepare clinical social workers as participants on their multidisciplinary teams when called upon to take part in end-of-life discussions in the adult ICU setting. All findings from this qualitative action research study apply to professional social work practice and provides implications for social change. The data provided evidence to support the literature themes of the need for the consistent inclusion in end-of-life discussions, the need for a process or protocol that ensures social workers are consistently consulted in end-of-life cases and the need for education and training for social workers who are embarking on a career as a medical social worker in the hospital setting, namely the ICU. The next section of this document will introduce recommendations towards solutions to address the barriers identified in this action research project.

Section 4: Recommended Solutions

The purpose of this qualitative, action research study was to identify barriers that prevented clinical social workers from consistently being included in end-of-life discussions and to explore how clinical social workers perceived their roles in end-of-life discussions in the ICU setting. The ICU has been described as a specialized unit in the hospital that cares for critically ill patients with severe and life-threatening illnesses (Modrykamien, 2012; Yang et al., 2015). According to Curtis and Vincent (2010), McCormick et al. (2007), and Truog et al. (2008), in the ICU setting, as many as 95% of the patients are incapacitated due to illness or sedation, death is common, and many decisions being made by the family members of patients involve choices to withhold or withdraw life-sustaining treatments. This qualitative action research study provided an opportunity for clinical social workers to share their experiences related to barriers that prevented them from being included in end-of-life discussions in the ICU on a consistent basis. This study also allowed clinical social workers an opportunity to share their perceptions of how they see their roles when end-of-life discussions occur in the ICU setting. Through qualitative inquiry, the themes that emerged included (Theme 1) the ICU setting, (Theme 2) role ambiguity, and (Theme 3) lack of confidence to perform expected roles when ICU discussions take place.

The ICU setting is viewed as an unpredictable, complex, and chaotic environment where many of the most critically ill patients are admitted. However, this complex and continuously changing system produces order while simultaneously creating unpredictable system behavior. Patients and the family members of patients in the ICU face many challenges due to the patient’s diagnosis of a critical illness and the multifaceted ICU environment itself (Brown et al., 2015). The process of having to make decisions on behalf of the patient is burdensome for families because of high levels of acute stress and the patients’ risk for death (Brown et al., 2015). Family members of patients in the ICU environment experience stress, anxiety, and posttraumatic stress disorder (Davidson et al., 2012; Paul & Finney, 2015; Schmidt & Azoulay, 2012). This experience can be overwhelming for the patient as well as their family members.

Complex and overwhelming environments, such as an ICU setting, require timely problem solving for both the patient and for the health care system (Grant & Toh, 2017). Social workers provide interventions in the ICU that enable patients, families, and staff to deal with the uncertainty that accompanies the stress of critical illness and making end-of-life decisions. According to Stein and Fineberg (2013), social workers are qualified to address and guide patients and families through effective end-of-life discussions; however, they are not consistently used in ICU settings.

In this study, I sought to explore barriers that prevented consistent social worker inclusion and the perceived role social workers feel they play when end-of-life discussions occur in the ICU setting. In this section of this qualitative action research study, application for professional practice, including what was learned from this study and how the findings impact clinical social work practice, will be discussed. Following this, recommended solutions for clinical social work settings and suggestions for implementing those recommended solutions will be presented. Lastly, the implications of this study for positive social change will be addressed.

Key Findings

Clinical social workers who were participants for this qualitative action research study described the ICU setting as being unique, fast paced, not collaborative most times, and overwhelming for patients and their family members. There is often miscommunication as well as varying goals of care in the ICU setting, depending on the unit and members of the multidisciplinary team present. Participants in this study further shared that they see the ICU as a setting that is uncertain and chaotic and unintentionally creates barriers between patients, their families, and the medical team. According to Reeves et al. (2015), because various disciplines provide care for patients, and each discipline is focused on their area of specialty and its professional roles and tasks instead of having a holistic view, teamwork in ICU settings has been characterized as being disjointed throughout a typical workday, and the participants of this action research study agreed with the findings noted by the researchers in literature.

