



Summer 6-19-2013

How do social workers in the ICU perceive their role in providing end-of-life care? What factors impede or help them in carrying out this role in end-of-life care and is social work education a contributing component?

Allison L. Gonzalez

University of Pennsylvania, allison.klugmangonzalez@gmail.com

Follow this and additional works at: http://repository.upenn.edu/edissertations_sp2

 Part of the [Social Work Commons](#)

Recommended Citation

Gonzalez, Allison L., "How do social workers in the ICU perceive their role in providing end-of-life care? What factors impede or help them in carrying out this role in end-of-life care and is social work education a contributing component?" (2013). *Doctorate in Social Work (DSW) Dissertations*. 46.

http://repository.upenn.edu/edissertations_sp2/46

This paper is posted at ScholarlyCommons. http://repository.upenn.edu/edissertations_sp2/46

For more information, please contact libraryrepository@pobox.upenn.edu.

How do social workers in the ICU perceive their role in providing end-of-life care? What factors impede or help them in carrying out this role in end-of-life care and is social work education a contributing component?

Abstract

Death occurs often in the intensive care unit (ICU), which makes it a natural place for the social worker to collaborate with the interdisciplinary team to provide end-of-life care to patients and families. However, the role of the social worker in the ICU varies because social workers do not have a formal role in providing end-of-life care. This study utilized a qualitative approach to better understand how social workers perceive their role in the ICU managing patients and families at end-of-life. The goal of this study sought to uncover the factors that aid or impede the social worker's ability to perform that role, as well as the ways education contributes to the social workers competency in that role. The researcher interviewed 17 master's degree level ICU social workers who are currently assigned to a minimum of one ICU unit on their caseload. This study found that participants perceive their role as discharge planners, counselors, advocate and educators. The major impediment to end-of-life care is heavy caseloads, time constraints, and lack of an ICU interdisciplinary team. The study also found inconsistency in the MSW programs and CEU opportunities for the participants. As a result, there was a breadth of comfort levels and perception on what the role of the ICU social worker should be. Further research is needed to identify ways to improve the field of palliative care social work, potentially through interventions such as improved end-of-life care training in MSW programs, education about the social work role on an interdisciplinary team, in addressing end-of-life ethical dilemmas, and improve on-the-job training for social workers currently practicing in ICU.

Degree Type

Dissertation

Degree Name

Doctor of Social Work (DSW)

First Advisor

Joretha Bourjolly

Second Advisor

Paul Kinniry

Third Advisor

Andrew McCormick

Keywords

ICU Social Work, Social Work and End-of-life, Palliative Care Social Work, Social Work Education, Social Work and Interdisciplinary Team, Hospital Social Work

Subject Categories
Social Work

University of Pennsylvania
School of Policy and Practice

How do social workers in the ICU perceive their role in providing end-of-life care? What factors impede or help them in carrying out this role in end-of-life care and is social work education a contributing component?

Allison Gonzalez, DSW LSW

Committee:

Joretha Bourjolly, PhD, MSW
School of Social Policy and Practice
Associate Dean for Academic Affairs
Chair of Committee

Paul Kinniry, MD
Pennsylvania Hospital
Director of Critical Care Medicine
Associate Professor of Clinical Medicine
University of Pennsylvania
Perelman School of Medicine
First Reader

Andrew McCormick, PhD, MSW
Social Worker at Harborview Medical Center
UW Medicine
Seattle, WA
Second Reader

Abstract

Death occurs often in the intensive care unit (ICU), which makes it a natural place for the social worker to collaborate with the interdisciplinary team to provide end-of-life care to patients and families. However, the role of the social worker in the ICU varies because social workers do not have a formal role in providing end-of-life care. This study utilized a qualitative approach to better understand how social workers perceive their role in the ICU managing patients and families at end-of-life. The goal of this study sought to uncover the factors that aid or impede the social worker's ability to perform that role, as well as the ways education contributes to the social workers competency in that role. The researcher interviewed 17 master's degree level ICU social workers who are currently assigned to a minimum of one ICU unit on their caseload. This study found that participants perceive their role as discharge planners, counselors, advocate and educators. The major impediment to end-of-life care is heavy caseloads, time constraints, and lack of an ICU interdisciplinary team. The study also found inconsistency in the MSW programs and CEU opportunities for the participants. As a result, there was a breadth of comfort levels and perception on what the role of the ICU social worker should be. Further research is needed to identify ways to improve the field of palliative care social work, potentially through interventions such as improved end-of-life care training in MSW programs, education about the social work role on an interdisciplinary team, in addressing end-of-life ethical dilemmas, and improve on-the-job training for social workers currently practicing in ICU.

Table of Contents

Dedication	4
Introduction	5
Literature	10
Theoretical Framework	31
Need for Further Research	36
Research Questions	37
Methods	38
Findings	48
Limitations	105
Discussion	109
Implications for Clinical Practice and MSW Education	121

Conclusion	
.....	127
References	
.....	128
Appendix I: Demographic Information and Interview Guide	
.....	142
Appendix II: Consent Form	
.....	145

Dedication

This dissertation is dedicated to my family for their love, support, and patience throughout this process, as well as to the members of my committee for all of your guidance.

Introduction

A social worker's role practicing end-of-life care in the intensive care unit (ICU) is one that varies among practitioners, yet it is an important element in good end-of-life care. The social worker is able to provide support to patients and families as they navigate the ICU, improve the communication between the medical providers and patients and families, and advocate for the wishes of patients and families. The social worker acts as an intermediary between the patients, families and medical team and is an integral member of the critical care interdisciplinary team. Yet social workers in some institutions may not have a formal role in working with physicians, patients, and families regarding end-of-life care and decision making.

Often it is the responsibility of the physicians to communicate the medical issues and decision making (Larochelle, Rodriguez, Arnold, & Barnato, 2009; Quill, 2000). Critical care physicians are generally unfamiliar with a patient's prior medical history, and do not have a prior relationship with the patient and family. As a result, physicians in the ICU are often ill prepared to discuss end-of-life decisions with patients and families in the beginning of the ICU stay because they do not have a relationship with the patient or family prior to the ICU admission. This is compounded by significant variation in physicians' approach to treatment, quality of communication with patients and families, and attention to comfort level in treating patients at end-of-life (Larochelle et al., 2009). In addition to communication variance, different personal, cultural, religious and moral beliefs held by the caregivers and family members can impact decisions made for the patient, and may create disagreement in the treatment plan for the patient. These disconnects may lead physicians to prefer treatments that do not adhere to the wishes of

patients and families. This can result in feelings of helplessness for families making critical decisions (Rose & Shelton, 2006).

The ICU is an intense environment where families often feel “stressed and confused by complex technical information” (Ahrens, Yancey, & Kollef, 2003, p. 317). The medical language communicated is confusing to the lay-person because words such as a “mechanical ventilation” and “cardiopulmonary resuscitation” are difficult to understand and family members may have difficulty grasping the full meaning of these treatments. In addition, medical providers typically work individually with patients and families. There is often a lack of communication between the physicians, nurses and social workers, which can lead to different medical providers communicating varying information to the patients and families. This further increases the confusion for patients and families as they work to understand the medical prognoses and make the appropriate decisions. Compounding misunderstanding of medical information are the differing beliefs families, patients, and medical staff have regarding end-of-life care. “Decisions regarding end-of-life care are among the most controversial ethical problems, involving dilemmas related to the sanctity of life, autonomy, and beneficence” (Werner, Carmel, & Ziedenberg, 2004, p. 33-34). Everyone deals with death differently, some want the patient to be as comfortable as possible even if that may hasten death, whereas others believe in maintaining life as long as possible. Varying beliefs can create conflict amongst family members and between family members and medical providers.

Social workers can provide a bridge between families and medical providers because “the social worker has the skills to work with individuals in diverse environments, understand their social ecological contexts, and help them make meaning

of their decision-making experiences” (Bomba, Morrissey & Leven, 2010, p. 75). Social workers are able to assess the needs of the patient and family, as well as appreciate the medical provider’s perspective and thereby aid in developing an appropriate medical intervention in the ICU. The social worker is able to bring the individual medical providers together to work as an interdisciplinary team. Interdisciplinary teams, defined as a group of clinicians from various disciplines working together to provide care to patients and families, are uncommon in ICUs because of the individualistic approach to ICU medicine. As the physicians, nurses, and social workers partner together to provide comprehensive care to the patients and families, they are able to increase communication between medical providers and patients and families, and provide opportunities for patients and families to openly discuss their beliefs regarding end-of-life care. As the team supports the patients and families through the end-of-life process, they are also able to support one another as they care for the dying patient.

Most of the research that exists regarding end-of-life care is from the perspective of physicians and nurses. Research on the ICU tends to focus on caregiver stress, communication variance, and the roles of physicians and nurses. However, there is a lack of research to examine the social worker’s role in end-of-life care in the ICU. The literature regarding end-of-life decisions demonstrates that frequently patients’ wishes are not followed by care providers and families, despite living wills and advance care directives (Rabow, Haueser, & Adams, 2004). Despite some evidence that supports the social worker’s role in the hospital, the importance of good communication, and the common barriers social workers face when providing end-of-life care evidence (Burford, 1981; Christ & Sormanti, 1999; Csikai & Bass; 2000; Dubus, 2010; Forrest & Derrick,

2010; Hartman-Shea, Hahn, Kraus, Cordts, & Servansky, 2011; Heyman & Gutheil, 2006; McCormick, 2011; McCormick, Curtis, Stowell-Weiss, Toms, & Engelberg, 2010; Rose & Shelton, 2006), there is a lack of research on the perception of social workers in the ICU providing end-of-life care (Larochelle et al., 2009). It is unclear whether this is caused by difficulties in measuring what is “good” end-of-life care, or a lack of appreciation of the role social workers can play in this setting.

There needed to be further study on how the perception of the ICU social worker’s role providing end-of-life care impacts the way care is delivered. It is important to understand what social workers in the ICU are doing when end-of-life care is needed. Are ICU social workers taking an active role in providing end-of-life care? If they are taking an active role, what factors aid them in providing that care and how can the profession continue to improve how it provides end-of-life care in the ICU? However, if social workers are not providing end-of-life care in the ICU, is it because they do not value it as a professional duty? Do they feel inadequately prepared or lack an understanding of how to provide end-of-life care? By investigating how the social worker views their role as an end-of-life care provider this study has identified ways to improve the field of palliative care social work, potentially through interventions such as improved end-of-life care training in MSW programs, education about the social work role on an interdisciplinary team in addressing end-of-life ethical dilemmas, and improvement of on-the-job training for social workers currently practicing in ICUs.

A qualitative study allowed the researcher to gain a broad understanding of the role of the ICU social worker from the individual social worker’s perspective, exploring how social workers value their role in providing end-of-life care, and what factors may

impede or help them in that role. By comparing the information gleaned with the current literature, the researcher determined how this information relates to dominant models in palliative social work, and how to leverage these models to create consistency in ICU practice. This will potentially advance both social work practice and social work education, as well as evolve interdisciplinary teams in providing end-of-life care. In addition, social workers participating in this study were able to reflect on their experiences working with the medical team, patients and families, as well as the different activities they perform related to end-of-life care.

The role of the social worker in providing end-of-life care in the ICU is becoming increasingly complex. “Social work in the ICU has become a subspecialty of medical social work just as the ICU’s themselves have become more specialized” (McCormick, 2011, p. 55). Social workers may be assigned to one ICU in a large hospital, or may cover multiple ICU’s in smaller hospitals (McCormick, 2011). This study examined how social workers perceive their role in practicing end-of-life care in the ICU and what changes need to be made with an effort to enhance and improve social work end-of-life practices.

Literature Review

History of Medical Social Work

The history of medical social work began in the early 1900's at the Massachusetts General Hospital (MGH) (Beder, 2006). It was a time in the United States when treatment for the sick was moving into the acute care settings, away from the home environment (Beder, 2006). Different medical conditions, including tuberculosis, syphilis, polio, coupled with pregnancies of unmarried women and poor living conditions were impacting how medical clinicians were able to care for their patients (Beder, 2006).

In 1905 a physician, Dr. Richard C. Cabot, realized the need for a hospital social worker, known then as a caseworker. Patients were not able to adhere to the recommendations of the physicians, hindering their ability to recover and heal, because of personal social problems and living conditions that were impediments to adherence (Beder, 2006). Hence, he appointed Garnet Pelton, a nurse, to act as the first social worker for the MGH (Beder, 2006; Bartlett, 1975). The social worker's role was to assist the physicians through providing social interventions (Chachkes & Foster, 2004). After six months, Garnet Pelton resigned due to medical conditions, and in 1906 Ida Cannon, who was first trained as a nurse but later received a degree in social work from what is now called Simmons College, was appointed as the next social worker at MGH (Beder, 2006; Bartlett, 1975). This marked the first shift from the use of volunteers to hired and trained social work professionals (Bartlett, 1975).

Ida Cannon's work centered on "bridging the gap between the hospital environment and the patients' usual social environment in order to remove barriers to effective medical treatment" (Beder, 2006, p. 3). She was appointed Chief of Social

Service in 1914 and, in 1919, MGH made the Social Service Department an integral part of the institution (Bartlett, 1975). In 1912 Ida Cannon partnered with Simmons School of Social Work to include a specialized course for medical social workers and in 1918 she was one of the founders of the American Association of Hospital Social Workers (Bartlett, 1975). She helped develop the Committee on Training for Hospital Social Workers, which identified the need for professional education. Through Cannon's work in the 1930's, the MGH recognized and supported the work of the social worker on the multidisciplinary team, and as a professional who documented useful and important information in the patient's medical record, as well as the need for research to support the role of the hospital social worker (Bartlett, 1975).

The 1960's was a time of civil rights, including the leadership of Dr. Martin Luther King Jr., civil rights legislation, and the implementation of the Office of Economic Opportunities Program. The social work profession developed an awareness of the need for professional research and accountability (Biestek, 1978). The focus of social work began to shift from working with the individual to also working with the broader society (Biestek, 1978). Advocacy in social work was also introduced during this time in the social work profession. Social workers needed to understand the social systems and social institutions in the client's world to help guide them (Biestek, 1978).

The 1960's and 1970's was the time when the term "the medically needy" was coined, which later influenced the implementation of Medicare in the United States (Harper, 2011). "The program[Medicare] promised to pay hospital care, nursing home care, home nursing services, and outpatient diagnostic services for Americans 65 years of age and older" (Harper, 2011, p. 13) as well as "to help the poor, indigent elderly and

chronically ill disadvantaged” (Harper, 2011, p. 13). This resulted in the appointment of the social worker Ruth Knee as the Program Director of Long-Term Care at the Massachusetts General Hospital. In addition, Bernice Harper was appointed as the Director of the Division of Long-Term Care and was as a member of the National Long-Term Care for the Elderly Research Review and Advisory Committee for the United States (Harper, 2011). In addition, with the implementation of the Health Maintenance Organization Act of 1973, there was a shift from inpatient care to outpatient care, “leading to the marked increase in the number of health social workers providing case management and discharge planning needs” (Encyclopedia, 2012, p. 1).

In the 1980’s cost containment took over health care (Judd & Sheffield, 2009). In 1983 the prospective payment system based on the Diagnostic Related Group (DRG) was introduced, resulting in the need to discharge patients rapidly from the acute hospital setting to ensure full reimbursement (Judd & Sheffield, 2009). This continued the shifting role of hospital social workers from providing primarily psychosocial support to providing discharge planning needs (Judd & Sheffield, 2009).

By the 1990’s, there was a reengineering of hospital social work (Judd & Sheffield, 2009). “Dramatic changes were undertaken with a focus on targeted cost containment by means of eliminating middle management positions, altering traditional roles and responsibilities of current staff positions to become transdisciplinary, flexible, and empowered” (Judd & Sheffield, 2009, p. 858). Social work was under the spotlight and was now being threatened by nurse case management (Judd & Sheffield, 2009). Social service departments began to collapse, social workers were put into the nursing case management departments, leading in some cases to a competitive environment

between the nurses and social workers (Judd & Sheffield, 2009). To compensate for this social workers have reengineered their positions to include counseling, crisis intervention and discharge planning, with a heavy emphasis on discharge planning (Judd & Sheffield, 2009).

Role of ICU Social Worker

ICU social workers play a key role in end-of-life acting as case managers, counselors, teachers, mediators and advocates (Bomba et al., 2011; Christ & Sormanti, 1999; Csikai, 2006; Heyman & Gutheil, 2006). They are trained to work with the whole person, and understand diverse cultural, ethnic, and socioeconomic backgrounds (Heyman & Gutheil, 2006). They are trained in crisis intervention, strengths perspective, cognitive restructuring, as well as individual and family therapy (Hartman-Shea et al., 2011). “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” (McCormick, Engelberg, & Curtis, 2007, p. 930). Palliative care is often included in end-of-life care due to its focus of caring for terminally ill patients.

Social workers help families navigate the ICU environment through understanding how it functions and the roles of the staff involved in the care of the patient (Heyman & Gutheil, 2006; McCormick et al., 2010; Rose & Shelton, 2006). Social workers develop coping skills with families to deal with the stressful environment, clarify medical information regarding prognosis, decision making options (do not resuscitate, artificial hydration/nutrition, mechanical ventilation, antibiotics, renal dialysis, etc.), and the difference between supportive/ comfort care and life-maintaining

care (Burford, 1981; Heyman & Gutheil, 2006; McCormick et al., 2010; Mann, Durgin, & Atwood, 1977; Rose & Shelton, 2006; Young & Iverson, 1984). “Families require accurate, clear, and timely information presented in a language that invites a beginning integration not only of the issues at hand but also of the potential outcomes” (McCormick, 2011, p. 54). It is imperative that families of ICU patients understand and are aware of the different end-of-life care options; including how and where the patient’s death can occur and the process surrounding the death in order to make decisions congruent with the patients’ wishes (McCormick et al., 2007). The social worker has the ability to assist with those needs through spending time with families to review the medical information and process their emotions. “Other stressors such as financial matters, past conflicts between family members, problems at work, difficulty with transportation, and finding lodging close to the hospital complicate the life of families of patients in the ICU” (McCormick, 2011, p. 54). These social work interventions reduce family stress and improve communication between the ICU team and families (Hartman-Shea et al., 2011; McCormick et al., 2007; Rose & Shelton, 2006).

Social workers also provide support to the ICU staff (McCormick et al., 2007) while juggling the other demands of a medical social worker. “Social workers who work in the ICU must balance their work with families with many other responsibilities including discharge planning and finding the legal next of kin of patients” (McCormick et al., 2007, p. 930). Hartman-Shea et al. (2011) identified twenty four medical social work interventions: organ donation, hospitality services, identify proxy decision maker, identify support system, anticipatory grief work, transfer to another social worker, cultural assessment, funeral assistance, spiritual needs, post discharge follow-up,

facilitate support groups, advance directives, discharge planning, practical assistance, medical team collaboration, arrange/attend family conferences, assess perception of illness/injury, family education, end-of-life care, staff support, facilitate family communication, psychosocial assessment, crisis intervention, and psychosocial counseling. Many of these interventions are not recognized outside of the ICU as necessary services provided by the social worker. However, interventions such as advance directives, arranging and attending family conferences, and locating next of kin are integral in providing effective end-of-life care (Hartman-Shea et al., 2011).

The social worker fills in the gaps that ICU clinicians may leave for families, working as ‘context interpreters’ for family members (Cagle & Kovacs, 2009). “Health care social workers help families put pertinent information into context and deal with feelings evoked by the information” (Cagle & Kovacs, 2009, p. 18). Social workers are often the most knowledgeable and comfortable discussing end-of-life care and hospice and “assist patients and caregivers in understanding available end-of-life options, including benefits and potential burdens” (Csikai, 2006, p. 1307). Due to their work with families, social workers decrease family member’s feelings of helplessness in the ICU (Miller et al., 2007).

The ICU Environment

The Intensive Care Unit (ICU) is a complex and confusing environment for patients and families. Levels of stress, anxiety and depression increase, due to the poor medical condition of the patient, varied communication with physicians and other medical personnel, and differences in cultural and religious beliefs (Rose & Shelton, 2006). Death is a deeply personal experience for all involved. Individuals interpret such

an event very differently depending on their cultural, religious, and environmental backgrounds, and life experiences.

Death occurs regularly in the intensive care unit (Curtis & Vincent, 2010). “Approximately 9%- 10% of patients admitted to the ICU will die there or shortly after they leave the unit” (McCormick, 2011, p. 54). Statistically, 20% of all deaths in the United States occur in ICUs (Curtis, 2005; Gries, Curtis, Wall & Engelberg, 2008). Between 11.5 and 30% of US hospital cost is 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 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), which results in the family making treatment decisions and participating in goals of care discussions with the critical care clinicians (Curtis & Vincent, 2010; McAdam, Dracup, White, Fontaine, & Puntillo, 2010; McCormick et al., 2007; Rose & Shelton, 2006). Due to biomedical advances and technical skills, patient’s lives are extended, there is prolonged suffering, and the dying process has become complicated (Christ & Sormanti, 1999). This highlights the need for qualified professionals to work with patients and families as they experience end-of-life issues.

Admissions to the ICU are often decided by non-critical care physicians and many times are unexpected and emergent (Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002). Often, end-of-life care is not discussed with patients or families prior to the decision to admit to intensive care (Rady & Johnson, 2004). This can create a level of tension between the ICU team and the family, patient, and prior medical team. Critical care physicians are often unfamiliar with a patient’s prior medical history, do not have an

existing relationship with the patient and family and hence are not fully prepared to discuss end-of-life decisions. This can lead to a medical treatment plan that is incongruent with the patient's wishes because the physicians do not feel comfortable addressing end-of-life issues with the patients and families or the families are not comfortable discussing end-of-life issues with the ICU clinicians. As a result, some patients may undergo aggressive treatment in the ICU that may not be beneficial to their overall prognosis and may only prolong the dying process. Sometimes aggressive care is provided because the medical team cannot predict if the treatment will be effective until tried, or families choose aggressive care even when they know the hope for a good outcome is slight or nonexistent.

Families must balance life outside of the ICU, such as paying bills, working and meeting other obligations, and, at the same time, care for and support their dying loved one (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001). Families often feel stress, confusion, depression, helplessness and many suffer from symptoms of post-traumatic stress disorder, acute stress disorder or posttraumatic stress reaction (Abbot et al., 2001; Ahrens et al., 2003; Bailey, Sabbagh, Loiselle, Boileau, & McVey, 2009; Carlet et al., 2003; Curtis, 2005 & Gries et al., 2008; Delva et al., 2002; McAdam & Puntillo, 2009; McAdam et al., 2010; Rose & Shelton, 2006). Family members in ICU's are usually in a state of crisis (Delva et al., 2002; Mann et al., 1977) and feel unprepared to act as the patient's decision maker (Rose & Shelton, 2006). These factors increase family members' levels of stress and anxiety, which affects their treatment decisions for the patient as well as their satisfaction with the quality of care received in the ICU (Abbot et al., 2001).

Patient and Family Autonomy

In healthcare, medical providers have an obligation to provide a level of care they feel is appropriate to the patient's condition and to clearly communicate the patient's diagnoses and disease process, available treatment options, and an unbiased recommendation about how to proceed with care. However, there are many obstacles in the ICU that impede medical providers and family members from providing that level of care, such as varying personal beliefs, cultural backgrounds, religious/spiritual beliefs, and emotions. In ICUs there are no formal rules about what is the right choice for end-of-life care. Each person has a unique set of values and beliefs impacting how they or their families wish to die. This can often come into conflict with the medical team's treatment plan for the patient.

Family members of ICU patients face the dilemma of separating their wishes from the wishes of the patient. "The moral question correspondingly shifts from what is 'right' to what is 'right for me'" (Gilligan, 1993, p. 52). Death is a finite event. Family members will not be able to touch their loved one again, to share experiences, or to have conversations. This is difficult and sometimes impossible for family members to handle. The social worker assists families in differentiating their wishes from the ones of the patient, which is an important element when working to provide quality end-of-life care.

Families often feel intimidated by the physician; they do not speak the same language, have different educational backgrounds, and have learned through society that 'the doctor knows best' (Nadicksbernd, Thornberry, & von Gunten, 2011). Physicians are seen as the top of the hierarchy in the hospital and hence family members are often uncomfortable asking the doctor to re-explain something that they do not understand. As

the interactions continually occur, the level of stress increases for family members, creating further confusion as to what is the “right” decision to make for the patient’s care (Nadicksbernd, Thornberry, & von Gunten, 2011).

Every patient has the right to choose or refuse their medical care, and the social worker has the obligation to ensure that personal bias and beliefs do not interfere with those rights. The concept of self-determination is an integral part of social work practice across all micro, mezzo and macro fields (McCormick, 2011). End-of-life care is a key element in the practice and debate about what self-determination means for the patient and family. Social workers are charged to understand and utilize the concepts of self-determination to promote the well-being of their patients, families, and society.

The social worker must understand internal and external conflicts in order to guide patients and families in an unbiased way (Rothman, Smith, Jakashima, Paterson, & Mustin, 1996; Weick & Pope, 1988). Often there is lack of congruency between social worker’s needs and the patient’s needs and it is the responsibility of the social worker to respect the differing wishes of the patient. Standard 1.02 in the NASW Code of Ethics (2008) states that “social workers respect and promote the right of clients [patients] to self determination and assist clients in their efforts to identify and clarify their goals” (p. 5). Rothman (1989) identifies the need for social workers to have an understanding of the legal and statutory restrictions on patients. Often there are parameters on what resources are available to patients based on their legal eligibility as well as boundaries on what the social worker is able to provide (Rothman, 1989). Social workers should facilitate the patient’s self-direction by applying that knowledge.

Self-determination has become a defined concept in medical social work practice and end-of-life care (Wesley, 1996). Social workers advocate for the patient's freedom for self-direction individually and systemically. End-of-life care in the medical setting is an environment where social workers need to employ the fundamental concepts of self-determination in his/her everyday work with patients, families, and medical providers.

Without a broader image of the common good, without a reciprocal relationship with community, death and dying become private and isolated. Self-determination as a value within social work practice must be coupled with a vision of the common good that demands a sense of reciprocal responsibility within the community (Wesley, 1996, p. 7).

Social workers have the ability to work with and identify the needs of patients, families and medical providers. In the ICU, this is a time when social workers can “promote an environment that supports open discussion of medical treatment options and how each will affect patients” (Csikai & Bass, 2000, p. 17). Ingrained in self-determination is a respect for people of different backgrounds, lifestyles and an understanding of the differences in groups of people (Mizrahi, 1992). Social workers are able to use that knowledge and guide patients and families through the decision making process. The social worker is able to address the physical and emotional needs of the patient (Dubus, 2010), as well as educate the patient and family on all available treatment options (Mizrahi, 1992).

The National Association of Social Workers (2008) stresses the right of the patient to determine his/her level of care. If families have a better understanding of the patients medical condition they can make end-of-life decisions significantly earlier on.

“The appropriate role of social workers in end-of-life matters is to help patients express their thoughts and feelings, to facilitate exploration of alternatives, to provide information to make informed choices, and to deal with grief and loss” (In Social Work Speaks, 2006). Patients have a right to control their bodies and minds, making decisions that accord with their own values and beliefs (Mizrahi, 1992; Wesley, 1996). It is the responsibility of the social worker to help patients maintain dignity and control as they move through the dying process. Social workers are able to inform patients and families of the resources available to them, including information on insurance, treatment options, hospice care, pain management, advance care planning, and nursing home placement (In Social Work Speaks, 2006). It is the responsibility of the social worker to help patients and families feel comfortable with their decisions and provide counseling through the end-of-life process (Csikai & Bass, 2000; Dubus, 2010). Coined a 'fundamental freedom' by Rothman (1989), self-determination holds that all clients have the right to make their own decisions in life. Hospital social workers have a duty to respect the patients' decision-making process and ensure that their wishes are represented and honored.

Advance Care Planning

Advance care planning is the process where patients either clearly explain or write out their wishes for care at their end-of-life in the event that they become incapacitated. However, advance care planning has not been proven to affect outcomes in the ICU (Carlet et al., 2003), it does guide the medical providers and families to create appropriate treatment plans consistent with the wishes of the patient. “Directives give individuals an opportunity to exercise a certain measure of control over care and treatment, especially life-sustaining treatments” (Blondeau, Valois, Keyserlingk, Hebert & Lavoie, 1998, p.

328). Advance directives provide a framework to guide families and physicians.

However, Carlet et al. (2003) found that only about 10% of ICU patients have advance directives.

Social workers play a central role in advance care planning, primarily through education and advocacy (Bomba et al., 2011). Social workers assist with the planning, completion and execution process of advance care documents (Morrissey, 2005), due to their ability to engage the patient and family in discussions regarding their wishes for end-of-life care (Morrissey, 2005; Soskis & Kerson, 1992). They are able to educate the patients on the various documents, their meaning, and how to complete them (Morrissey, 2005). Patients are often intimidated by the content of advance care documents, because they discuss scenarios such as, advanced life-support, cardio-pulmonary resuscitation, and withdrawal of life-sustaining treatment. Social workers acknowledge those anxieties and work through them as the patients prepare their documents (Morrissey, 2005).

Communication in the ICU

Communication variation in the ICU occurs amongst all healthcare practitioners. There are three components to end-of-life discussions that are used most frequently by physicians: delivering prognosis, goals of care discussions, and code status discussions (Larochelle et al., 2009). Each of these topics can have a different meaning to the patient and family depending on how the information is presented (Larochelle et al., 2009). However, Rose and Shelton (2006) found inadequate communication between ICU physicians and families, which results in misunderstandings of prognosis, diagnosis, and/or treatment suggestions. Misconceptions can create confusion, heightened levels of stress, and decreased family satisfaction with care in the ICU (Carlet et al., 2003; Gries et

al., 2008; Rady & Johnson, 2004; Rose & Shelton, 2006). “Problems in communication and conflicts between family decision-makers and the medical team have been implicated as barriers to quality medical care, including postponing palliative care and continuing invasive, potentially nonbeneficial treatment” (Rose & Shelton, 2006, p. 5).

Inadequate communication is a significant problem in the ICU because families often have to decide if they should withdraw or withhold care from their dying loved one (Rose & Shelton, 2006). Curtis (2005) found that families need careful explanations to understand “how interventions will be withdrawn, how the patient’s comfort will be insured, the patient’s expected length of survival, and the continuation of care by the clinical team” (p. 126). Open and ongoing communication aids families in deciding the best treatment option for their loved one to ensure quality of care at the patient’s end-of-life (Browning, 2008; Curtis & Vincent, 2010; McCormick, 2011).

Many physicians have difficulty with end-of-life decisions (Curtis & Vincent, 2010; Quill, 2000). “Clinicians often wait until death is in sight before discussing dying” (Sullivan, 2003, p. 395), which can be due to the physician’s fear of taking away one’s hope (Barclay, Blackhall, & Tulsky, 2007; Sullivan, 2003). Physicians may offer “one more” procedure or treatment that is futile in order to feel as though they did everything possible (Sullivan, 2003; Quill, 2000). “This inability to relay unfavorable prognostic information results both from medicine’s inherent prognostic uncertainty and from clinicians’ fears that they will be perceived as ‘giving up’ if they talk about dying, thereby eliminating hope and depressing patients” (Quill, 2000, p. 2503). In addition, physicians often do not have time to listen to or discuss the emotions felt by the family

members (Curtis et al., 2005), which results in increased opportunities for miscommunication.

Differing personal and moral beliefs of the medical providers and families can impact end-of-life decisions (Barclay et al., 2007; Carlet et al., 2003; Curtis, 2005; Laroche et al., 2009). The religious, ethnic or cultural background of the physician can influence the treatment options that are presented to the family (Carlet et al., 2003). When a physician's belief conflicts with those of the family quality of care may be jeopardized. For example, withdrawal of life support is a recurring debate in the ICU. The family may not believe in withholding or withdrawing life-support. The patient may then be left on mechanical ventilation or other life-sustaining treatment, which can prolong suffering. Such divergence of opinion can erode the doctor-patient relationship, create "conflict" and lead to feelings of "mistrust" (Curtis, 2005). Sullivan, Muskin, Feldman and Haase (2004) found that "42%-44% of hospital patients report that religious belief is the single most important factor in coping with their illness" (p. 120). However, discussing how the patient and family's religious views affect their end-of-life care is not common practice in the ICU (Sullivan et al., 2004).

Interdisciplinary Team

The introduction of interdisciplinary teams resolves many of these aforementioned controversies of inadequate communication and conflicting personal beliefs on end-of-life care. Interdisciplinary teams provide patient and family-centered care (Connor, Egan, Kwilosz, Larson & Reese, 2002). The team is able to leverage the specialty training of each member to educate, support and guide families and patients

through the end-of-life experience in the ICU (Connor et al., 2002). Improved support by medical providers has been linked to family satisfaction (Truog et al., 2008).

Campbell and Guzman (2003) found that an interdisciplinary approach to working with critically ill patients aids in decreasing hospital length of stay, and shifts the focus of care to comfort earlier in the disease process. “Improved outcomes regarding patient time spent at home, patient and family satisfaction, reduction of days in the hospital, decreased costs, and patients’ likelihood of dying where they want, can all be attributed to interdisciplinary care” (Goldsmith, Wittenberg-Lyles, Rodriguez, & Sanchez-Reilly, 2010, p. 94). Interdisciplinary teams allow for increased interaction between the patients, families and the medical team. Each member of the interdisciplinary team has a role when working with the family and the patient. Physicians, guided by a biomedical orientation, explain in detail the medical condition and treatment options for the patient (Werner et al., 2004); nurses clarify the medical information and provide support through daily care of the patient (Werner et al., 2004); and social workers, utilizing a psychosocial orientation, play a key role in communication with patients and families (Bomba et al., 2011; Werner et al., 2004). Cagle and Kovacs (2009) and McCormick and colleagues (2010) stress the significant impact social workers have on improved communication between patients, families and health care providers. Social workers are more likely than nurses to involve family members in decisions regarding life sustaining treatment (Werner et al., 2004), spend time with the patients and families to process their emotions, request additional information from the medical professionals as needed, and guide decisions made throughout the ICU admission. In addition, social workers educate

the medical team on the patient's religious and cultural background, and advocate for the wishes of the patient and families in cases of conflict.

Social workers address communication problems that arise in the ICU (McCormick et al., 2010). Social workers spend time speaking with families directly, discussing the family's perspective on the patient's condition, clarifying information, organizing and attending family conferences, and providing relevant psychosocial information to the ICU medical team (Rose & Shelton, 2006; Young & Iverson, 1984). Social workers "can encourage health professionals to understand and clarify their own role in the decision-making process, promote communication and problem solving, and identify and improve systems that may interfere with optimal communication and problem solving regarding such sensitive problems as end-of-life decisions" (Werner et al., 2004, p. 34). Hartman-Shea et al. (2011) found that psychosocial counseling and support was one of most frequent social work activities most linked to family satisfaction and the reduction of anxiety. "Assessment of the family's response to crisis and understanding their communication patterns can guide the team in a more compassionate and effective approach to sharing information" (Hartman-Shea et al., 2011, p. 152). Social workers bridge the gap that often exists between the medical team and families because of miscommunication (Hartman-Shea et al., 2011).

Family conferences are an effective strategy in the ICU for medical providers to discuss end-of-life care and deliver poor prognosis, and have been linked to the reduction of the family's symptoms of post-traumatic stress disorder (PTSD), anxiety, and depression (Browning, 2008; McAdam & Puntillo, 2009). Csikai (2006) found that social workers and physicians were the most involved health care professionals in end-of-life

communication and decision making. Family conferences are an effective method for communication with patients and families, which “enables patients, family members, and providers to discuss together the illness experience, care options, and end-of-life decision-making” (Fineberg, 2005, p. 858). A primary benefit is that all the family members hear the same information at the same time, and physicians, nurses and social workers do not have to repeat information to many people in separate meetings. In addition, family conferences give everyone on the interdisciplinary team a chance to discuss the treatment plan with one another. End-of-life discussions have been associated with less aggressive care close to death and earlier hospice referrals (Bomba et al., 2011).

It is important for families to obtain pertinent information regarding their loved one’s health (Carlet et al., 2003; Curtis & Vincent, 2010; Rady et al., 2004). Families need ongoing and direct communication from ICU clinicians as well as assurance (Browning, 2008; Delva et al., 2002; Truog et al., 2008). “The facilitation of accurate and thorough communication between healthcare professionals and the patient’s family is essential for appropriate decision making in the critical care setting at end-of-life” (Browning, 2008, p. 22). Families have higher rates of satisfaction of the ICU care when clinicians take the time to listen, rather than talking without listening to the family members and when clinicians provide understandable, complete and consistent information (Curtis & Vincent, 2010; Rose & Shelton, 2006; Stricker, Kimberger, Schmidlin, Zwahlen, Mohr, & Rothen, 2008). Interdisciplinary teams create an environment in which the physicians, nurses and social workers provide clear explanations about the disease process (Werner et al., 2004). This improves the family’s understanding of the patient’s medical condition, creating opportunities for families to

make end-of-life decisions significantly earlier in the ICU stay. There is evidence that shows good communication and opportunities for families to express their concerns and emotions can reduce psychological morbidity and decrease posttraumatic stress reactions (O'Mahoney et al., 2010; Truog et al., 2008).

MSW Education

Existing literature on end-of-life care in the practice of social work identifies many gaps in the traditional MSW curriculum. Specifically there are no required end-of-life care courses in an MSW program, and of the required courses that integrates end-of-life care into the curriculum, such as Human Behavior in the Social Environment, the content is limited and is a fraction of the course content (Berzoff, Dane & Cait, 2005; Bomba et al., 2011; Christ & Sormanti, 1999; Csikai & Raymer, 2005; Fineberg, 2005; Forrest & Derrick, 2010; McCormick et al., 2010). Some schools offer specialized elective courses in end-of-life care, but end-of-life care is not required in either the courses taken or in the field placements (McCormick et al., 2010). Csikai and Raymer (2005) note inconsistencies in elective course offerings. For example when an elective course on end-of-life care is offered, the course often becomes oversubscribed, leaving many unable to enroll. At other times faculty is not willing to teach the course. In some cases where an adjunct or part-time faculty member teaches the course, he or she is often unable to teach the course every semester due to time constraints with his or her own direct practice (Csikai & Raymer, 2005). Some adjunct faculty may teach from their perspective as a clinician, thereby resulting in inconsistency throughout the teaching of end-of-life care (Csikai & Raymer, 2005). The MSW education provides the core set of values and knowledge that social workers have as they practice in the field. Without

consistent information on how to provide end-of-life care, social work practitioners are at a disadvantage in the ICU.