Participants of this action research study shared their experiences regarding their work in ICU settings in end-of-life discussions and how they perceived their roles. The participants provided insight concerning the reasons for the lack of consistent inclusion of clinical social workers in end-of-life discussions. I uncovered challenges related to the structure of the ICU in a hospital setting, inconsistent communication, varying processes for how social workers are consulted in each unit, uncertainty of the role of the clinical social worker, and lack of familiarity with the clinical social worker skill set. Moreover, additional key findings were derived from participants sharing their desire to always be involved in end-of-life discussions. However, the participants felt that their lack of formal training on the job and education related to end-of-life discussions diminished their confidence levels and posed challenges in them taking an active and self-assured stance in being involved in end-of-life discussions when they are called to do so.

Applicable Solutions

The data collected for this qualitative action research study were representative of the experiences and feelings of clinical social workers and not the other members of the multidisciplinary team in the ICU setting. There is a constant influx of physicians and new residents that rotate into the ICU setting weekly, monthly, and sometimes annually. One applicable solution that can be made is to first collect further data that involves the other members of the ICU multidisciplinary team to explore their perspective on the barriers to social work inclusion and their perceptions of the social worker role in end-of-life discussions. Based on the data collection and analysis at that point, a process should be developed where the other members of the multidisciplinary team are educated on the skillset and role of the clinical social worker in end-of-life discussions that occur in the ICU setting. As a second applicable solution, an order set that automatically generates a consult to the clinical social worker could then be implemented as a standard of practice when end-of-life discussions are set to take place. The development of this protocol is proactive, creates an integrated treatment approach, and is a start to ensuring social workers are informed early in the process when end-of-life discussions occur.

Additional applicable solutions are related to the key finding of clinical social workers' lack of preparation and education when it comes to their participation in end-of-life discussions in the ICU setting. Many of the participants shared that they would like to always be included when end-of-life discussions take place. However, the overall feelings were that none of them received any formal training at the hospital that prepared them for working in this setting with such a sensitive topic as end-of-life care. An applicable solution in the hospital setting that was recommended by the participants of this study is the provision of training for social workers in the hospital and ICU settings. This solution could include the development of a formal inhouse training program for clinical social workers who are newly hired to work in the ICU setting and annually for clinical social workers already employed in this setting to continue to improve their knowledge and skills in this area. This training and education could also include on site shadowing of clinical social workers who have a history of working in the ICU setting and who have experience in participating in end-of-life discussions individually and as part of a multidisciplinary team.

Application for Professional Practice

Based on the data collection and analysis of information provided by clinical social workers who participated in this qualitative action research study, there is no formal process or protocol in place to include clinical social workers in end-of-life discussions. Implementing a formal protocol that consistently includes clinical social workers in end-of-life discussions, demonstrates the ability of social workers to work in this very complex field. In developing a process that consistently includes social workers in end-of-life settings, this qualitative action research project contributes to the delivery of high-quality, dignity-based care in clinical social work practice.

Although the findings from this qualitative study cannot be generalized to all hospital ICU settings, it does contribute to the existing body of knowledge on this topic as there is a significant gap in the last 5 years that addresses the social worker's role in the adult ICU setting and end-of-life discussions in this setting. The findings from this study can also inform other members of the multidisciplinary team who provide end-of-life care of the challenges faced by patients, family members and the clinical social worker when they are not consistently included in the discussions. Lastly, the findings from this study can inform other members of the multidisciplinary team of the unique and positive benefit of consistently having social workers included in the discussions.