Upon careful review of the course descriptions for 5 MSW programs in the Greater Philadelphia area there was little mention of end-of-life care except for a few elective courses. This researcher went to the websites of each of the programs under the course descriptions to gather this information and found that the University of Pennsylvania offers the most elective courses that either integrate or are focused on end-of-life care. Courses such as Loss through the Life Cycle and Loss and Crisis Intervention focus on bereavement. However, the program required course does not include end-of-life care. Temple University offers a specialization in health and mental health. Within this specialization, students are required to take three health and mental health courses: Dynamics of Health, Health Care, and Health Systems, Health/Mental Health Policy, and Social Work Practice in Health and Mental Health, but end-of-life care is not expressly covered in these three courses. Temple offers one elective, Loss and Grief, which focus on end-of-life care. A review of Bryn Mawr College's Masters of Social Service electronic course-book did not uncover any end-of-life focus. West Chester University has one elective, Older Adults, which does discuss social work assessment and intervention with elderly clients regarding death and bereavement. Lastly, Widener University offers one required course, Social Work and Aging, which mentions ethics, bereavement, dying and advance directives, as well as an elective course, Grief and Loss across the Life Cycle, which deals directly with end-of-life. All five MSW programs offer an elective on aging, however only one of the course descriptions exclusively mentions end-of-life care. This review illustrates a gap in end-of-life care

education and points to the need for MSW programs to increase the amount of end-of-life care offered in the practice and elective courses.

Medical social workers are pushed and pulled in many directions. Christ and Sormanti (1999) found that many do not have time for continuing education programs/training due to the demand for discharge planning. This impacts the core elements of end-of-life social work practice, and creates inconsistency in the delivery of end-of-life care (Berzoff et al., 2005), because social workers lack formal training in end-of-life care. Csikai and Raymer (2005) found inconsistencies in how end-of-life care is taught, and when end-of-life care is included in a course syllabus, content is rushed through due to time constraints. As a result, Csikai and Raymer (2005) found that many social workers felt unprepared to provide end-of-life care after graduating from a social work program.

Dealing with issues of death and dying may create a strong sense of helplessness among practitioners if they are not educationally prepared. In today's death-defying society, few may be aware or have confronted their own feelings and values regarding their own mortality. This may make it more difficult to assist individuals and their families to cope with the dying process (Csikai & Raymer, 2005, p. 68).

A stronger focus on end of life care in MSW programs would help social workers bridge this gap.

Theoretical Framework

Ecological Perspective

The ecological perspective was used as the theoretical framework that best fits this study. The ecological perspective links individuals to their environment on the grounds that “human behavior is to be understood within the social environment in which the behavior takes place” (Norlin, Chess, Dale & Smith, 2003, p. 36). This perspective

views the individual and his or her environments as forming an ecosystem, consisting of the individual, all the systems with which the individual has reciprocal relationships, the wider environment in which the individual acts, and all the mutual interrelationships that occur between the individual and the various subsystems (Weiss-Gal, 2008, p. 65).

The ecological perspective is centered on the transactions of the person-in-environment, including the person’s ability to adapt to and cope with their environment (Zastrow & Kirst-Ashman, 2004). Those transactions occur at four levels, the microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1994).

As we examine the role of the ICU social worker providing end-of-life care, it is important to understand how that social worker functions within their ecosystem, which is the hospital, and their interactions with patients, families, and the ICU team. How the ICU social worker was trained, and what factors have influenced their ability to perform that role, are additional elements to consider. “The centrality of understanding people as they relate to their environment, and the reciprocal relationship of people to their environment” (Beder, 2006, p. 4) are integral to ICU social work practice.

Each person is a microsystem, interacting interpersonally with other microsystems (Broffebrenner, 1994). In the ICU, the social worker interacts with other microsystems that are the patients, families, and interdisciplinary team members. The social worker brings their own experience, education and training to those interactions. As a result, it is important to understand the perceptions of ICU social workers regarding their role in providing end-of-life care. Specifically, we hope to understand what they do value in their role and what experiences have shaped their ability to perform that role as the ICU social worker. In addition, the ICU social worker must understand that each person brings his or her own perspective and experience, which shapes how they behave and react in the ICU.

People have internal resources, which are the psychological components that aid the person in their transactions with the environment (Germain, 1981). A person's age, sex, culture, physical condition, emotional state and prior experience influence their perceptions (Germain, 1981). Patients and families react differently than medically trained staff because they do not have the experience and knowledge of medical terminology and diagnoses that is common to nurses and physicians. Social workers need to be aware of that difference and guide the patients and families as they make end-of-life decisions, as well as educate the medical staff on the views and perceptions of the patient and family.

The mesosystem is the interaction between a microsystem and a larger unit, such as the interdisciplinary team and the family (Broffebrenner, 1994). It is important to understand how the social worker identifies with the team and the family, the communication patterns between the two, and the role of the ICU social worker as a

member of the interdisciplinary team and working with the family. In addition, it is important to understand how the social worker interacts with the family unit. Conflict can occur within a family dealing with end-of-life. How the ICU social worker identifies that conflict and works through the problem with the family is integral to ICU end-of-life care.

The next level, the exosystem, is the interaction between the microsystem and the organization, such as the hospital (Broffebrenner, 1994). The hospital may dictate the size and composition of the social worker's caseload, therefore it is critical to examine the influence and attitude of the organization towards the ICU social worker (Roer-Strier & Rosenthal, 2001). One "can consider the institution not only as an entity in and of itself but also a conglomerate of all the individuals and groups that comprise it" (Higgins, 2001, p. 35). The ICU social worker's job is also structured and outlined by the hospital administration. If not in a separate department of social work, hospital social workers might be situated in a department with a title such as Clinical Resource Management, which is headed by a nurse and where the focus is around utilization review, short lengths of stay, and rapid discharges. As the ICU social worker balances the demands of the organization, it is important to uncover whether they are able to participate in end-of-life care in the ICU if it is not related to a discharge plan.

Lastly, the macrosystem is the interaction between the microsystem and the broader cultural, economic, and historical context (Broffebrenner, 1994). It is "the influence of history, values, laws and regulations, aspects of social policy, and customs from the culture of origin and from the host culture" (Roer-Strier & Rosenthal, 2001, p. 218). ICU social workers providing end-of-life care must have a broader understanding

of how society looks at death. “Every society and faith system has developed some way of integrating the reality of death into their belief systems and ways of life” (Silverman, 2004, p. 128), and it is important for the ICU social worker to be aware of differences in beliefs on end-of-life. Individuals are part of a community and a social network. In that community, power, privilege, and common beliefs influence individual values (Ungar, 2002). The community influences the physical and social environments through cultural norms, values, beliefs, knowledge and technology (Gitterman & Germain, 1976). As people develop and evolve, the person adapts to both their physical and social environment (Germain, 1981). The unwritten rules of society are not absent in the medical settings. Rather, societal norms influence how care is provided and which choices patients, families, and medical providers ultimately make. Often social workers are faced with guiding families through the decision of when to provide or not provide aggressive care at a patient’s end-of-life. Social workers must work to determine what society is pressuring someone to do versus what the needs and wants of the patient truly are, as patients, families, and medical practitioners make choices for care in socially charged medical conditions. Ethical issues arise in the healthcare system constantly, often stemming out of conflict between the patient’s wishes and the medical team. Social workers must work to mediate between the patient’s right to self-determination and the medical’s team’s belief of the proper treatment for the patient. The social worker acts as an educator to the patient and staff, a facilitator during the meetings and conversations about potential treatment options, and an advocate for the patient.

Utilizing the ecological perspective, ICU social workers maintain an awareness of their role within the ICU and within the hospital. ICU social workers need to justify their

worth as end-of-life practitioners to the healthcare organization and staff. Social workers do not have the medical training of nurses and physicians. This can create tension and disconnect amongst healthcare professionals. Therefore, social workers must balance their professional values with the needs and demands of the health organization as well as the patients and families. The purpose of social work is to help foster healthy and independent transactions between individuals and their environment (Ungar, 2002). “Social work seeks to promote adaptive transactions and to prevent or correct maladaptive ones” (Germain, 1981, p. 325). Using an ecological perspective allows the ICU social worker to utilize interventions that aid the patient and family in developing the tools needed for healthy functioning in the ICU. “Intervention then takes on the character of natural life processes that alter, use, or support properties of the environment, the coping qualities of the person(s), and the nature of the transactions between them” (Gitterman & Germain, 1976, p. 602). This provides a framework for the social worker to work with patient and family, understanding the transactions between the patient and his or her environments, which influence their ability to cope with and make decisions regarding end-of-life care. As the social worker identifies the interactions between themselves and the various systems, as well the interactions between the patients and families, they can help guide the patient and family through the end-of-life process in the ICU as well as the transition out of the ICU.

Need for Further Research

There is a lack of research on the role of the ICU social worker in end-of-life care (Heyman & Gutheil, 2006; Kramer, Christ, Berk-Klug, & Francoeur, 2005). McCormick et al. (2007 and 2010) and Hartman-Shea et al. (2010) discuss the need for further study of the experience of the ICU social worker, clarification of activities that social workers in the ICU engage in to meet the needs of families, and an understanding of the ICU social worker's case load. Knowledge of how social workers perceive their role, and some of the factors that may help or impede them from providing end-of-life care, will help increase our awareness of ways in which we can increase the value of social work in the ICU.

The majority of the literature available on end-of-life care in the ICU is based on the attitudes and perceptions of physicians and nurses (Heyman & Gutheil, 2006). Medicine and nursing dominate the research, which does not include ICU social workers. Further research into the work of social work in the ICU and with end-of-life care is long overdue. It is important to understand how the social workers view their role working with patients and families in end-of-life care and what factors satisfy or impede that role and how to improve the training and preparation for that role.

Research Questions

Microsystem:

- (1) How do ICU social workers perceive their role providing end-of-life care in the ICU?
- (2) What educational programs have ICU social workers found helpful to them in their work?

Mesosystem:

- (3) What is the ICU social worker's experience working on an interdisciplinary team?
- (4) How do ICU social workers handle advance directives?

Exosystem:

- (5) What are the factors in the social worker's department that impede the ICU social worker's ability to provide end-of-life care?
- (6) What are the factors in the social worker's department that help the ICU social worker's ability to provide end-of-life care?

Macrosystem:

- (7) How do the ICU social worker's values or world view impact how he or she provides end-of-life care?
- (8) What do ICU social workers think about how to improve the field of ICU social work?

Methods

Qualitative Approach

Qualitative research methods were used to gain an in-depth understanding of how seventeen ICU social workers perceive their practice of end-of-life care and what the barriers and facilitating factors are that may impede or aid them in delivering that care. In order to create cohesion in the profession for how end-of-life care is delivered in the ICU, it is important to understand how social workers approach their work with end-of-life, their various roles and responsibilities, their interactions with the different family members and members of the interdisciplinary team, and the experiences of the ICU social worker. At this time there is a lack of research in the area of ICU social work practice examining, from the perspective of social workers, how they view their role, what are the factors that help or impede their ability to perform that role, and how their MSW education has influenced them. A qualitative study permits exploration of this topic in depth, connecting what social workers should be doing, to what they are doing, and determining if the MSW curriculum is preparing MSW graduates for that role.

Recruitment/ Data Collection

Interviews were conducted with seventeen ICU social workers in the Greater Philadelphia Area, which was comprised of Philadelphia County, Montgomery County, Chester County, Delaware County and Bucks County of Pennsylvania. Seventeen face-to-face interviews with experienced ICU social workers who are currently assigned to at least one ICU in his/her hospital were conducted and recorded. A semi-structured interview guide was used to explore how the social workers perceive their role in providing end-of-life care, the factors which have aided or hindered their ability to provide that care, an understanding of their past educational experiences on end-of-life

care, and what may be needed to improve the care they provide. The interview guide was developed out of the existing literature, using concepts and themes on what is “good” social work practice for end-of-life care. The interview guide aided the organization and analysis of data (Bowen, 2005). It was organized into sections that are organized from an ecological perspective, beginning with the social worker as an individual bringing his/her own experience to the interaction. The interview guide then examined each social worker’s interaction with other microsystems, then the mesosystems, exosystems, and lastly the macrosystem. The topics covered within those sections was the social worker’s perception of end-of-life care in the ICU, what skills and knowledge are needed to provide end-of-life care, how his/her MSW education influenced their ability to provide end-of-life care, the social worker’s work with the interdisciplinary team, how the hospital influences his/her role, potential ethical dilemmas that arise in the ICU, and his/her satisfaction with care in the ICU. For the complete guide please refer to Appendix 1.

The interview with each social worker was conducted in an agreed-upon location in a space in or near his/her hospital, at a local restaurant, or in the participant’s home. Hospital social workers have a hectic schedule making it difficult for them to leave their workplace for an extended period. The space chosen was removed from his/her ICU, and the majority of the interviews were completed at a closed and private place free from distraction. However, three of the participants chose to be interviewed in his/her hospital’s cafeteria, lobby, and at a restaurant near his/her hospital. Each participant was compensated with a \$30 gift card at the completion of the interview. The interviews lasted about thirty minutes to one hour, and were audio recorded. After a series of twelve

interviews the participants were reporting similar themes. At that point saturation was reached on some topics, but not every topic. The interviewer continued with five more interviews, at which point saturation was reached on the majority of the questions.

The inclusion criteria for the interviewees were that (1) he/she must be employed as a medical social worker and, (2) he/she must be assigned to a minimum of one ICU, and (3) the social worker must have worked in a hospital ICU for a minimum of one year. This minimum work experience requirement is important in order to understand how the social worker has integrated end-of-life care into his/her practice, and has an understanding and balance of the different responsibilities as a medical social worker. Often social workers are assigned to multiple units and it is important to understand what their perspective is regarding their role in that ICU and if they value end-of-life care as part of their daily practice.

The exclusion criterion for the interviewees was (1) any ICU social worker without an MSW degree, and (2) he/she spends little to none of their time in the ICU on a weekly basis.

Purposive and snowball sampling were used, resulting in seventeen in-depth interviews (Bowen, 2005). Through purposive sampling recruitment the lead social workers, managers, and medical social workers at the various hospitals in and around Philadelphia were targeted. They were asked to identify the ICU social workers who may be contacted to participate in this study. In addition, they were provided information on the nature of the study and the time commitment requested from the participants. Once the social worker was identified, he/she was emailed directly with a brief summary of the interview process and the general topic for study, called over the phone with the same

brief summary of the interview process and general topic for study, or the potential participant contacted the interviewer to discuss participation. One week after the initial call or email to the manager, team lead, or social worker at the various hospitals, a follow-up phone call or email was conducted for follow-up, and another every week until contact was reached. Purposive sampling also enabled the interviewer to include social workers of different ethnic and racial backgrounds as well as varying length of time working in the ICU. Snowball sampling was applied by asking the interviewed social workers if he/she knew of other ICU social workers in the Philadelphia area, and if so, ask the interviewee to connect the interviewer to him/her. This strategy was useful because it was purposive and designed to identify other ICU social workers in the medical field (Morrow, 2005). This resulted in the recruitment of three participants.

Data Analysis

Thematic analysis was conducted on the data. “Thematic analysis focuses on identifiable themes and patterns of living and/or behavior” (Aronson, 1994, p. 1), 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 finally connecting the data to the existing literature to support the argument for those themes (Aronson, 1994). Deductive coding is derived from the ecological framework and by having the literature guide the analysis of the data and inductive coding relies on “themes emerging from participant’s discussions” (Fereday & Muir-Cochrane, 2006). The coding was conducted in NVIVO 10 software. Thematic analysis afforded researchers the opportunity to connect the themes in current ICU end-of-life practice to

the literature, discovering what methods of practice are/not being utilized in the field and why.

The interviews were transcribed by a reputable transcription service and the researcher then used an inductive approach to identify “patterns in the data by means of thematic codes” (Bowen, 2005, p. 217), as well as a deductive approach, whereby themes were also derived from existing literature. The categories and themes then emerged from the data. The researcher then used a constant comparative method; examining each line, sentence, and paragraph sections of the transcriptions to identify which codes match the concepts from the literature and other interviews (Bowen, 2005). The researcher then moved to focused coding, whereby the open codes were compared, condensing them into themes that are consistent with one another. In order to stay grounded in the data, new and emerging data were compared to the existing themes, and the researcher used memoing during the analysis and transcription process. The memos aided in the analysis of the data, encompassing code notes, theoretical notes, hunches, and interpretations that emerged from the beginning through the end of the research process (Morrow, 2005; Rubin & Babbie, 2011).

Methods to Ensure Rigor

To ensure the rigor of this research the researcher implored various methods to ensure the trustworthiness and dependability of the results. The methods implored were an audit trail, member checking, an engagement in reflexivity and negative case analysis.

An audit trail is important for the dependability and trustworthiness of the findings. To begin, the researcher triangulated the data. “Triangulation is a means of corroboration, which allows the researcher to be more confident of the study

conclusions” (Bowen, 2005, p. 215). Two other DSW students from a different discipline independently reviewed one transcript. He/she conducted the same level of thematic analysis of the transcriptions and then they reviewed the codes for similarities. The DSW students and the researcher then compared what they agreed and disagreed on and then come to a consensus. Clear and organized 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. NVIVO 10 was then used to organize and manage the codes developed.

Member checking is another important element to ensure the credibility of the research. Throughout the interviews the researcher asked for clarification and engaged the participant in providing a deeper meaning and explanation from the questions asked, maintaining a naïve stance on the topic (Morrow, 2005). “This is particularly important when the interviewer is an ‘insider’ with respect to the culture being investigated or when she or he is very familiar with the phenomenon of inquiry” (Morrow, 2005, p. 254). In addition, three of the participants, participant three, ten, and eleven, were contacted to confirm the accuracy of the transcription, and all three confirmed the interviews were transcribed accurately.

Member checking and a clear audit trail aid in the process of reflexivity, through ‘monitoring of self’ and being ‘rigorously subjective’ (Morrow, 2005). The researcher engaged one of the members of the committee in reflective conversations about the interviews. This debriefing provided for the opportunity of the committee member to act as devil’s advocates, “proposing alternative interpretations to those of the investigator” (Morrow, 2005, p. 254). The researcher also compared the codes and notes taken to her

own evaluative process of the findings, to identify and be aware of any personal biases the researcher may hold. “These strategies for managing subjectivity can assist the investigator in achieving the goal of *fairness*” (Morrow, 2005, p. 255), whereby the identification of personal biases allows one to limit the degree of skewed or lopsided interpretations based out of those biases.

Utilizing negative case analysis the researcher thoroughly searched for cases that did not fit her interpretations (Rubin, 2000). This “involves a deliberate and articulated search for disconfirmation and helps to combat the investigator’s natural tendency to seek confirmation of her or his preliminary or emerging findings” (Morrow, 2005, p. 256). By repeatedly comparing the transcriptions and codes, the researcher decreased the influence of personal bias and increased the accuracy of the codes and categories (Morrow, 2005).

Statement of Human Subjects Protection

Medical social workers were studied who have in their assignment a minimum of one ICU, medical or surgical. Prior to the recorded interview, the researcher reviewed the purpose of the study, had each respondent complete the demographic information, and provided each participant with an informed-consent agreement for signature. The social workers were asked to describe the work they do with patients and families at end-of-life, their interactions with the other ICU team members, relevant educational history on end-of-life care, and how they feel their practice could be improved. The researcher did not ask the interviewees to discuss any specific patient or team member, or to provide identifying information of a patient or other staff member, nor were they asked for any personal experiences with death or end-of-life care. Rather, the focus of the interviews was on the social worker’s professional experience of providing end-of-life care in the

ICU. In addition the interviews and transcriptions were stored in a locked cabinet in the researcher's home office.

The interviewees may have had questions or concerns about how well or not well they are performing end-of-life care in the ICU or uncomfortable discussing problems in their workplace candidly. To address these concerns they were educated from the beginning that this was an exploration into how ICU social workers in general provide end-of-life care and that the interview will not be an evaluation or judgment on their skills as an ICU social worker. The interviewee also signed the consent form prior to the recorded interview as well as was provided with the researcher's contact information in case a referral for support services was needed at the conclusion of the interview. Each interviewee was compensated with a \$30 gift card to a coffee shop for their participation. The interviews were then transcribed by a reputable transcription service, Landmark Associates. The interviews were sent to the service without any identifying information; each interview was assigned a number. The transcription service kept all interview information confidential. To conclude, this work was submitted and approved by the University of Pennsylvania Institutional Review Board before any participants were contacted or data was collected.

Reflexivity Statement

Death and dying has been a prevalent topic in my life as the official ICU social worker at Pennsylvania Hospital. At the start of my time at Pennsylvania Hospital the ICU did not have a designated social worker. As a result, families complained that the medical team lacked an understanding of and empathy towards end-of-life care. I quickly learned that a system of care for end-of-life patients was necessary to provide quality

care. At Pennsylvania Hospital I helped establish and implement two new processes for the ICU interdisciplinary team: (1) identify the patient's medical decision makers and meet regularly to discuss the patient's diagnosis, developments and prognosis, and (2) provide support to the patient and family throughout the patient's stay in the ICU. As the ICU social worker I took an active role in the identification of the medical decision makers and organized the family meetings. I had found that the nurses and physicians were focused on the medical care and management of the patient and family meetings often occurred without the appropriate family members. This created conflict, confusion and repetition. In addition, as the social worker, I provided support and understanding for patients and families throughout their conversations with the physicians.

A significant experience with death in my personal life affected how I view the process of end-of-care in the ICU. A friend of mine died from leukemia in a large teaching hospital. He had appointed me as the primary medical decision maker, which put me in a position to work with the ICU team after he was intubated to discuss goals of care, his treatment plan, and eventually withdrawal of care. Throughout this experience I did not work with a social worker or any member of the medical team who specialized in palliative care.

Palliative care is provided by a team of medical providers who focus on alleviating physical pain, providing emotional and spiritual support, and help the patient and family understand the patient's medical condition. There were never any formal meetings where, as the 'family', we were able to meet with the attending physician privately. At the time near his death, the medical team, nurse that day and ICU Fellow called for a meeting with us to discuss his prognosis and withdrawal of care. After the

meeting, there was a great deal of conflict among the patient's friends and family, and at the time of withdrawal of care there was a significant amount of tension.

This experience showed me, from a caregiver's perspective, how an ICU social worker can decrease a family's confusion. As the 'family' we were left to process his condition ourselves. Consequently, family members consulted their friends in the medical field for advice, which created mistrust in the 'family' and confusion regarding the patient's medical care. I became acutely aware of the need for ICU social workers to educate and advocate for our needs and the importance of a family meeting regularly with patient, family and ICU team to discuss the patient's treatment.

My experiences, both personal and professional, showed me the importance of having an ICU social worker work with the ICU clinicians to provide the best possible patient care. The benefits of such a team 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.

As a researcher I am biased towards the inclusion of a social work intervention as crucial to provide end-of-life care. 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 interdisciplinary ICU team, I challenge the other physicians and nurses to understand and respect these cultural, religious and ethnic differences, and to provide care sensitive to the patient's wishes.

Findings

Sample Characteristics

The majority of the participants were Caucasian females. There was a wide range of religious beliefs; however Christianity and Catholicism were the most predominant religious beliefs. Thirteen of the participants worked at city hospitals, and seven of those were at large university hospitals. In addition, the average amount of years with an MSW was 15.6 years, and the average time working in the ICU was about 6 years. The participants spent a little less than half of their time in the ICU (see table 1).

The goal of this study was to examine the role of the social worker in the ICU from an ecological framework. The researcher has used the ecological framework to organize and guide the results of seventeen in-depth interviews. The results will begin with a presentation of information on the social worker as a microsystem, how he/she perceived his/her role in the ICU, the skills needed to perform that role, and how education has influenced their practice. The findings present information on the social workers' interactions with the mesosystems, including their experience on the ICU team and their work with families around advance care planning. The research findings are then presented on the exosystem, reporting on the social workers' interactions in and with the hospital and in his/her department. The factors that impeded and aided the social worker in his/her ability to provide end-of-life care are reported. The results show how the macrosystem impacts care in the ICU, specifically, how the social worker's worldview impacted care delivered, as well as how ethical dilemmas were managed in his/her ICU's. Lastly, ways to improve the field of ICU social work are presented.

Sample Demographic

Table 1

Characteristics of Interviewees (N=17)

Age	Range	27 - 63
	Mean	43.5
Race	African American	2
	Caucasian	14
	Mixed	1
Gender	Female	15
	Male	2
Years as Medical Social Worker	Range	4 - 30
	Mean	13.2
Type of Hospital	Affiliated University Teaching Hospital	4
	Cancer Hospital	2
	Suburban Hospital	4
	University Teaching Hospital	7
Religious Belief	Abstract	1
	Agnostic	1
	Catholic	3
	Christian	6
	Jewish	2
	Methodist	1
	Mixed	1
	None	1
	Worldview	1

% of work on End-of-life Care

Range	5% - 80%
Mean	30.0%

% time in Intensive Care Unit

Range	17.5% - 100%
Mean	44.4%

Years in Intensive Care Unit

Range	1 - 30
Mean	6.1

Interviewee Description

Table 2

Characteristics of the Interviewees

Interviewee	Age	Race:	Sex	Type of Hospital	Religious belief
1	27	C	F	UTH	CH
2	41	C	F	UTH	M
3	43	C	F	UTH	CA
4	39	C	M	AUTH	J
5	63	C	F	SH	A
6	55	C	F	SH	CH
7	27	AA	F	UTH	CH
8	33	C	F	AUTH	N
9	40	C	F	UTH	AG
10	35	C	F	UTH	CA
11	56	C	F	UTH	J
12	50	AA	F	SH	CH
13	43	C	F	SH	CH
14	42	C	F	AUTH	J
15	37	M	F	CH	CA
16	59	C	M	CH	CH
17	49	C	F	AUTH	W

Notes:

Race:

C= Caucasian

AA= African American

M= Mixed Race

Gender:

F= Female

M=Male

Type of Hospital:

UTH= University Teaching Hospital

AUTH= Affiliated University Teaching Hospital

SH= Suburban Hospital

CH= Cancer Hospital

Religious Belief:

CH= Christian

M= Methodist

CA= Catholic

J= Jewish

A=Abstract

AG=Agnostic

N=None
W= Worldview

Microsystem

The microsystem is the individual person, the social worker, who interacts with other systems. Each person brings his/her own internal resources, beliefs, education, and experience to each interaction, which influences those interactions (Germain, 1981). It is important to understand how each social worker views his/her role and the factors that influence his/her ICU practice.

Discharge Planning Role. Throughout the literature, various roles and skills have been identified for ICU social workers. Social workers are trained to manage crises, to promote patient autonomy, and to provide counseling. The participants were asked to identify the major roles they perform in the ICU. The largest role identified by all but one of the participants was discharge planning. This ranged from sending patients to a rehabilitation facility, coordinating home care, arranging hospice, or providing funeral and bereavement resources once a patient had already expired. For example:

My role is strictly getting people from the hospital, who can't wean on a ventilator, into an LTAC (Long-Term Acute Care Hospital). (Interviewee 4)

Yeah, I mean, it's the basic hospital social work job, in terms of making sure you have a discharge plan for everybody. (Interviewee 5)

I would say primarily—certainly, we do—pragmatically, we do discharge planning. On the ICU units, it's mostly like vent-level facilities (ventilator weaning rehabilitation center) for more complex care, and family issues, and if they're complex social issues, drug and alcohol. (Interviewee 9)

My role is a discharge planner—if we have 25 patients which need to leave that day, that's where I'm needed, and I have to prioritize my capacity. (Interviewee 13)

The other major aspect that was identified by many of the participants to discharge planning in the ICU is arranging hospice. The components and responsibilities of coordinating hospice consists of sending a patient home with home hospice,

coordinating the transfer of a dying patient to an inpatient hospice center, or bringing the hospice to the hospital for inpatient hospital hospice. Some examples from participants are:

If the medical team has identified that this is a patient who the family is 100 percent on board for hospice care or whatever it is, then generally if they need me to set up hospice, those types of things. (Interviewee 1)

We will have a family meeting in terms of—I always pull a family meeting together when a hospice consult comes. Whatever members are available; first to make everyone understand what exactly that means, what hospices are available. Then, I bring the hospice person in. (Interviewee 6)

Once the doctors and families have determined that someone is at an end-of-life stage, depending on what time of day it is, and/or the level of involvement of the doctors, either someone gets in contact with me, to speak to the family and figure out what kind of level of hospice they would be interested, or, more often than not, the doctors just call someone from X hospice. ... If I'm involved, then I would speak to the family, find out, are they looking for hospice in a skilled nursing facility or at home, or are they appropriate for inpatient? I want to talk to them about what area they're looking to go to. ... We'd have the provider come in and do an education meeting, and go from there, depending on what level they choose. (Interviewee 4)

The other major component identified by the participants regarding discharge planning is coordinating and connection families to burial and bereavement resources after the patient expires. The participants may not have worked with the family during the patient's time in the ICU, but were consulted post death for arrangement of resources, or through the participants work with the family they may have assessed the family's need for bereavement and burial resources:

Sometimes, I do get called after a patient has expired to go meet with the family to provide them counseling resources. For a lot of our families, it's an overwhelming time because they just don't have a whole lot of money. In explaining how do they go about preparing for a funeral and burial and all that. (Interviewee 1)

Some families aren't clear on the process of having a funeral director receive a body from the morgue. I mean, it sounds very kind of pragmatic, but some

families aren't—if they haven't been through it, they're like, "What happens now?" kind of thing, and they're not sure what the next steps are. That happens here and there. (Interviewee 9)

To provide them with information about—also even afterwards, a lot of families may not have things like very concrete tasks, such as funeral situations, or if they don't have money for a burial, how we can help provide that information and give resources. (Interviewee 10)

Support and Counseling Role. The second largest role identified by many of the participants is his/her role providing support to patients, families and staff. Many of the participants introduce himself/herself to the patients or families in the ICU and identify themselves as a support person while the patients and families are in the ICU. Support is viewed as an important part of the ICU social worker's work, listening to and bearing witness to the stories of those in the ICU:

I mean, I always, when I introduce myself to patients and families, tell them that my role is to be a support person. (Interviewee 5)

The typical trauma social worker role is that of core support and counseling for the families and the patients. (Interviewee 13)

I feel like that's where my role is important, in terms of facilitating and being a source of ongoing support. The nurses change shifts; the social worker remains the constant. Although they connect with the nurses, they like that I'm the person they see in the ICU, and then I'm the person who sees them when they leave the ICU; or if the patient never leaves the ICU. (Interviewee 15)

I will try to get some time with patients and families, kinda get to know them, and kinda get a better understanding of what they're about. I begin joining with them about, what are some of their issues? what are some of their concerns? On the other hand, kinda meet with the physicians and nurses and try to get a sense, what their perspective is. The beauty of working in a place where I've been for so long is, I've developed some really good relationships with patients and families. (Interviewee 16)

The other aspect of the key role of social work in ICU is you become the social worker to the nurses. You become the therapist for them 'cause where are they going with all this? They don't wanna admit that they have a need either, but at the end of it all, when we've done everything we can and the curtain is pulled

people start to make a joke. I'll just say to a nurse are you okay? This day sucked, this day was rough. They oh yes, yes. (Interviewee 6)

Another component to providing support that many participants identified was providing support to families during the time a patient has a cardiac arrest requiring CPR by the medical team. Social workers will sit with families during the codes, help them process the information that is given during that time period, and once the code is complete the social worker helps them understand the meaning behind the event and how he/she may be reacting to it:

Even with codes, I've definitely gone in after a code that's been unsuccessful. Just the way some doctors—I've had doctors that are fantastic and very compassionate, but you can just see the person trying to make sense of what the doctor's telling them. Sometimes it's better just to be very plain and direct, you know, give them a warning shot, but still be very direct with the language. I think I'm pretty good at that. (Interviewee 2)

Especially for younger patients, we're often asked to provide support to the families because it's a stressful time because they're not standing at the bedside during the code. We're often there to help, you know, with any anxiety or questions they have. Sometimes we go back and forth from the ICU or the room to the family, give them updates, you know. They're working on your mom. They're doing all they can. They got her on a machine, you know, but the physicians actually go through the event or what exactly has happened as to why they feel the person coded or that kind of thing. (Interviewee 12)

Sometimes it's literally just stopping in, introducing yourself and saying, "I'm here." I would say, even, I tell people, "If you need a cup of coffee, if you need a minute to get out." I have certainly done that. I have certainly gone to the coffee cart and paid for families that are—cuz sometimes I feel like it is difficult. We're expected to support these families, but what can we really do? We're not—so to me, sometimes it's just as simple as, like, "Have you had anything to eat today?" (Interviewee 10)

Facilitator/Liaison Role. Another key role identified is the role of facilitator and liaison in the ICU. This role encompass' facilitating the communication between families and the medical team, to help the ICU team understand the families perspective, and vice versa. As the group works together, the social worker guides the communication and

helps with everyone's understanding through reflections, asking clarifying questions, and assessing reactions to information:

There are times I that I actually feel like the interpreter, or the translator; I guess interpreter's the true term, because they're in such shock that they didn't really hear what the doctor said, so I just paraphrase it, break it down and say to them, "I know this is very hard." You know, provide support and explain to them what the process is going to be. (Interviewee 6)

At the same time, there's, also, sometimes issues with physicians, where some physicians do not believe in palliative care or do not believe in hospice care, whereas the family may very well want that. Sometimes we step in as, for lack of a better word, liaison in those situations, as well, to explain to the physician what the family's wishes are, try to represent the family and what their wishes may have been in hopes that they'll follow the family's wishes and go ahead and put in a consult, if not a transfer to palliative care. (Interviewee 14)

I mean, I think, primarily, the piece—if I had to sort of identify what is my primary role in that setting—is facilitating discussions; pulling the medical people in with where the family is. Sometimes people think they're doing what the family wants, but nobody has really asked the family what they want, or they're talking to the wrong people in the family. If you don't know the dynamics, you're not really clear as to what is going on. Sometimes these are patients I have known outside the ICU, so I have a baseline on them. (Interviewee 15)

We're sorta the conduit between the medical team and the patient and family, in trying to get them together. Even if it's just sorta, hey, let's sit down and talk about what's going on. We're trying to interpret to the medical team, what is it exactly that is going on with patients and families, why they seem to be resistant, why they're having trouble understanding what we're trying to put forth to them, and vice-versa. Why do we observe them or feel like they're not compliant to what we say, or not getting what we're saying. We help facilitate the communication, interpretation of a lot of what goes on. (Interviewee 16)

Advocate Role. Social workers are trained on promoting self-determination and patient autonomy. They often do this through a strengths based perspective. Often in the ICU, patients may be too weak to loudly voice their opinion on care or the patient and family may feel intimidated by the medical team and the technical environment. Over half of the participants recognized their role as an advocate. The social worker advocates

for the patient and family to ensure their needs are being listened to and met. For

example:

Patients in the ICU are weak, in terms of their ability to verbalize things, to make their needs known, so I see it as part of my role to advocate for patients. If they're ready to die, or if they're ready to have a dangerous surgery, or they don't want to have a dangerous surgery, or whatever the situation is, as long as they're competent, I see it as my role to make sure that the doctors know that they have a particular wish and a particular direction, so the doctors can go in and talk to them and be clear about it, too. (Interviewee 4)

Sometimes it's our role as a social worker to kind of help families think back. Can you remember any instances where your loved one said "I would never want this" or—I often do view that as in my role, because I think what happens in a sudden situation is people don't want to give up right away. They feel a lot of guilt or that something's wrong if they make a decision that never gave a person a chance. But sometimes for us it's the social worker's role, I feel, to kind of really help families understand what a realistic picture would be like. (Interviewee 10)

Assessment Role. A key aspect to social work practice is performing comprehensive assessments. In the interviews assessment emerged in various forms. ICU social workers assess patient's prior living situation and potential needs post-discharge for discharge planning, he/she assess the family dynamics to understand the family's beliefs around end-of-life care and potential conflict that may arise, as well as assess the various stressors impacting the patient and family. Some examples of assessments from the participants are:

I think that my role is to kind of provide a context for the people that we're dealing with because people don't come in as islands to the hospital. They come in from complete context and I think that my role is to flush that out for the team so it's something they can keep in the back of their minds as they work with a family. (Interviewee 7)

I usually will start off by meeting with patients if they're available to participate in some sort of discussion or with their family to just kind of get the ball rolling and find out how—first of all, how they perceive their family member's current state of health, their understanding of where things can progress from the point that we're at. (Interviewee 8)

Another major component of the assessment identified by many of the participants is determining if the patient has an advance directive or a designated medical decision maker. Often, this is unknown when patients are first admitted to the ICU. As a result, the social worker takes on the role of investigator to determine and locate next of kin:

We identify who the next of kin is, if the patient is unable to make decisions and then we go through the process that we have in place from our legal department, determining who would be the appropriate decision maker, if there's consensus, things like that. (Interviewee 2)

Also, sometimes, when it comes down to getting consent for further procedures, someone's consented their own lung cancer treatment or something, and now, they're on a vent and they can't do it anymore, and who do you call? A lot of it is helping them through the decision-making tree of who's the next person to call, and hunting people down on the Internet and phone books and medical records, to try to find people. (Interviewee 4)

The one piece that comes up, I would say, not routinely but often sometimes, is identifying a surrogate decision-maker, and I think social work has a specific role policy-wise in the hospital for helping—if there is question marks about that—helping to kind of review the Act 169 policies and determining who the appropriate decision-maker is and seeing if they're available, if they would like to serve in that role, and also helping review and highlight issues that may be in an advance directive. (Interviewee 9)

Educator Role. The final major role that the participants identified is that of educator. The social worker may be educating the ICU staff on the dynamics and beliefs of the patient and family, or they may be teaching the patient and family what resources are available and what the meaning is of the different options for care available:

Also, my role is educator, educating doctors about medical management in a comfort-based setting. Perfect example, we had a patient with an open fracture. They took them to the operating room. Our hospice providers, our agencies we work with are more than able to manage. An in-patient hospice unit is more capable of supporting patients with fractures, but the surgeons felt that it was a comfort issue. It's not that they were trying to fix the patient; they just wanted the patient to be comfortable. It's just an education piece that they know that taking an elderly demented patient to the OR may have done the patient more damage

than good, depending on whose opinion—you know, so as a team, to work through issues like that. There's not a right or wrong answer, but it's just how are we going to approach end of life care? (Interviewee 2)

At least I feel like education is a big piece of what we do with both the family and with the team, as a social worker. (Interviewee 10)

Unfortunately, a lot of times people really feel as though they can do an advance directive when a patient is not alert and oriented. I think that is one of the biggest struggles is having people be educated prior to the point of being sick and having an advance directive done. Most people want to do it when it's too late for that. (Interviewee 1)

The role of the ICU social worker is a “mixed-bag”. The social worker may be helping the patient transition to the next level of care, or they may be helping a family cope with the loss of a loved one. The social worker is an advocate, a context interpreter, and counselor for all involved in the ICU. The ICU is a high-context and high-stress environment, which requires the social worker to wear many hats in his/her role:

I think it can be a little bit of a mixed bag. Sometimes I'm working with people just—they come to the ICU. They know that they want hospice right away. There are really no questions, so it's just a matter of where, how, the logistics. Other people, they come in and it's working with them from when the patient comes in to actually making the decision. It can be a variety of different things. I think that I'm there really to be a witness, to be an advocate, and to validate people wherever they are in the process. (Interviewee 7)

He/she may be providing support, advocating, or connecting to families to the necessary resources. ICU social workers act as facilitators, as well as manage crises that arise.