Although there has been major discussion regarding social worker involvement in end-of-life discussions in ICU settings in the past, there is a gap in the literature that addresses the social worker's role in the adult ICU setting. However, previous literature that does exists as it pertains to the social problem of barriers to the inclusion of social workers and how social workers perceive their roles in end-of-life discussions and was confirmed in this current qualitative action research study as themes emerged. The previous literature identifies barriers that prevent social workers from being included in end-of-life discussions including the social workers' lack of confidence in addressing end-of-life issues (Albrithen & Yali, 2015; Chow et al., 2015; Kirby et al., 2014; Kwon et al., 2014; Wilmont, 2015). Additional barriers previously identified in previous literature and confirmed in this action research study include, social workers lack of knowledge regarding end-of-life care (Albrithen & Yalli, 2015), lack of communication amongst team members and with family (Anderson et al., 2015; Curtis et al, 2016; Howell et al., 2014, McAndrew & Leske, 2015; Steinhauser et al., 2014; Wilmont, 2015) and lack of clarity regarding the role of the social workers on the multidisciplinary team (Kramer (2013). Other barriers previously identified in the literature and was confirmed in this study are related to the complexity of the ICU and the hospital system as a whole (Flannery et al., 2016; Kramer, 2013). Furthermore, although social workers reported feeling comfortable in dealing with issues related to specific psychological issues, grief and bereavement, funeral planning, and spiritual issues of dying patients, they reported feeling ill-prepared to meet the multidimensional needs that arise when having discussions at the end of life (Kramer, 2013).

Participants in this qualitative study who work in smaller ICU settings, round with their teams regularly or have an office that is accessible right in their ICU settings, shared that they are always included in end-of-life discussions when they are available. This information was not previously noted in the peer reviewed literature and can extend the knowledge in this area.

Solutions for the Clinical Social Work Setting

The knowledge base and communication skill set of social workers make them uniquely suited to take the lead in addressing and guiding patients and families through effective end-of-life discussions. In challenging environments, such as the ICU, social workers have knowledge and training and are in essential roles that allow them to support and empower patients and engage patients and their systems in their care (Findley, 2014). As social workers are able to mediate between systems and set the tone for being knowledgeable regarding evidence-based practices regarding end-of-life care, it is important for clinical social workers to be adequately trained when participating in end-of-life discussions. The National Association of Social Workers Standards for Social Work Practice in Health Care Settings (National Association of Social Workers Standards for Social Work Practice in Health Care Settings, 2005) and the National Association of Social Workers Standards for Palliative & End of Life Care (National Association of Social Workers Standards for Palliative & End-of-Life Care, 2004) practice standards require social workers to have skills in empowerment and advocacy and an ability to identify and resolve barriers to meet the needs of marginalized and vulnerable populations. As noted in the National Association of Social Worker's Code of Ethics (2008) practice standards social workers must be competent in values and ethics, knowledge, assessment, empowerment and advocacy to effectively support implementation of changes that occur in practice providing care at a patient's end-of-life.

The findings of this study extend the body of knowledge regarding how clinical social workers in the ICU setting view their roles and responsibilities when participating in end-of-life discussions. During the four online focus group sessions, the participants shared their perceptions of the barriers that prevent them from consistently being included and how they perceive their roles in end-of-life discussions in the ICU setting. The participants of this study concluded that the ICU setting is very complex, chaotic and predictable and communication is inconsistent. The overall feeling is that clinical social workers should always be included in end-of-life discussion and they would like to always be included in end-of-life discussions. However, they do not feel they have the proper training and education needed to feel confident and competent when they are called to participate in end-of-life discussions.

The findings of this qualitative action research study validate the problem of inconsistent inclusion of clinical social workers and lack of adequate training and education for these practitioners across many ICU settings and demonstrates the fact that this is not an isolated problem, unique to one ICU setting or one clinical social worker. This qualitative action research study will empower clinical social workers who work in the ICU setting and participate in end-of-life discussions by highlighting the challenges faced across many ICU settings and how inconsistent communication and processes creates challenges. The study will provide evidence that will increase their knowledge and awareness of recommended solutions that are applicable to address this problem. Furthermore, the findings of this study will support the need for the development of collaborative protocols to address these inconsistencies. The findings will empower clinical social works to advocate for training and education in this area so that they are able to better serve their patient population and demonstrate the skill set of clinical social workers to other members of the social work profession and the multidisciplinary team focused on end-of-life care. In addition, this qualitative action research study will help clinical social workers feel empowered when their clinical skillset related to end-of-life care is acknowledged and they are utilized to their potential in the ICU setting.