Skills Needed As an ICU Social Worker

Clinical Skills. Social workers utilize and value many of their different skills in the ICU. Stemming from their work providing support, thirteen of the participants discussed needing strong clinical and relationship building skills. This includes understanding family dynamics, empathizing with others, and listening skills:

I think it's important to have a good clinical background because you deal with people who often have unresolved issues. Not everyone passing away is a senior citizen and gone through life, so you deal with everything from people who've been in accidents to, you know, cancer patients. ... because you're dealing with different emotions and different feelings, so I think it's important that you get somebody who has some experience there. (Interviewee 12)

I think all of that kind of wraps into just having a core set of clinical skills, as well. (Interviewee 14)

I think ability to build rapport with families quickly and genuinely. (Interview 9)

Attention to detail is also really important because a lot of what we learned in social work school, with the body language, and the non-verbals and all of that, is so key in that setting. I find that a lot of the information I get is from things people aren't even saying; it's more just, like, you interpret the expressions. You're reading what maybe would be going on for someone just by the way they're interacting with the patient, or the way that they're coping in front of the patient, and then what you see when they're not at the bedside. (Interviewee 15)

A major component to strong clinical skills is the ability to listen. ICU social workers need to be open to and listen to the wishes and needs of the patients, their families, as well as the different members of the ICU team:

I mean I think a lot of is just really listening to people at that point in time. It's more about them. It's not about what's going on. It's also really meeting the need of where that patient is and what that patient has always wanted. (Interviewee 1)

I think definitely a willingness to listen; a willingness to kind of share the journey with people. (Interviewee 5)

Three skills: listen, listen, listen. I think you have to. Listening is a lot of work. Listening well is a tremendous amount of work. Listening, calming what's going on inside of you down, so that you can listen is a huge amount of work. (Interviewee 16)

Empathy and patience are core skills that many of the participants highlighted. As one listens to the different feelings and beliefs of those involved, it is important that the social worker empathize with other's beliefs and to patiently take the time to listen and understand their perspective:

Just a level of understanding that what people are going through is difficult. Depending on how old they are and where they are in their lives, it means different things to different people. (Interviewee 4)

Empathy. Empathy. That's huge. Going where the person is going. ... Seeing the person where they are and going there, and taking it one step at a time with them. (Interviewee 6)

Patience. Patience working with families. Patience working with the team. Also just kind of an understanding of the way that other people might be processing what's going on. (Interviewee 8)

Three of the participants each identified the need for good communication skills, organizational skills, and an understanding of the ICU environment and some medical knowledge:

You have to have very strong communication skills because you wanna really be there with the person. Then bring them to the full focus of coming to the understanding and allowing them to make the decision. You have to really be able to have excellent communication skills. (Interviewee 6)

I also think organization is key in the ICU because it's such an intense setting that if your thoughts aren't organized, and you feel all over the place, then you're not really gonna be able to be as supportive. You have to be pretty concise when you're in there. People want you to get in, do what you need to do, and move on to the next thing, because it's time limited. (Interviewee 15)

I think truly and honestly being aware of the complexities of a patient particularly in the ICU because there can be multiple factors going on with a patient that really contribute to their end of life. (Interviewee 1)

An understanding of palliative care versus hospice care—a clear understanding of the difference, and the scenarios, and the medical process with where the patient is from a medical standpoint. (Interviewee 13)

Due to the nature of the ICU environment people are exposed to death, human suffering, and crisis. ICU social workers need be aware of their own personal beliefs and drives, understanding how that may affect their work in the ICU, and methods to manage those potential influences. The ICU social worker needs to also be skillful in taking care of oneself to decrease the risk of compassion fatigue and burn-out:

When a patient comes in and there's no family and no one, and they're in the room dying, that affects me. (Interviewee 6)

I think you have to sorta know yourself, and know how you are in stressful situations, cuz there's gonna be things banging at both ends. By that I mean, patients and families will be high anxiety, and nurses and doctors get high anxiety about their opinions about what things should happen. (Interviewee 16)

We don't usually have students in the ICU from social work, you know, on a regular basis because the people are very sick and it can be kind of overwhelming, a lot of tubes and drains. I think it's important to have someone with good clinical skills and someone with at least a year of hospital experience under their belt because you see a lot. (Interviewee 12)

Also, you have to really know how to take care of yourself. ... but I think that you have to be pretty good at boundaries and taking care of yourself and not measuring the work by how much you've done, but just checking in with yourself and knowing what satisfies you and a lot of times it's nothing that's tangible. (Interviewee 7)

Other skills that were discussed by at least one of the participants was knowledge of resources, knowledge of the laws around advance directives and determining the next-of-kin, hospital politics, investigative skills, and knowledge of end-of-life ethics. For example:

Then just also like a realization of the resources that are available for end-of-life care because that's also a big problem is that you'll have doctor be like, oh, well this patient's from Delaware, so what do we do? Being able to pipe up quickly with a resource that would be available and then get that resource here in the hospital. (Interviewee 8)

I think, certainly in my experience, knowledge of the—what I just mentioned, the decision-maker, and helping the treatment team make sure we're connecting with the right people, just from a policy perspective. (Interviewee 9)

Education

MSW Experience. The participants had different experiences in their MSW program. For some, their focus was not to pursue medical social work and as result they did not take a course on end-of-life nor have an internship in a medical setting. However,

for others there were little to no opportunities to take a course that discussed end-of-life care. Even if he/she was aware of their interest in medical social work, the opportunities to enrich their learning was missing:

We had an elective on grief and loss, and I never took it. I do think looking back, it's something that—I think in conjunction with everything else that I took, it's one of those classes that I wish I would've taken to help to understand slightly a little bit more. (Interviewee 1)

The school was different, and my thing was in criminal justice, so I had no idea I was even going to end up here. I don't think I took a lot of courses in that. It just wasn't an area of my interest that I ended up, I landed in. I just, I can't remember taking—really, I—I don't remember my MSW really preparing. (Interviewee 10)

If there were any offered, but I did not elect to take them because at the time I was an administrator and a director. I went along the macro path with my education and my choices, so I don't know, but it's fabulous and should be part of—I think – every program. (Interviewee 13)

We didn't have any palliative care courses... there was nothing specifically centered—or at least that I was eligible to take just based on the way my schedule was—that focused on death and dying, you know, early stages of death and dying, and just how to carry through the process. (Interviewee 8)

End-of-Life Elective. At least half of the participants noted an elective offered on end-of-life care in the MSW program. For those that were interested in end-of-life care, they were able to elect the course that had an end-of-life focus.

I did have a death and dying course that was very good. It brought up a lot of different cultures and things like that, you know, different cultural groups and things like that. There's a lot of variability of how different cultures view death and that can influence decision making and religious beliefs. (Interviewee 2)

I also took a course in Alzheimer's. It was at X and it was great. It was with medical students and advanced nursing students. It was interdisciplinary, so it was like the team approach to dementia care, including end of life care. (Interviewee 3)

I know I took a course, like, on religion. I think that might have helped, and I think I took some courses geared towards psychology and dealing with people in crisis. (Interviewee 12)

The most common elective course was focused on grief and loss or death, dying and bereavement, and about six of the participants discussed taking this course. The experience of those that took this course was positive:

I took an elective course called, “Death, Dying & Bereavement.” That was an interesting course. On a personal level, I had an experience in my life where both of my parents, when I was really young, probably around three years old, they each lost one of their parents. It was a struggle for both of them, and they were both trying to be very strong for each other. It caused a lot of tension growing up and kind of raised my awareness of the importance of going through the grieving process. I think that taking a class like that helped me to understand more of what should have happened, or what could have happened better, in my personal life, and adds to the reason why I became a social worker in the first place.

(Interviewee 4)

There was one course I remember taking, and it was an elective, and it was on death and dying and different cultures and how they approach it and cope with the process. But that was it, and that was an elective. We didn’t even have to take it, necessarily. I chose to. (Interviewee 14)

I actually did take an end-of-life class that was called “Death and Dying.” I actually have one of my textbooks, *The Last Dance*. I actually really liked that textbook because it talked all about, in the different cultures, you know, how to be culturally sensitive, and how death is viewed and perceived in different cultures. I try to keep that in mind because people’s culture beliefs, I think, have a lot to do with how they’re gonna cope in the end-of-life setting. In the ICU setting it’s interesting how people perceive withdrawal of care, or withdrawal of nutrition, or withdrawal of antibiotics—like how they make these decisions, and what it goes against in terms of their belief system. As a social worker, how you have to have some level of awareness of what this means for them. It’s not just like the logical decision, it’s also culturally and spiritually, and, “What is my family gonna think?” and who, maybe, gets to make this decision; and the respect of the hierarchy of who’s who in the family. Our assumption is always it’s the spouse, but in some families that’s not how it is. I’ve found that that brought a level of awareness. I might not have thought that way, had I not—I had a great professor, and learned a lot. I think that was probably one of the key courses I took in graduate school that helped translate into hospital social work. (Interviewee 15)

Lack of End-of-Life Curriculum. However, many of the participants discussed missing a class or integration of material on end-of-life care in their MSW programs.

They discussed wanting a course on medical social work, medical terminology and the health care environment, as well as stronger clinical skills:

I think that the master's program that I came from was very good, but I think that there was that component missing in regards to overall end of life or trauma even, to deal with patients. A trauma patient coming in, even though they may go to your ICU, is completely different than someone who's had this illness. If you have a trauma come in, a family's gonna be more in shock than somebody who's been sick and who's kind of almost been a little bit more prepared for the end of life talk, some of those tips and differences. (Interviewee 1)

I think if there were courses out there that were more specific to the reality of what the students are going to be doing, not just theoretical stuff, but maybe a course on end of life issues or—you can't just say hospital work, but there's people dying—and you're associated with them that are not just hospitals and any agencies or private practice, things like that. It's the whole process of being a human being. I think it would've been useful to have a course like that, something about how to deal with it. (Interviewee 11)

I would love to see something about, again, listening and empathy and helping patients cope with loss, potential loss, and maybe something on, a separate course, maybe, on medical social work, as a general rule. To learn a little bit about the terminology and the different roles that are played, because I think, if you don't have that, it can kinda be a little overwhelming. I think you need to have a little bit of medical knowledge, and a lot of it does come from experience, of course, but it would be nice to have maybe a course on that, too, something with medical social work. (Interviewee 14)

Limited Availability of End-of-Life Elective. For those schools that offer a course on end-of-life, it is not offered every semester. This results in many students not having the opportunity to take the course. For those students that have the opportunity to take the course, one semester is not enough time to cover the content needed for a comprehensive understanding of the different facets of end-of-life:

You know, I think they could've done more than just offered one class in end-of-life, because you get it for one semester, and it's like, you're supposed to learn all of this in one semester? Again, I had a good professor, but there was so much more we coulda learned beyond the cultural piece. That, I think, was an interesting avenue into things that maybe you're not always thinking of, but I think our own grief reaction would've been interesting to look at. Like, what does this do to you? What does this do to your level of self-awareness of life, and

peace—you know, cause it's hard to work in a setting like this, and then not have some of it translate into your personal world. Then what do you do with that? You know, when you see people dying all the time, and you see pain, and suffering and grief, then you go out and you're like "Oh, I'm supposed to be the life of the party tonight," ya know? Like, "Oh, yeah, I'm sorry your loved one died. I'm gonna sit here and cry with you," and then, "Oh, yeah, but, ya know, at ten o'clock tonight I'm going out and doing this." It's just—sometimes it's hard to switch gears, so I think it would've been a little interesting, and helpful, if they sorta had a course in just, as a practitioner, what kinds of things you do, and ways to sorta help yourself in that. (Interviewee 15)

MSW Internship Experience. When looking at the participants MSW internship experience there were two common trends. Those that were not planning for a career in medical social work did not have experiences that were beneficial for their career:

Honest, I mean with initially, my MSW program, I thought that I would strictly be doing mental health, and I wanted to work in more of a psychiatric type setting. My first job landed me doing medical social work. I've had the opportunity to go back, but I think I—that's where I saw myself, not necessarily doing medical social work which is the only thing I've done since graduating and getting my first job. (Interviewee 1)

My MSW experience was doing outpatient psychotherapy at a mental health clinic, so, in no way, did it help me. It helped me with what I thought was gonna be my career, which, I think, a lot of people imagine they're gonna be a therapist, and then, they go to school and find out it's a hell of a lot harder to do that, and you don't get insurance, unless you're buying it yourself, and all those other things. (Interviewee 4)

However, for those that did have experiences in healthcare settings, their experiences were positive:

Well, I mean, my first year was, as I said, home care. That helped me to understand, you know, I mean, just that experience of visiting. I had done public assistance casework before I got my master's, so I certainly had a lot of home visiting experience. This, of course, was a different focus, so getting the medical focus of visiting patients in home care. Then from there, I went in my second year hospice, so certainly that helped a lot because that's what I was doing. It was—X Hospital. (Interviewee 5)

My second-year placement was hospital-based, so that was useful, just familiarity with the culture of working in a hospital and functioning, things like that, and, I guess, a social worker working within a medical model. That, I think, is specific

to understand how you fit in there, so I guess that was probably the most useful. It was on a different—it was a psychiatric in-patient unit, but I think overall, working in a hospital, it was helpful to understand the culture. (Interviewee 9)

Oh, it helped me a lot because I knew I wanted to work in a medical setting. (Interviewee 12)

All through graduate school I geared my internships towards that. I did one at the X Association, so I worked with people with brain tumors, and then other injuries, from like, motorcycle injuries and things like that. Then my second year was at The X Institute. I ran a support group, I did all kinds of patient outreach, I planned activities; I did a kids group. (Interviewee 15)

Lack of Continuing Education. Participants were asked to discuss his/her experience with post-masters education. For at least half the participants, continuing education has been lacking thus far. This is because they have not come across a continuing education program that discussed end-of-life care in the ICU, or because they do not have the time or flexibility with their workload to go off-site to a training. Many of the participants have continuing education through their department. However, for the majority of those respondents, the education is repetitive, geared towards other disciplines, or is not relevant to their work in the ICU:

I think a lot of it just kind of comes from experience. I can't say I've had one outstanding thing or a CEU or something like that I can say really was great and I learned something from it. (Interviewee 1)

My institution doesn't offer any educational conferences to us. (Interviewee 3)

Now frankly, when we're having an in service on hospice, it's like, oh again, you know. (Interviewee 5)

I think CEUs can be helpful if you are active about doing them, which can get away from you when you're working every day. (Interviewee 7)

Obviously you know how difficult it is to get off-site to go to something. You know, it's just—it can be, like, to stop what you're doing in your day to go attend an in-service and then come back, it's just really disruptive. (Interviewee 8)

Unfortunately, they just don't happen often enough. But if I recall, I guess what was interesting about it was the fact that they even mentioned social work, for one, as a member of the palliative care team, which is usually not recognized. It's usually a very medical model, as far as keep the patient comfortable, you want to use such-and-such measures. (Interviewee 14)

Positive Continuing Education Experience. Although many participants reported negative feedback on continuing education, some discussed positive opportunities that have influenced their practice. The continuing education programs that were beneficial discussed communication on end-of-life care, the legal aspects of end-of-life, grief and loss, children and grief, self-care, end-of-life resources, bioethics, religion and loss, second trauma and initiating palliative care in the ICU:

I think that some of the hospice and services that we've had have been helpful in looking at things possibly a little bit different or figuring out how to word things slightly different in regards to how we approach something or working with a different family. (Interviewee 1)

I've been to an attorney, who gave a series on end-of-life stuff and planning with clients. That was interesting, to learn about the legal aspects of it and who is the decision-maker at different points in time, and yeah. (Interviewee 4)

I went on something with coping with grief. The speaker was great. He was hilarious, which really made everything better. He told these great stories. He gave us a packet on what our role is, our role as bridges to helping people, our role as listeners. So helping us understand that people's grief comes in different ways, you know, the complicated grief or traumatic grief, but also knowing that we can intervene in that. (Interviewee 7)

So work, yeah, so working with kids, and not—and not even necessarily with bereavement after a loved one passes away, but just kind of helping them through the entire process. You know, what would you expect a five-year-old's reaction to be, if they learn that their mom has terminal cancer, you know? Once they're—if they're able to understand what terminal cancer is or, you know, what their reaction would be to find out that, you know, mom's lying in bed sleeping, and she's never gonna wake up. You know and just kind of being able to learn what to expect and then how to work with kids in those situations. (Interviewee 8)

I think the training that I took on the second trauma—I went to a training in Virginia two years ago, seven years ago, on that. That probably is one of the most useful, to understand that coming into a hospital, and the hospital experience is

actually a trauma for the patient. You can use that with any—the first trauma is your illness, your diagnosis, and the second is the hospital experience. That, talking about from very small things to like someone overhearing something in the hallway about their loved one that they weren't supposed to. Or that a secretary is like, "Is that the patient who died?" and a family hasn't even been notified yet. I mean, it's just, it's a training about how to talk to persons who get bad news. Whether that's a death, a diagnosis, whatever. I think that was one of the most—that program stuff helped the most of one of my trainings. (Interviewee 10)

Continuing Education Topic Suggestions. When participants were asked to discuss topics for continuing education he/she would be interested in or topics he/she would recommend for a new ICU social worker, a continuing education program on medical information and technology was the most frequent topic. Five of the participants discussed the importance of understanding and being prepared for the ICU environment, and having a basic understanding of the medical terminology used. Some examples of this are:

Medically, we learn as we go. When the neurologist looks at a patient and says the brain stem function is limited, or things like that, I don't try to report to them about the medical ways. I just try to break things down because it's not my job. I don't want to misrepresent the patient and what their condition is. Sometimes I feel at a loss when I'm sitting with a family and they're saying but she's moving her arm. They would first need to understand all the equipment the patient is on. I think, even for myself as a veteran, that when you go in a room and they're hooked up to a vent, and they're hooked up to beds that you haven't seen, and some beds are actually vibrating and shaking to keep the lungs moving, and all kinds of things. I do think that—an inservice of what equipment to expect in an ICU would be very, very good. They'll throw terms at me; BiPAP (bilateral positive breathing pressure), CPAP (continuous positive airway pressure), this is the PEEP level (positive and expiratory pressure), this is the vent, a big hemodialysis machine, this big tank sittin' there. These are pieces of equipment that are not part of our social work studies. I think those things make—that that would be helpful. I do, I think that would be helpful. Just thinking in terms of a new social worker, what would I be sharing with them? What they're facing, what they see, the infections and all, and why they would be gowning up. The basics over that. (Interviewee 6)

Well, ... I would recommend just learning about that topic to begin with, because you need to kind of know all the different things that could happen to your brain. I think that would be a good start. (Interviewee 11)

Well, I think because modern technology and medicine is so advanced, sometimes, you know, this would play out in the social work point of things. I think it might be helpful to have some training on some of the things having to do with all the technology. For example, some patients are on what's called ECMO, which is the acronym for this long process of heart/lung, keeping your circulation going kind of thing, and different things with ventilators, because we do send patients to LTACs, long-term acute care hospitals. We often have to know vent settings or BiPAP (breathing device) settings or other things, so maybe occasionally something just updating you on what's going on with technology, the people who may be on high-tech things, so if we have to translate that to other hospitals or bring people in we know, we're a little more knowledgeable. That might be helpful. (Interviewee 12)

Another topic discussed by four of the participants, is the desire to learn more about how to have conversations around end-of-life:

As far as the end of life sort of stuff, I think it's just learning how to provide the information to your customers, your patients and their families in a way that's going to be supportive. (Interviewee 11)

Mostly adjustment to terminal illness. I would love to see something done on just helping families cope or a patient cope with a terminal diagnosis of any kind because you know you're gonna immediately end up, at some point, at that end stage. I think it would be wonderful to have that type of discussion or that dialogue as to how you can prepare families and patients now so that you don't have these issues further down the road when they are in the ICU. (Interviewee 14)

As discussed earlier, the ICU is an intense environment. At least one-third of the participants discussed how their work affected them personally. As a result, three of the participants identified a course on self-care and self-awareness as topic that would inform his/her practice:

Yeah, I mean I think debriefing is always key when you're in the ICU, because I feel like, again, I keep using that word "intense," but I think that because it is such an intense environment sometimes you don't have an opportunity to debrief. You're so busy sort of checking in on everybody else, and making sure—patient has what they need, family has what they need—if something really bad has

happened in the ICU, then we try to check in with the nurses, but it's like, as a social worker, where do you go for yourself with all of that? I find that the debriefing thing, for me, because of the intensity in the ICU and all of the issues that come up, with all the different comorbidities that might exist, you see things that—like I can think of some really difficult cases in the ICU where I've seen things that I'm like, "Oh God, I would never wanna see that again." (Interviewee 15)

The other topics discussed by one to two of the participants are CEU's on medical ethics, end-of-life resources, running support groups in the ICU and group dynamics, working on a team, grief and loss, and learning how to bill for palliative care and end-of-life services:

Really the ethical considerations with the decision—the whole process. I'm big on ethics and making sure people are educated—families and the patients, if able—on what their rights are and their responsibilities. (Interviewee 13)

Well, I know that there are a lot of different options, when it comes to planning for hospice. It goes well beyond the home or SNF or inpatient. I know that there's a lot of different companies that offer different things. I really would love some education on the local resources beyond X... I think, if more social workers were aware of differences like that, it could really make an impact on the final moments that people have with their families. (Interviewee 4)

I think I would want—the thing that's been hardest is I've been trying to start a support group in the ICU and it just hasn't worked... For right now, I'm not finding a support group to be—well, no one's coming so I don't know if it's helpful or not because nobody has shown up. That might be something interesting. (Interviewee 7)

That would be an interesting topic to me, is how to make this more appealing to doctors, from a financial standpoint, in hospitals, but just learning to sit back with the doctors, and know when to talk, is really important, too. (Interviewee 17)

Mesosystem

The meso system is the interaction between a microsystem, social worker, and a larger unit (Higgins, 2011). Examples of these larger units are a family system, the ICU team or the palliative care team. It is important to understand how the social worker interacts and approaches these different systems in the ICU.

The ICU Team. The participants had a range of experiences on the ICU team, ranging from very positive and collaborative to negative and discharge driven. Over half of the participants noted that his/her relationship with the attending physician drove the intensity of his/her involvement in end-of-life care:

I think from what I can see it really depends on the personality of the attending. (Interviewee 7)

Depending on who the attending ICU physician is and their flavor, and depending on the other consulting physicians that are involved, for the most part, they invite social work in, and they collaborate. They value our input. There may be some players that don't, as well. For the most part, I'd say they respect and value our input here. (Interviewee 16)

Depends on who the doctors are that are involved in the case, to be honest with you. When it's docs that I have good relationship with, I think they really appreciate all of the team members, and they really get what we do. They're on board with, "Hey, I'm not God in every case. I can go in and do my piece, but sometimes my piece isn't good enough," I feel extremely satisfied. Then when you have some of these physicians, some of the surgeons and stuff, they are adamant to fix the problem because that's what they started out to do. It's frustrating and you just want to bang your head against the wall. (Interviewee 15)

Then we have one physician who will come—there's four that rotate. One physician will say to the family member you know, it's looking good, I think we can give it more time. We can do whatever's necessary to keep it going. We have time to work with. The next shift comes in and says you know, your mother's really end-stage, it's time to make a decision. That's very stressful. This really is how it works. (Interviewee 6)

Factors that Positively Impact Team. However, the participants who identified working on a collaborative team did identify the physicians as a great resource as well as the ICU nurses and other staff:

Usually, the nurses can kind of give me a better feel for what they've seen in regards to family dynamics, how the patient has been, whereas the doctor kind of gives me more of the medical or these are the—very matter of fact. These are the issues we're having with the family that we need to move forward from, whereas sometimes the nurses tend to get a little bit more involved, or too overly involved, in trying to play that social worker role which they don't really have the training in. (Interviewee 1)

They (nurses) call all the time. Sometimes, they'll make me aware of something before anybody else will, which is very helpful, too. This patient was found down in a horrible situation; what do we do? Okay, let me look over the chart and then I'll get back to you. I do appreciate the heads-up as well. (Interviewee 3)

Oh I think it's fantastic. I really like it. I think that it's not formal. It's definitely more informal, but I think if you are somebody who wants to hear what other people say or you are accepting of other people's information or you can spot people who are interested in what you have to say, it works out really well. (Interviewee 7)

The director of nursing in the CCU, I touch base with almost every day, just to check in and make sure that there's nothing going on behind scenes that maybe I haven't been made aware of yet. Then the residents, I will check in with them as well, but I find a lot of times either the attending physician, the director of nursing, or the patient's nurse themselves, they may have something to say that really, they haven't said to the rest of the team that can influence the course of care. (Interviewee 8)

I think they have a very, very good team where I am, and the people come there with that anticipation that it's a team approach, so I've had a positive experience 'cause they have rounds every day at a certain time. I round with a nurse on the ICU when I'm there, and often it's me, the nurse, and actually, the bed coordinator because you have to coordinate who's getting out of the unit to make room for maybe someone in the emergency that needs to come into the unit, or from the cath lab if they have heart cath, or other places in the hospital, and so they look forward to you being on that team and getting your input and wanting to know where people are going or what their family dynamics are. (Interviewee 12)

A common theme amongst the participants that influences their role on the team is his/her visibility and availability on the unit. The participants noted that the more the ICU staff witnessed his/her work, the more they were aware of the different approach to care and skill set the social worker offers:

I think being present on the floor is important. People see that you're up there and active on the unit. (Interviewee 9)

As long as people can understand, like, here's what they do and this is when you call them; here's what we do, here's when you call us, I feel like, as a team, it works better. Then people sort of value and appreciate what each person offers, cause they know it's different from what they're doing. (Interviewee 15)

Trauma ICU Team. Three trauma social workers were interviewed for this study. Each trauma social worker identified a strong interdisciplinary approach to end-of-life care, as well as feeling valued by the other team members. They all reported seeing every trauma patient within 24 hours of admission, having daily communication, and having a mutual respect for one another. Examples of their work are:

The case manager and I work closely together. I would also say it's a teaching hospital, so the residents—the ICU residents are really key. They're the ones that are on the—in the ICU units 24/7 and they're the ones having the front line conversations. The attendings do direct care, but the residents are really the people that are on the unit and have the most frequent contact. The nurses are also—you know, because they are bedside they are spending the most time with the patient. Their feedback is very good about family dynamics and things like that and how the patient's status is and how comfortable they are, what they seem to be indicating. (Interviewee 2)

I feel like a lot of the times they are multidisciplinary approach to end-of-life decisions. The physician often will discuss prognosis and talk to a family about what's happening, and social work is often present. ...My work on trauma is a model for how multidisciplinary teams should work. I think I've stayed on that service because I've been very fortunate of the collaboration along teams. (Interviewee 10)

It's intense in that we're all—communication is so key. Even just the English language—how a word or a phrase can be misunderstood or misconstrued. People making sure the team hears accurate information and also that the families hear the accurate information and they understand what is really communicated with them. We're very close-knit—we're a close-knit service, I guess—Trauma. We communicate all the time. (Interviewee 13)

Team Communication. A key to the success of trauma and to a collaborative team is frequent communication. This can take place one-on-one as many participants discussed taking an active role in seeking out the physicians, nurses and other staff to gain updates on the patients, as well as in the formal setting of ICU rounds:

We do do rounds. I'm part of the trauma team, so we cover the trauma patients in the ICU. They round daily in the ICU and then trauma rounds are Monday, Tuesdays and Fridays. You know, you discuss the patients, obviously there's—I will bring up repeatedly palliative care consults and things like that. We'll talk as

a team if we think that that's an appropriate referral. We have daily interdisciplinary rounds. (Interviewee 2)

Through our multidisciplinary rounds, I would say, most likely. We do that daily. ICU patients are talked about daily on trauma, which also is not probably for all services. (Interviewee 10)

Once a week—like I said—the whole group gets together to discuss each case in the morning reports and rounds, as many as people that can participate. (Interviewee 13)

Interdisciplinary Rounds. For those participants who identified being on a collaborative interdisciplinary team, not on trauma, rounds is a part of their week:

Well, we have interdisciplinary rounds in the ICU Monday, Wednesday and Friday, and in the NCICU (Neuro Critical Intensive Care Unit) on Tuesdays and Thursdays. I have rounds every morning at 8:30. It's the same medical director for both units. I find the rounds helpful, but he's extremely structured in the way he does it. Depending on his mood, sometimes he's more open to me bringing up issues or asking certain questions of the nurses. Other days, he's more like, let's stick to the script here. (Interviewee 5)

We have board rounds in the morning, so if the doctors are like, "Well, can you just see this person or put them on your radar?", I'll do that. If a nurse calls me and is like, "This person is interested in this or we just had rounds and the family's agreeable to hospice", they'll pull me in. It can come in a different variety—different ways. (Interviewee 7)

The only time we really ever get together as a team are in the ICU rounds and that's Monday, Wednesday and Friday. That's fairly new. It's maybe six months we've been doing that. Up until then in the ICU, never really felt like a team. ... The rounds brings us a little closer, at least in my feeling—and I know the case managers feel the same way—a little closer to feeling like part of the team. (Interviewee 11)

Our rounds are the main place where we function. (Interviewee 17)

Negative Team Experience. However, for some of the participants who are not able to attend ICU rounds because of his/her caseload, they shared a different experience on the team. The interactions were geared towards discharge planning, focusing on how to move the patients who are ready for discharge out of the ICU:

I came to rounds the other day and they were, like, “Social worker,” like, nobody knows my name, they just know I’m a social worker. They were, like, “We have many things for you. Room 4 can’t find his pants. Room 6 needs medication. Room 7 doesn’t have a guardian and Room 10 needs a life—what do they call it—a life care facility.” (Interviewee 3)

When I go to rounds, I try to make it at least once a week, and generally, they call me when there’s someone who’s ready for discharge. I work with the families and I just kind of fill in and let the doctors know what’s happening. I don’t get very much of a multidisciplinary approach from the ICU. They round, but the rounding is all the doctors and the nurse for the room, and it’s the surgical team and the ICU team and the medical team, a whole bunch of doctors. If I don’t go to rounds for a month, I don’t think anyone would notice, because they don’t talk to me. They don’t involve me in the process. There’s no thought about the emotional responses of the patients or the families that are going through this. (Interviewee 4)

Consulting the Social Worker. The social worker’s involvement on the team, or lack thereof, is evident in the frequency and types of consults he/she receives from the ICU staff. The social worker who takes an initiative driven approach to his/her work in the ICU will find cases on their own, is consulted by a variety of staff frequently, and feels the consults they receive are appropriate and timely. For example:

I try to open every single patient and see—I mean, we’re supposed to see every patient. Just open ‘em. If they’re on a vent I reach out to family, but that gives me at least a day. We have 24 hours; sometimes I need a little more time because of the volume. (Interviewee 6)

So it’s initiative driven as well. I don’t wait for all of my consults. I might do them just because it makes sense to just check in and see how people are doing. You never know, they may tell me that they want hospice, which is something they haven’t told the team or whatever, which happens as well. Just depends on what’s going on. (Interviewee 7)

The team will usually let me know if there’s any follow up that they feel like is maybe needed with the family, or some kind of stray issue with the case—but typically, the team’ll let me know if they anticipate having that discussion with the family, like goals-of-care discussion. (Interviewee 9)

Unfortunately, due to heavy workloads, some of the participants are consulted at the end of the patient’s life when death is imminent:

In the ICU, I'm typically informed by the doctors that it's already there, and generally speaking, it's always an inpatient situation, because it's usually someone who, at that point, they're already on a ventilator. They're going through all the life-saving stuff, before they figure out that they're not able to save the life. Then, all we have to do, at that point, when someone's so far gone and so far medically complex, that you just remove one or two things and they have under two weeks to live, at that point. (Interviewee 4)

The problem with the referrals through the computer system, I may not get it until the next day. It's how fast is the person in the office getting the referrals that get printed out, picking up the paper and then putting it into my list, then when it shows up on my list. To me, that's not the most effective way for me getting cases. I can't get it through the nurses' heads that if I'm the only social worker here, call me. I have a cell phone. I have a beeper. I have an office number. There's all these ways of reaching me. You don't have to just put an order in on the computer with the risk that I'm not going to know. (Interviewee 11)

Family Conferences and the Social Workers Role. Family conferences are an effective method in the ICU to deliver end-of-life information in a supportive way. This is an opportunity for social workers to facilitate conversations that are open and honest, as well as support the patients and families as they learn of the prognosis and options for care.

The participants identified various roles in relation to family conferences: initiator, coordinator, witness/observer, interpreter, advocate, and support. For example:

I really feel it's an advocate and just making sure that the family is understanding the terminology that's being discussed and the consequences and knowing what services are available to the patient. (Interviewee 2)

Yeah, and then I usually am the one that gets the conference room, then meets the people in the waiting room and gets them in there, that kind of thing. Then generally, the meeting itself, the doctor starts out by giving a synopsis of what's going on, opening it to questions from the family. Then that helps us get to the point of patient is going to need, you know, some options usually—extubation (remove ventilator) to comfort care, LTAC (Long-term Acute Care Hospital), whatever. Then the doc, kind of, eases out and lets me go on from there with, well, here's your options with this or your options with that. (Interviewee 5)

I usually am involved in I would say, like, over 90 percent of the family meetings that go on, whether it be to discuss end-of-life issues, to discuss surgical issues,

really, even if it's just to kind of, you know, if it's a family that is having a difficult time getting through the hospitalization. (Interviewee 8)

Probably support with the family, and helping—I find that sometimes helping the family if they're having trouble verbalizing questions or concerns sometimes, to interpret that a little bit for the treatment team, and kind of be a little bit of a conduit. (Interviewee 9)

Sometimes we're just the observer so that we are aware of a situation, should we need to be involved. Sometimes they just want us there as an observer, just to kind of be aware and to be able to offer social work services to a family, should they choose to utilize it or take advantage of that availability. Then sometimes, if there is any type of conflict with the family, then that's when we'd, obviously, step in, as well. (Interviewee 14)

I like to dumb-down the information. I've seen a lot of people, the doctors come in and say things in a way that even medically illiterate people could understand, but given that it's so devastating and overwhelming sometimes, I like to slow things up and make it clear. (Interviewee 17)

Participants have also reported their involvement in family conferences center around crisis management and disposition issues:

However, when there's a conflict that is present between the physicians and the family, a social worker is usually forced to step in when there's a conflict in beliefs regarding the end-of-life care of the patient. (Interviewee 14)

I think I tend to be involved more in the family meetings in the ICUs when it's a disposition issue, more than when it's an end-of-life issue. (Interviewee 4)

Lack of Social Work Involvement. However, many participants report minimal involvement in family conferences. This primarily stems from time constraints, the demands of discharge planning, and limited involvement on the team:

Yeah, I do it, I like to do it, but I don't get to do it as much as I'd like, partly because of time constraints. (Interviewee 5)

If the family totally doesn't understand it, I break it down as much as I can. I've been in a room where a surgeon comes in and says A, B, and C, and walks out and the patient didn't understand anything. Or, I'll say to the doctor, I don't think he totally understood you. Review it again. That type of thing, but no, they don't—when they're ready to discuss that they pick up the phone and call family

or they just go in and tell the patient. They don't see the skills of social work as an important part of the program. (Interviewee 6)

Because I was covering two units, and the real priority is moving the medically clear patients through, if I have six placements, and there's a family meeting going on, I'm not gonna stop and go sit in on the family meeting. (Interviewee 17)

Utilization of Advance Directives. The majority of the participants identified some involvement in advance directives. Their work and comfort level varied. Many of the participants are consulted for every patient that asks to complete an advance directive, whereas others do not have a role in advance directives because of their institution's policy. For example:

Anytime that a patient, whether it's the unit or any of the other floors, anytime that they have questions about advance directives, it's our job to go talk with them. We here have an actual book that we can give to patients that will work for this hospital stay that is an advance directive booklet for patients going to surgery and those types of things. We do encourage them to fill it out. (Interviewee 1)

The only involvement that I have at this hospital with advance directives is if a family calls and wants to know if it can be done here, and all that. I will take a Pennsylvania advance directive, I also have *The Five Wishes*, which is a booklet; it's wonderful. I take that to bedside and I make as clear and sure as I can that the patient is alert, and oriented, and understands what they're discussing. (Interviewee 6)

If anyone asks to do one, I'll see them. What normally happens here is between the admissions and the nurse who does—the admitting—the nurse that's admitting the patient, they'll ask if an advance directive is needed or wanted. If the answer is yes, they'll say yes in their computer flow sheet and that generates a referral to me. (Interviewee 11)