Clinical social workers have an obligation to maintain competence in their practice setting. As a clinical social worker who is employed in a hospital ICU setting, the recommended solutions can be applied to my day to day practices with the members of the multidisciplinary team. Annual training provides an opportunity to engage with other practitioners in the field, to evaluate and improve practices, and share strategies that could better serve patients and their families as they move toward end-of-life care. Clinical social workers should possess skills that include cultural competence, and understanding of the norms, language and beliefs of their patient population. Understanding the hospital and ICU subcultures, plays an important part in understanding the needs of patients, their family members and medical providers as end-of-life discussions occur. The solutions presented highlight the need for social work education programs to include end-of-life care as part of the curriculum. The recommended solutions serve as a guide to improve my own skills as a clinical social worker. The knowledge gained from this study brings an increased awareness of similar challenges faced by clinical social workers in the ICU setting and dealing with end-of-life care as documented in the previous literature. Going forward I am able to be more mindful of how I can better communicate with members of the multidisciplinary team as I continue to advocate for patients and display best practices as noted in the National Association of Socials Workers' Code of Ethics (2008).

A method for stakeholders to evaluate and ensure the recommended solutions have the desired effect is to first develop an understanding the role of social workers, how their skills can be utilized in the ICU setting when having end-of-life discussions and highlight the challenges that arise when social workers are not consistently included and the dissatisfaction of family members when a clinical social worker is not included. Once a protocol has been implemented to consistently include social workers, the recommended solutions can be annually evaluated for effectiveness by having a team conduct an annual review of the protocol and routinely surveying family members, clinical social workers and members of the multidisciplinary team regarding their perceptions of having clinical social workers consistently included in end-of-life discussions. Through the annual evaluation of the protocol, changes can be updated and adjusted to ensure the desired effect is reached.

Implications for Social Change

The goal of this qualitative action research project was to explore the barriers to consistent social work inclusion and how clinical social workers perceive their roles in end-of-life discussions in the ICU setting. While the literature seems to document the positive presence of and need for social workers in palliative and hospice care settings, there is a gap in the literature in the last five years that supports the presence of social worker inclusion in these discussions in ICU settings and the need to have social workers in end-of-life discussions is still warranted. The implications for social work practice and positive social change is to close the gap between the patient, family members, social workers and the medical team, the implications for social change at the micro or individual level is once barriers are identified by both clinical social workers and the other members of the multidisciplinary team, ultimately propose and implement a protocol through that will consistently include social workers in end-of-life discussions in ICU settings. The participants of this qualitative study can educate the members of the multidisciplinary teams of the ICU where they work on the skill set and role of clinical social workers in end-of-life discussions. The participants can also share key findings from this study to educate the multidisciplinary team members in their units. In educating the other team members and sharing key findings, a protocol could be developed to consistently include social workers in the end-of-life discussions that occur in their respective ICU’s. Using education and a specific protocol that consistently alerts clinical social workers to end-of-life discussion occurring in their unit, the various team members are able to foster effective communication which could prove beneficial to patients and family members and result in positive outcomes, as patients and family members work to navigate through the complex ICU environment.