Advance Directive in Assessment. Around one third of the participants ask about advance directives in their assessment. This is because they may value the completion of advance directive or are expected to ask because of their institutional demands:

Typically we want to establish, you know, part of the social work interview is that the patient has an advance directive. They do ask on—they should be asking on admission and they do. Every patient at X is given an advance directive booklet. Usually when I'm identifying family or I'm talking to a patient, that's one of the

questions that's actually in our social work assessment is do you have an advance directive? Then we try to get a copy of it. (Interviewee 2)

Well, all the social workers are supposed to check on advance directives when we're doing our—it's one of our regular questions for our assessment form, you know, checking to see if people have them. (Interviewee 5)

I usually will ask people if they have them, which for me is a good segue if the person isn't already talking about it. I always ask in my assessments, "Does your loved one have an advance directive or living will or anything that formally says who would make their end of life decisions for them or what they would want?" I usually ask that. I ask that of my patients as well. If they say no, then I say, "Well, have you discussed anything with anybody?" If it's a family member, "Has this so-and-so patient told you what they would want or wouldn't want?" Some people say yes, some people say no. For my patients, if they say no, I say, "Well, would you be interested in information?" Those who say yes, I will get them a *Five Wishes* document. (Interviewee 7)

I ask it in all my psychosocial assessments if the patient has an advance directive, and if they don't have one, I'll offer to print out the paperwork and either review it with them or just give it to them to hold onto to even take home and think about later and complete. (Interviewee 8)

Provide Education on Advance Directives. In addition to determining if patients have an advance directive, many social workers take an active role in educating the patient and family about the contents of the document, how to complete it, and then help them to complete the document. Often the documents can be difficult to understand or, because of the content, are difficult because of the emotions that it stirs up:

I'm generally not involved in guiding anyone towards any direction; maybe, helping them understand, if there's words or phrases that they don't understand, and, also, encouraging them to make sure that, when they're done with it, that they hand it to the doctor and tell the doctor they'd like it to be part of their medical records, so that's active during the hospitalization, and not something that they hold onto and fill out, and think that it's gonna impact the decision-making. (Interviewee 4)

I teach them, personally, about the purpose of the document, who should have copies of it, verses holding onto the original, so who they should share it with, who should have a copy, what its purpose is very clearly because a lot of people are concerned that it's used at any time. I'll go through, page by page, part by part, to ensure that there's a clear understanding. But I'm very much against

guiding them, only because, then, it looks like we're influencing their decision. I always encourage them that if they are comfortable, they should discuss it with their family members, as well, what their wishes may be. (Interviewee 14)

Generally, I mean, we probably help with some of the educational pieces of that. You know, sometimes people think a code looks like what they see on television—it's really neat and pretty, and, you know, it's like *pound, pound, pound*, then you're back, and your make-up wasn't smudged, and everybody was happy. When you really sit there and try to explain to somebody, like, ya know this would mean people come running in the room, somebody's pounding on your chest, or shoving a tube down your throat. I mean, we try to give them a graphic interpretation of what it can look like, and then just sort of help with the emotional impact of what that might bring up for people. (Interviewee 15)

Limitations with Advance Directives. Other participants noted being uncomfortable explaining the contents of advance directive documents:

The DNR (do not resuscitate) conversation, and even if the patient wants to complete an advance directive, I always refer the patient to the medical team so they can explain. It's important that they understand the interventions in relation to the current condition and also because the doctors have to indicate, because if they choose—if a patient chooses to be DNR, there's a protocol where the doctors have to—two physicians and a nurse have to witness it and things like that, to place a DNR order. It's a very prescribed process. (Interviewee 2)

We don't review all the content because it's medical, and it's the information that we give does describe each thing, like, it's when a PEG tube describes when a feeding tube is or isn't. If you want to be on a breathing machine. It's not put in strong medical language so that the information we have to give the person, you know, they know what it is. Then we definitely direct them to their physician, their primary, so they can say what they want or don't want. We just say this is what it is; please review it with your doctor. You know, that kind of thing. (Interviewee 12)

Lastly, another finding was the issue of time and caseload in regards to helping patients and families with advance directives. One participant noted:

When a patient can do it, I have to figure out my priority. Do I need to do this discharge or I'm going to run and do this advance directive? A lot of times it's the discharge planning that has to happen. The problem is I could miss an opportunity to have helped a patient with an advance directive prior to them going to the OR or something like that, if I don't know they're going to go to the OR. I always feel like a little uncomfortable feeling when the patient went to the OR

and they wanted to do an advance directive and I didn't get to them on time. To me, that's a problem. (Interviewee 11)

Palliative Care Consultant Team in Reference to ICU Social Worker. The participants also noted the involvement of the palliative care team in the ICU. Palliative care teams are typically a consult service comprised of a physician, as well as a nurse, nurse practitioner, social worker and chaplain. The palliative care team works with any service or discipline throughout the hospital to provide comprehensive care to patients and families. Many times the participants will utilize the palliative care team to provide support to patients and families as well as to facilitate the goals of care discussions. In addition, the social worker may consult the palliative care team himself/herself:

Generally, if they think that's it's going to be more of a process, then they'll bring in the palliative care team. That's not to say that I don't work with our palliative care team because I do, but sometimes I think that there can be too many social workers and too many hands in the pot. It confuses families because they don't always necessarily understand or find it difficult to know why am I working with two different social workers regarding the same type of area. If the palliative care team is involved, generally, I've kind of let them take the lead to not confuse the family. They also have a smaller caseload and can provide that family with more attention, support, those types of things. (Interviewee 1)

I think my primary role—we're in the Department of Discharge Planning, so our role is really to refer to palliative care; as a discharge planning social worker our—it's more referrals than actually providing the actual counseling to the family with end of life care. (Interviewee 2)

The palliative care people, there's a bunch of them and they have a little bit more time, so they end up sometimes spending really a long time with families going over things. That's a great service. It's always something that I think, I wish I was the one who was doing it, but I can't do everything. (Interviewee 5)

The social workers who work with a palliative care team noted a more interdisciplinary approach to working with patients and families. They are included in family meetings organized by the palliative care team, and noted improvements in communication amongst the team:

When it's the palliative care team, there's palliative care people. They'll have the nurse practitioner there. They'll try to get a doctor as well. They'll have the nurse there. The chaplain will be there and I'll be there. It's more of a team with the palliative care. We'll also meet with the palliative team care. It could be one person or it could be three people, depending on who's available and if they have students or whoever is with them. We'll meet before we ever meet with the family to kind of know what we're talking about, what we—our goal is and to make sure everyone's on board before we ever meet. When it's the doctors doing it, they don't think that's necessary because they know what they want to talk about. (Interviewee 5)

Well, I don't know that it's a team as much as it's a physician who the hospital participates with who initiates that, and then the team caring for the patient will work under that palliative care physician's instruction, and often we have family meetings together so everybody can be on the same page with what the family wants and where they want to go. (Interviewee 12)

However, ICU social workers cannot rely on the palliative care team to take the lead on providing supportive end-of-life care to patients and families. Many institutions do not have palliative care teams, and for those that do, often the palliative care team is composed of only a physician. In addition, not all ICU physicians will choose to consult the palliative care team to assist in end-of-life care. “Some of our trauma surgeons say, ‘I don't need palliative care to talk to a family’ (Interviewee 2).”

Exosystem

The exosystem is the interactions between the microsystem, social worker, and a broader system (Higgins, 2011). This broader system is often the hospital, or the department that the social worker is a part of. These broader systems influence, either positively or negatively, the practice of the social worker.

Hospital View of Social Work in ICU. Social workers are impacted by the culture of his/her hospital. It is important for the social worker to be aware of how administration views their role and what the focus of care centers on. “Our administration

starts us working on plan of care, day one (Interviewee 3).” Some hospitals do support end-of-life care, which is reflected in the hospital’s culture around end-of-life care:

I think it's an initiative in the hospital that they really try to provide very good end of life care. I think it's an institutional value, in terms of—we always try to put the patient—if we know a patient is actively dying—in the unit they're in their own room. If they're on the floor, we always try to put them in a private room to give the family—you know, if we're not able to move them out of the hospital. (Interviewee 2)

Utilizing Resources Affiliated with Hospital. However, the field of end-of-life and palliative care is still a growing trend. Social workers are often faced with a hospital that has limited resources for end-of-life care, or who pushes to keep resources within their particular hospital system, and therefore limit the resource options available to patients and families:

Unfortunately, we’re given a lot of information only about one company (hospice agency), because it’s affiliated with the hospital. I think it’s hard for the other companies (hospice agencies) to even come in and do education in-services, because it’s impeding on our business. If another company comes in and says, “This is what we offer that’s so much better than what your agency offers,” there’d be opportunities to do things that might be nicer for the patients and families, at the expense of the health system, which, really, the patients and families don’t really care about, and I don’t care about. It’s more I care about that, in the final moment, someone has an opportunity to do things the way they want to do them. That’s significantly more important than who gets paid for what, and I don’t think the system looks at that. Not to get too off track, but there’s a push in our system to have more hospice referrals, and I don’t know what that necessarily means; I guess, to increase the awareness, to some extent, but it’s about numbers, and it should be about people. (Interviewee 4)

What we are missing is a palliative care committee. I think this was poorly handled. I think when they have someone that they know has no supports or anything, they should come as a team to that person. Not one doctor come in and go you know, she may not make it, it’s time to try to extubate (remove the endotracheal tube) her. I just don’t think that process is appropriate because we don’t really have the focus in place for palliative and end-of-life care. I think if we had a committee, they would be visiting him and I think if there is a committee, a social worker should be dedicated to it. Then that social worker would be available just for that instead of being pulled betwixt and between. (Interviewee 6)

Social Work or Nurse Case-management Department. In addition to being mindful of the hospital culture, ICU social workers need to be aware of the demands and culture of his/her department. Often social workers are not located in a Social Work Department. They often work within a nurse case-management department:

I am under a nurse as a social worker. In the hospital, nurses are the focus. Social work cannot go online and find another area to go to. It's very limited where we go and where we—what our abilities are to grow in the hospital. It's definitely a medical model and nursing focus. When you are a combined department with nurses and social workers and your boss is a nurse, social work has very little focus. Even at staff meetings, that's just a fact. (Interviewee 6)

Ideally I like the model of a clinical social work department, but this hospital does not have it. It's a discharge plan model. Some hospitals have both. They have a discharge planning component and they have the clinical social work department. This hospital is not set up with that. (Interviewee 2)

Negative Culture. Eleven of the participants discussed a negative culture in his/her department around the social workers role in the ICU. For many, the department demands a focus on discharge planning:

The design of hospital social work now is discharge planning. The faster we move, the faster we get 'em out. (Interviewee 6)

I think our department really sees the social work view on end of life if identifying is the patient (is for) hospice, is it a hospice referral? Would they like to go home—it's in relation to the patient's disposition. You know, obviously to provide supportive counseling we really are not set up (with) staffing or just as a priority for the department, unfortunately. (Interviewee 2)

For them, I can say that the department and the people above the heads of the department, it's like, "When are we getting people out? When are we getting people out?" (Interviewee 7)

Many of the social workers felt devalued in their department noting and feel they do not have an identified role:

Our department director doesn't value social work. She doesn't even really think that social work should have a role in hospitals. She came from an institution

where social workers were not there. I think that our institution micromanages everything, so I think they don't value you as a professional, which is sad. (Interviewee 3)

The social worker didn't have to do an assessment on someone until day seven, because the discharge planning on the unit that person has was more important. There's really no impediment. I mean, it was kind of considered a light assignment, to have part of the ICU, because, if you didn't get to it, it was okay. Discharge planning comes first. (Interviewee 17)

Impediments for Social Work. In addition to feeling minimized and under-appreciated, there were many impediments to the ICU social worker's ability to provide end-of-life care. In addition to feeling pressured to focus on discharge planning, many noted caseloads that were overwhelming due to their large size. Some participants noted feeling "stretched too thin" resulting in feeling inadequate around the quality of care he/she is able to provide:

Only that we're stretched so thin with our assignments, that the majority of us either get here early; leave late; don't have lunch. We don't have a caseload that allows us to think about what we can do beyond the discharge planning. We're stretched so thin. (Interviewee 4)

I'm lucky today's actually an exception, because I was able to actually have lunch and then meet with you and have my student upstairs, you go do this. I'm usually lucky if I can get to a quarter or a third of what I need to do every day so that each day, the next day there's a lot left over that I didn't get to. (Interviewee 11)

Unfortunately, there's just not enough time and we're stretched too thin to be able to do it the way I would think would be a really good way. (Interviewee 14)

I think the biggest thing that I would say would impede our ability to do things is the demands of all the other work we have to do.... You always feel like you're being pulled in 1,000 directions. You can be in the ICU and your beeper is going off to outpatient to help somebody with meds, and it's like—I'm not saying that's not important, but when I'm in here and I'm trying to get something done, and facilitate this conversation, and wanna be present for the family, that's hours. You can't do that in ten minutes. (Interviewee 15)

Role Issues. Role definition and boundaries issues emerged for two of the participants. As social workers integrated in nurse case-management departments, there

can be confusion between the nurses and social workers as to what his/her responsibilities are. However, a factor that helped one participant was clear role boundaries:

The fact that I'm the designated trauma social worker because—today we had nine patients. Yesterday we had eight patients, so I was able—coming in after being off for four days in a row—be a part of that meeting. Being designated gives me the edge because I have to see all the patients, or I'm involved in all of them, so then I know. I can prioritize my day, I can prioritize my schedule, and I go around where I believe the priority is. (Interviewee 13)

Positive Culture. However, other participants did note a more positive culture in his/her department. They felt their work in the ICU is supported and valued by either their manager or direct supervisor:

I think it's valued; but everybody knows that there's also palliative care, so it's not just me. I'm happy that they made a decision a while back to take me off coverage for other social workers. Usually when someone's out, the caseload is broken up and every other social worker has a piece of it. Sometime back, they made the decision that I should just be able to cover the units, because the units kind of need to have somebody there. That's nice. I appreciate that little concession to ICU work. (Interviewee 5)

I would say that my supervisor finds it more important than the whole department because in the hospital, the primary roles of the discharge planners and CRC (clinical resource coordinator who is a nurse) is to discharge. (Interviewee 6)

I think our department sees that as an important part of things because we get a lot of consultations for that, for setting up things or talkin' to people about end-of-life care and what hospice is, and how it can be provided, or if they want to participate in that or not. (Interviewee 12)

As significant. They feel like that's a major part of what we do. It's on our statistics, too, like how many end of life discussions we've had. They see it as a major part of what we should be about and facilitating and coordinating and bringing up. They keep track of that. (Interviewee 16)

Aiding Factors. In addition to departmental support, other factors that aid the participants in performing his/her job were colleague support, a supportive supervisor and independence:

My coworker, one coworker, if I said to her, “I have a meeting to help this family make a decision,” she would hold my pager. (Interviewee 3)

Yeah, I function pretty independently from my department, so I think that really the only factors that influence my ability is the availability of X hospice agency to come onsite regardless of whether or not it's gonna be to assist and conduct an end-of-life discuss for a patient that is eventually gonna return to New Jersey or Delaware where they don't cover. (Interviewee 8)

Each participant identified an impediment to his/her ability to provide end-of-life care. For almost all, time constraints, a large caseload, and the push to discharge negatively impact end-of-life care. In addition, at least twelve of the participants discussed working in a nurse case-management department. This has led to competition between the nurse case-managers in the department around responsibilities, and has led many social workers to feel devalued and underappreciated. However, a few of the participants did note a supportive supervisor or colleagues as the aiding factor in providing end-of-life care.

Macrosystem

“The macrosystem consists of the overarching pattern of micro-, meso-, and exosystems characteristic of a given culture or subculture, with particular reference to the belief systems, bodies of knowledge, material resources, customs, life-styles, opportunity structures, hazards, and life course options that are embedded in each of these broader systems” (Broffebrenner, 1994, p. 40). For example, how one’s religion values and views end-of-life practice influences the decisions one may make, as well as how one views withdrawal of care and hospice. Social workers in the ICU must be aware of societal and environmental influences on end-of-life decision making. This requires an awareness of one’s own beliefs on end-of-life care, an ability to manage those beliefs so

as not to impact how one provides care, and the understanding and recognition of how others values and views impact the decisions made.

Personal Values and Beliefs. The participants were asked to discuss how their values and worldview impact the care he/she provides. Over half of the participants identified the need to be aware of one's own personal views so as not to allow them to impact how care is delivered. It is imperative for social workers to gain an understanding of how patients and families view end-of-life care and then work to support and advocate for those wishes:

I can't say that things necessarily—I think that you have to take each case and look at it differently and really look at the person and understand where that person is at meeting their needs to make sure, regardless of what their situation is and everything else, are you acting in the best interests of the patient when it's all said and done? (Interviewee 1)

I am always aware of transference and countertransference issues. I think it's hard sometimes. You know, you look at things and you think, "Why is this family making this decision?" I think it's very hard. Why is the team making this decision? (Interviewee 2)

I hope that my thoughts and feelings, my personal thoughts and feelings and values don't come through. I certainly try—I can't say I don't have them, but I certainly try to keep them to myself and support the family with whatever their decision is. (Interviewee 5)

My values, I always think—well, I always think, "I wouldn't want to live like that," but I don't push that on the patients or the family. I always think how would the patient want to live, and then I always stress that to the family. In the end, it's really what they want. I always say, "Do they have an advance directive?" When they say no, I say, "Would your loved one want to live like that forever?" That usually gets the ball rolling. Then, they always say my favorite, "Well, what would you do?" Oh, dear heaven, what would I do? I never felt comfortable saying that until recently. I say, "I wouldn't want to live like that, but that's not my decision; it's your decision." Sometimes, they think about it and sometimes they're, like, "We want everything," and I respect that, because that's what they want. Even though it's not the right decision, but that's what they want. (Interviewee 3)

I think, at all times, we all have to put our personal values aside as much as we can. That's interesting because my personal value is that people have the right to choose. That's my training too, in autonomy. (Interviewee 6)

Religion and Spirituality. Religion and spirituality were other elements to one's world view that the participants stated influenced how the participant views end-of-life. The social workers stated they needed to understand and respect other's religious beliefs in addition to being mindful of their personal beliefs. It was the general sense that an awareness of one's religious beliefs on end-of-life care aids the social worker on providing compassion to others rather than pushing one's own religious agenda:

I think some of the hardest to work with are Jehovah's witness, especially around blood products, because they are very set that absolutely not under no circumstances, and it's so easy to understand that if we can just transfuse you, it's gonna tremendously help you. I'm not saying that I'm ever gonna try to change their opinion. Most people who are very strong in their faith, they're not gonna change, but I think that sometimes those are some of the harder patients just because sometimes you wouldn't be having end of life conversation with them if it weren't for their religious beliefs. I think that it's part of their faith. It's part of their belief and that is also a large part of their end of life process, whatever they believe in, whether they're Christian, Muslim, Jewish; whatever they feel as though that next step is for them, you need to take that into account because that's how they view that next step. That's important for them, and that's important as a part of their dying phase. (Interviewee 1)

I feel like I have a lot of compassion. I'm a Christian. I personally participate in a lot of community service type things, so I think that that often does translate to my work ethic and view of making sure that people have their needs met whatever they are, which can be challenging 'cause some people are easier to provide service to than others. I think that it actually does sort of trickle over to what I do because I try show people compassion, respect, everybody no matter what. (Interviewee 12)

Did the spiritual side—and that's another thing about our own values. I could be a Buddhist. If this person is a Christian, I listen. I might not believe that she totally believe that her moms gonna get healed. If that's what you believe, that's wonderful. I don't have to give input to that. (Interviewee 6)

Social Work Approach to Cases with Conflict. In the ICU, social workers often work with cases where the families wishes for care contraindicate the patient's previously

stated wishes, or where the families wishes for care conflict with the medical team's beliefs on appropriate care. The social workers identified different approaches to this kind of care, from a personal approach to a team approach.