Contribution to Knowledge

Scholars documented the need to have clinical social workers included consistently in all end-of-life discussions in the ICU setting and the findings from this qualitative action research study confirmed the same. The findings from this qualitative action research study contributes to a wider body of knowledge by bringing an awareness to clinical social workers, additional members of the ICU multidisciplinary team and the hospital administrators about the valuable role of clinical social workers and how they are able to contribute to the multidisciplinary team when end-of-life discussion take place. There is a gap in the literature in the last five years that supports the presence of social worker inclusion in end-of-life discussions in ICU settings. This qualitative action research study can also contribute a wider body of knowledge by documenting this as an existing problem that still exists and warrants further exploration.

Summary

Research shows that family members who have a loved one die in the ICU report feelings of distress accompanied by depression, anxiety, and posttraumatic stress disorder that have long-lasting effects. Researchers also report that social workers' knowledge base and communication skill sets make them uniquely suited to take the lead in addressing and guiding patients and families through effective end-of-life discussions. The ICU is a potentially hostile environment to the vulnerable critically ill patient. In addition to the physical stress of illness, pain, sedation, interventions, and mechanical ventilation, there are psychological and psychosocial stressors perceived by these patients. While the literature seems to document the positive presence of and need for social workers in palliative and hospice care settings, there is a gap in the literature in the last five years that supports the presence of social worker inclusion in these discussions in ICU settings and the need to have social workers in end-of-life discussions is still warranted.

Findley (2013) indicated because social workers are not specifically mentioned in most chronic care models the complicated health and social care processes creates barriers to social workers collaborating with other health care professionals and suggest the role of the social worker needs to be more clearly defined. This action research study used focus groups to explore the barriers to the consistent inclusion of social workers, and how social workers perceive their role in adult ICU settings in end-of-life discussions. The findings support previous findings in the literature and suggests, while social workers lack and desire more training in end-of-life care, the overall consensus is that a social worker should be consulted for all patients when a discussion about end-of-life occurs in the ICU setting

Dissemination

Dissemination of key findings at the completion of this action research project is an important part of the research process. When disseminating salient findings, it is important to consider the goals and objectives of the dissemination effort and the impact this information will have, who is affected by this research and who would be interested in learning about the findings from this study. Also, dissemination efforts should consider the most effective ways to reach the target audience and the resources available to them to access the findings.

The information specifically from this qualitative action research study can be disseminated to stakeholders, through professional poster board presentation at the agency that was the focus for this study. In addition, this information can be disseminated at topic related seminars, conferences, community forums and/or health fairs that are held in the Florida area annually. Lastly this information can be disseminated by way of written communication to the participants to share with their various units and they agency of which they are employed. The dissemination of this information will provide an opportunity for the agency that was the focus for this study, to share emergent themes with all of the administrators and department members including clinical social workers who did not participate in this study. Through the sharing of information, the administrators and social workers are able to identify strategies that allow them to come up with processes and protocols that include social workers consistently being included in end-of-life discussions.

Conclusion

In conclusion, this action research project served to explore and inform about existing barriers that prevent clinical social workers from being consistently included in end-of-life discussions and how they perceive their roles in those discussions in the hospital adult ICU setting. Clinical social workers continue to possess a knowledge base and communication skill set that makes them uniquely qualified and beneficial in taking the lead in addressing and guiding patients and families through effective end-of-life discussions. Social workers must continue to advocate the need for change and the development of protocols that consistently include clinical social workers in end-of-life discussions in the ICU setting. Social workers should also advocate for education and training related to end-of-life care in the ICU setting. The current study affirms to all stakeholders the value of professional clinical social work practice in end-of-life care and highlights awareness of the social problem in a setting where social change can be initiated. ICU social work needs transformation, and the participants in this project expressed passion about being a part of a system of change. I am hopeful that the findings of this qualitative action research study may be disseminated to assist in implementing protocols to include social workers in end-of-life care in the ICU and promote formal training and education for social workers in the social work profession.

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Appendix: Focus Group Interview Questions

Introduction of Focus of the Study

The purpose of this study is to explore barriers to your role as a social worker that keep you from being consistently included in end-of-life discussions in the ICU setting where you work. An additional purpose for this study is to explore the perception you have of your role as the social worker participating in end-of-life discussions in the ICU setting. You were recruited for this study because of your role as the social worker in the hospital. The focus of the questions will be on perceived barriers to social work inclusion in end-of-life care on a consistent basis that you are aware of, your role as the ICU social worker, factors that aid or impede your role and your experience regarding end-of-life care. Everything you say during the focus group is confidential and all participants selected for this study will be asked to sign a confidentiality agreement.

Social work role, perceptions and barriers in the ICU

1. Describe your professional experience working in an ICU.

2. How would you explain your primary role as a social worker in the ICU setting?

3. How would you describe how end-of-life care in the ICU is managed?

4. How do you perceive your role providing end-of-life care in the ICU?

5. What are your feelings regarding social work involvement in end-of life care and /or discussions?

6. Describe how you feel not having a prescribed set of rules or processes where you as a social worker is consistently included in end-of-life discussions.

7. How are you initially consulted to get involved with an end-of-life case on your assigned unit?

8. Discuss your last experience where you felt role confusion because of lack of structure or process regarding social work inclusion in end-of-life discussions.

9. Describe your feelings and experiences in the hospital setting where sometimes social workers are included in end-of-life discussions and sometimes not.

10. What, if anything, would you change about your role in end-of-life discussions for you to be more effective?

11. How does your role fit with your understanding of standard social work practice regarding end-of-life discussions in the ICU setting?
    a. Probe: If it does not, how is it different?

12. Describe a time where you as a social worker felt your role positively affected an end-of-life discussion in a complex care situation.

13. Describe a time where you as a social worker felt your role negatively affected an end-of-life discussion in a complex care situation.

14. Describe how it feels to self-organize with no set structure when performing social work practices as it relates to end-of-life discussions?
15. Who are the members/disciplines of the multidisciplinary team in your ICU?
16. Who do you work with primarily on the ICU multidisciplinary team when you are included in end-of-life discussions?
17. What is your role on the multidisciplinary ICU team when end-of-life discussion do occur and you are included?
18. Describe your feelings about the interaction between the different medical providers when and if you are included in end-of-life discussions?
19. Tell me about the communication and interactions between you and the physicians, nurses, and other members of the multidisciplinary team when end-of-life discussions occur?
20. To what extent are you included in end-of-life discussions in your primary work unit?
    a. How often?
21. What benefits have you experienced or witnessed when SW was involved in EOL care?
22. What consequences have you experienced or witnessed when SW was not involved in EOL care?
23. What barriers prevent you from consistently being included in end-of-life discussions in the ICU where you work?
24. What is your experience working on the ICU multidisciplinary team?
25. What are your thoughts and feelings about being the first person on the multidisciplinary team to initiate an end-of-life discussion?

26. How does interconnectedness of the social worker to the other members of the multidisciplinary team and their roles in the ICU relate to being included or excluded in end-of-life discussions?

27. What makes you feel supported by your ICU team members in initiating end-of-life discussions?

28. What makes you feel unsupported by your ICU team members in initiating end-of-life discussions?

29. How does your department (social work) view your role with providing end-of-life care?

30. What are the factors in your department (social work) that impede your ability to provide end-of-life care?

31. What are the factors in your department that aid your ability to provide end-of-life care?

32. How satisfied are you with how end-of-life care is managed in the ICU where you work primarily?

    a. Probe: If you could change how you deliver care, what would those changes be?

    b. Probe: How confident are you providing end-of-life care?

33. To what extend do you feel your skills as a social worker are fully utilized in the ICU as it relates to end-of-life discussions?

34. How do you think the field of social work as it relates to end-of-life care could be improved?

35. What are your feelings on leaving social work because of the lack of structure or defined roles vs your level of understanding that this is the nature of this work for this setting.

36. What other questions are important for me to ask regarding social workers and end-of-life care in the ICU?