Advocacy. The common theme amongst many of the participants is promoting self-determination and advocating for the wishes of the patient and family. Social workers work to understand the families beliefs and support them through the decision making process. For example:

I think that for a social worker, I think it's a great time to advocate on behalf of the patient because that's the person that—it's their life, and it's about how they perceive themselves dying. It's about what they've always wanted. (Interviewee 1)

We want to be respectful and we also want to be mindful of how a family feels about—they're the survivor and we don't want them to feel badly about any decisions that they make. People feel horribly guilty. We've had situations where—we had a woman, her son was moving her and she fell and broke a hip, which turned into a whole—it wasn't that he didn't want to adhere to her advance directive. He just felt horribly guilty, because it was kind of perpetuated while he was lifting her. That was the dynamic. We did work through it, but it took a week and a half to do it. Yeah, I think the role as advocate and just trying to get at really what the primary issue is, it's usually workable. (Interviewee 2)

I mean I—I try to learn a little bit more about what they're thinking and what they're doing, you know. (Interviewee 8)

I think you need to meet with the families over time. A lot of times, they will work out, eventually. Families just have to have an opportunity. They, I think the role of a social worker in those situations, where it is conflictual, is really to sit with families and try to help them process what is their feelings versus what they believe their loved one would really have wanted. (Interviewee 10)

Education. Another common approach is the use of education. Social workers will work to educate the medical team on the family's wishes, or they will work with the team to educate the family on the different treatment options, prognosis, and expected outcomes:

Sometimes you just have to say to the doctor I understand that's what you want, but this is about the patient and what the patient wants. (Interviewee 1)

That's every day. Our team just did that. They prolonged a patient's life when they didn't want it prolonged. It's very difficult. I just keep sliding the advance directive over and saying, "Isn't this what the patient wants?" (Interviewee 3)

We try to really educate people. We try to do some counseling and just try to see where the disconnect is. Is it the dynamic with the family? If it's a family issue that it's clear what the patient would want, we really try to explore what it is, why the family feels that way, why they would not want to support the patient's wishes. We would not go against a family, if the patient—I mean, we would strongly advocate, but we just couldn't—I mean we get that a lot with donation (body and organ). A patient's very clear, they want to donate and the family declines. (Interviewee 2)

We try to educate people as much as we can, but if things were never put in writing, or if things were put in writing and somebody's contesting it, then legally we have to figure out, "What do we have to do here?" Sometimes things don't go the way, in your heart, you know they should, or the way you know the patient would've wanted. If legally it's the person's making decisions that's allowed too, it's sorta like our hands are tied. (Interviewee 15)

Utilizing Team Members. Another approach to helping the physician understand the family's perspective is to have another attending talk with the primary attending:

With the doctors, sometimes what we try is peer pressure. We have other physicians talk with—we've actually had that happen, where one surgeon would say no and then we try to have the other surgeon talk with them, like a colleague, someone they may listen to or palliative care, because there's physicians on palliative care, like a peer-to-peer kind of thing. (Interviewee 2)

Communication. In addition to education, the social worker will partner with the medical team to have family meetings and bedside conversations to with families. The goal of these meetings is to continue to provide support to families as well as continued updates and information on the patient's condition:

I think that sometimes it can be what ends up being kind of a bunch of small—not small discussions, but serial discussions over a period of time to allow a family member to kind of come to terms with if an end-of-life issue—if it's the prognosis is so poor it's not survivable, the admission isn't survivable, or what's going on

isn't survivable. Sometimes they're just given some room time-wise to come to a consensus with the goals of care. (Interviewee 9)

If there's a living will, if there's any question of what the patient would want or not want and it's in conflict, what I usually would do is request a meeting to kind of discuss whether it's just me with the family saying what's your understanding what this living will is or is it the doctors are also sometimes in conflict with what is in writing, so maybe they need to be involved also. (Interviewee 11)

Yeah, that's a lot of meetings. That happens. That's a lot of family meetings. (Interviewee 13)

Utilize Ethics Team. Another approach to managing cases where the social worker or team feels there is an ethical dilemma is to work with the hospital's ethics team. The social worker may be the one initiating an ethics consult directly, prompting other members of the ICU team to consult ethics, or ethics may be consulted independently by another member of the team. Four of the participants serve on the ethics committee, and one other discussed the prevalence of other social workers on the committee:

I'm actually a part of our entire ethics committee of the hospital, so I sit on a lot of different—anytime that there's an ethics consult, most of the time I'm involved in it in one aspect or another, or I'll hear about the case later on. We do have a multidisciplinary group, so if we do think that it's really gotten to a point where something, you know, that we need to bring ethics in, then we will have a formalized consult to sit down and really discuss the case. We've even brought family in to sit down with them within an ethics consult to sort through everything. (Interviewee 1)

Well, we have an ethics committee and I'm actually on the ethics committee. If it really gets to a point where we need some objective involvement, it can be brought to the ethics committee and some of the ethics staff. The directors, a physician, she's very good, and there's another social worker on the ethics team, too. (Interviewee 5)

We actually have an ethics committee. I'm a part of the ethics committee of the hospital, and two of the members of palliative care are on the ethics committee, too. We have the capacity to officially have an ethics consult submitted, or we just really work based on the ethics components with the families. (Interviewee 13)

Effective Ethics Team. Many of the participants discussed consulting and bringing the ethics team into the ICU to assist with difficult cases. There were many mixed reactions to the effectiveness of the ethics committee. Some of the participants had good experiences with their hospital's committee:

The ones I have been involved in, I think, are incredibly thoughtful examinations of really difficult cases, where you could make an argument that maybe either course is the most morally ethical course to go on. I think that there's—there's a lot, I think, for the—at least the ethics committee—there's a big emphasis focusing on a lot of staff education, and trying to integrate some education and discussion and thought on these issues, not just on specific consult cases, which can be educational for themselves for the staffs that end up involved in it, but more didactically at clinical conference meetings for the staff, things like that. I think that it's—my experience, there is a lot of thought and effort given to look at, in whole, a difficult situation. I think there's a lot of new emphasis with trying to get the information and some of the thought processes available to the staff to think about and talk about; case conference and things like that. (Interviewee 9)

Then we have an ethics committee. There's a time we will actually have the ethics committee come in to discuss the situation and then what do they suggest. ... It's really involvement of—it's looking obviously to the ethical pieces of it. If it's conflict of family members or a team not agreeing with what is the way to go, it's looking at what's in the advanced directive, looking at what maybe the patient said to one of them, but never wrote it down. Is it futile, you know, the futility care? Maybe the family wants everything done but the doctors are—it's not going anywhere. They will never agree to futility on their own around here. They need the kind of help to get to that point and the ethics committee can help them. They don't want to necessarily always let go on a case. It kind of gives them the support, as well. It's support for the doctors and the team, as well as the patients and families. (Interviewee 11)

Ineffective Ethics Team. However, others reported not having an ethics committee at his/her hospital, or a committee that was not effective in the management of difficult cases:

We do have an ethics committee, not a very vibrant one, but we have one that issues can be brought to. (Interviewee 14)

Ethics Committee Approaches. For the participants who discussed utilizing the ethics committee, he/she discussed different approaches the committee has to working through an ethical dilemma. The ethics committee will talk through the case with members of the treating team and then give their recommendation, or the committee may arrange team meetings to discuss the case as well as arrange and attend family meetings.

For example:

A lot of times they'll call the ethics committee, which I also happen to be on. I think they call the ethics committee a lot to see—we also have a lot of policies in our hospital. Then we also have legal. It just depends on what's going on. (Interviewee 7)

We have an ethics committee that we consult on a regular basis for situations where there is a question. (Interviewee 8)

I think I see those cases through the ethics committee most often, and they—if it's kind of intractable or, I mean—oftentimes, there'll be a consult with ethics, which can, I think, be helpful to broadly look at the circumstance and make sure everyone that's involved is heard and has a—that has a—I guess not an opinion, but should be involved, ideally, in the decision making. (Interviewee 9)

Manage Case within ICU Team. Not all of the ICU social workers rely on the ethics committee to the help work through ethical dilemmas. Three of the participants discussed working through the case as an interdisciplinary team. The team would discuss the dynamics together and develop a plan of care in a collaborative way:

Usually what we do is—usually I will go to the physician first, if I feel it's a real ethical issue, or the team, and kind of discuss, like, "Do we think this is a problem? This is not being really what the patient wants." (Interviewee 2)

Otherwise, you just keep trying to work it through, and help the patient and family and the physicians and everybody to look good. (Interviewee 5)

I mean, there is an ethics team, and they'll often be consulted if there are ethical decisions to be made. In my experience, the dilemmas are always tied on whatever the family is choosing, or the patient. I think most of the times we, the doctors, physicians—it's family-driven. Yes, we may talk to ethics, and we have multidisciplinary team meetings where all of us will get together and talk about

what the issues are at—an independent ethical body will be consulted. They'll leave their recommendations, but at the end of the day, it's really still up to the families. It's hard to go against the family's wishes. (Interviewee 10)

The participants identified different methods for dealing with conflicts in care and ethical dilemmas. Some social workers take an active approach in working with the ICU team and the family. They try to educate all parties involved, advocate for the wishes of the patient or family, and support those going through the process. In addition, some participants discussed a collaborative approach with the interdisciplinary team to work with these cases. However, when the team would feel stuck with a case or have additional questions on how to proceed, many consult and work with the hospital's ethics committee to come to a resolution.

Ways to Improve Field of ICU Social Work

Designated ICU Social Worker. The participants were asked to discuss ways to improve the field of ICU social work. The recommendation discussed most frequently, by eight of the participants, is having a designated ICU social worker. For twelve of the seventeen participants, the ICU was just one part of their assignment. This results in feeling pulled in many different directions and having to juggle many different needs and responsibilities:

I feel like as an institution and as a department, I wish they could, but there's no easy way to do that, unless they had an exclusive ICU social worker. Even in that scenario, that person could have four, out of the eight people, could all be going south quickly, and then that one person wouldn't be able to manage the intensity either. I don't know if there's a good way to do it, but I feel like that's probably the thing that impedes our ability to focus and do a great job more than anything else. (Interviewee 15)

I think in a perfect world there should be one social worker for the ICU and that should be their main focus all day. If it's slow, then you reach out and you help your colleagues. That's my perfect world, but I don't know about everybody else's. (Interviewee 3)

That's frustrating because some days, like especially on Mondays, I'm only supposed—well, every day that I'm there, I'm only there four to six hours, and if there are a lot of new patients where I have to assess them or meet the families, it's not like they're all sitting there lined up and waiting for me. It's sometimes challenging with the time restraints, so sometimes I wish it was a little bit of a longer day, and you know, some families are more needy than others. (Interviewee 12)

Smaller Caseload/ More Time. In addition to a dedicated social worker, participants identified wanting more time and a smaller caseload in order to adequately provide end-of-life care:

I think social work and case management is such a big part—should be a big part of the team because we're the ones that are doing the discharge. They don't look at social work as a supportive factor in the ICUs here because they have the chaplains that are in there all the time. Maybe it would be different if that's my only assignment, the ICUs, but most of the time I can do discharge planning in the other units. (Interviewee 11)

It's just, at our institution, I cover many other units, and my role is quite limited to what I can give and what the team allows me to give. I could do a very good job in the ICU if that was the only—I have five ICUs. If that was the only thing I got to focus on all day, every day, absolutely I could do it. (Interviewee 3)

I'm covering 30 beds and I have to do the assessments on all these people and I have to make sure that I've got discharge plans. I don't really have time to spend a long time with every patient that has an end of life need. (Interviewee 5)

Additional time would allow for social workers to provide support and counseling to patients, families, and ICU staff. The social worker would also be more present and available to the ICU team. He/she could be more actively involved in goals of care conversations, family meetings, as well as help navigate for families while in the ICU:

Covering three floors doesn't allow me to spend the amount of time that I think that some of the patients and families need or require. Sometimes families particularly in the unit, where there's end of life or not, or sometimes it's even a questionable time. They've come in; nobody really knows what the outcome is going to be. Just to even have that time just to check in with families just to say, how are you doing? Do you need anything? I think that families always have

different questions, that type of thing, especially from a social aspect or to even understand what's been going on with a patient prior to. (Interviewee 1)

I wish I had more time to be down there, to hear what decisions are being made, because I'm down there once a week for rounds. I'm down there when they call me for stuff down there. (Interviewee 4)

The focus is not really therapeutic. A social worker based in an ICU should be focused on the therapeutic needs—the therapeutic aspect of the patient in a social work setting, from the social work standpoint. Yes, that's what we're missing. We have physical therapy, occupational therapy; we don't have emotional therapy, we don't have spiritual therapy. (Interviewee 6)

Increased Resources to Perform Role. Social workers are known for a 'trick up their sleeve' when resources are needed. However five of the participants cited needing additional resources to improve the care they provide. Resources such as support groups on site for bereavement, orientation to the hospital, or support during the hospital stay. Also, readily available resource lists to hand out to families with information such as bereavement and funeral resources, and reading material:

I think palliative care has just been a remarkable addition to the hospital. Of course before, she started bereavement support groups. It's just fantastic to be able to offer that at the hospital. They had Compassionate Friends here, which is a community support group, which is nice, but it's nice to be able to offer that support service ourselves. (Interviewee 2)

One of the first things I did was run an orientation group. If it's your first or second day in the hospital, you come to the orientation group, and they give you what to expect, from the time you walk in the door, until the time you leave. It was very comprehensive, and you knew all the options. You knew to be asking the physical therapist what your dispo plan was, and to look at different facilities and different options and equipment. The orientation group set the pace for everyone, so they knew what to expect. (Interviewee 4)

Probably, really giving the families more support after the fact—like having a follow-up, like a six-month—I know hospice promises 12-month follow-up, so having some sort of follow-up for the families, because, the reality is, if we're having end-of-life discussions in the trauma unit, they're not going to hospice. Most of them—they're not. Although some do, and that's great, but they're not. There's no follow-up for the families. I would like to try and have that built into the services that we provide. (Interviewee 13)

I made up this sheet that talks about what to do when your loved one dies in the ICU. Being able to hand that out to people is very helpful. (Interviewee 7)

There should be a little library; a little area where they can sit and review things like that. Maybe even some literature on end-of-life care that they can read, or that I can have in my hand as I discuss things with them because they might not be at the point where they wanna read anything. (Interviewee 6)

Education to Providers. Some of the participants discussed the ICU team's lack of understanding of the social worker's role in the ICU:

Depends on the doctor. Depends on the nurse. Some doctors greatly respect the role of social work, and some of the nurses do, as well. They'll consult us frequently. Then there are some who do not at all, or very minimally, as needed. ... Again, I think some of that is just education, reeducation with the ICU team. (Interviewee 14)

As a result, some of the participants discussed the need for improved education to the other providers on the role and capabilities of the ICU social worker:

I think especially here if people really understood what a social worker can do and the background, the training—sometimes I think that especially within the hospital setting when other people can't fix things, do things, whatever, they just dump it upon us. I think that sometimes, physicians miss the point that it would be so helpful to be meeting with families earlier on to really start to even build that relationship. When you've had a patient who's been here and has been going up, down, back, forth for about a month's time, and they finally draw you in at the end, it's very difficult to really have a therapeutic relationship with that patient or with that family because they've met with all these people, but sometimes, I think more of our job than anybody else's is to sometimes just listen, not say anything to a family. I think they miss that a lot, and so that's kind of frustrating at times. Or when you look at a patient's chart and see all these social issues going on and say why was I never notified about this? How didn't I know? And covering so many floors, I can't be there in all these spots. (Interviewee 1)

Ongoing education with the physicians I think would probably be the single most important thing to change. (Interviewee 2)

Improved education can lead to increased social work involvement and consults.

Four of the participants discussed the need for increased presence and work with patients and families in the ICU:

I do think we don't support families enough under, regarding these questions. Like, regarding DNR. I feel like sometimes that the medical information is provided, but families are asked to make a decision and they're asked to make it quickly and with no support from social work or pastoral care. Ideally, I think everyone who's dealing with end of life should have support. Not everybody wants it, but I feel like we should at least be there to offer that. I don't think all physicians are trained or have the same level of expertise, either, in discussing these issues. (Interviewee 10)

I think it would be helpful to involve a social worker in those conversations, because what you're really doing by talking about all that stuff, is bringing up all these scenarios that are, I'm sure, anxiety provoking, and it can cause people to freeze a little bit in their decision-making. Sometimes the freeze is helpful, because you really need to think about it before you choose a DNR status, but I think, being able to process that information with families after, so they can make sure they understand everything, make sure the decisions they're making are for the right reasons, I think, would be very helpful, but I'm not invited to those meetings. (Interviewee 4)

When staff understands the role of the social worker, they not only consult them more readily, but the interactions become more collaborative. For many of the participants, they want to see an improvement in team collaboration. This could result in improved communication and family experience while in the ICU:

But I think there has to be better communication and I think it has to start from the moment the patient comes in. I think we have to have open communication, and I think I have to be involved. (Interviewee 3)

If most physicians would follow this kind of collaboration, I think we'd have a much better patient, family experience. Because in order to be on a multidisciplinary team, the doctor needs to respect everybody's role and input on the team. I think trauma is a great multidisciplinary team, and we each have our areas of expertise. I think when you meet together and provide options as a team, there's less confusion. If you're in the room with the physician, with the nurse, with the family, it definitely, I think, is a better way for families to obtain information. (Interviewee 10)

Going to other ethical grand rounds, apart from the Schwartz Rounds. Probably the biggest impact I've had is when there's been a forum by which we discuss particular situations and review what we did, and what we could've done better. That forum typically is in a grand rounds, or an ethical grand rounds, if that makes any sense. (Interviewee 16)

Supervision/Debriefing. Working with dying patients in the ICU impacts those involved. However, in many social work or nurse case-management departments, there are limited opportunities for supervision and peer support and debriefing:

Here, there's no such thing as supervision, so when I first came to X, I had never did this before. I had never dealt with end of—I was in cardiothoracic, so people died but it wasn't the amount of end of life stuff that we have here, because so many patients don't even make it to the hospital with bleeds in their heads. There's a big population that get to the hospital, but don't make it out of the hospital. (Interviewee 11)

After that, I remember thinking to myself, “I just witnessed something so horrible, and now I’m getting beeped to go see the next patient.” It’s like, where do I go with that? You can’t even process it. Then by the end of the day you’re so tired, you just don’t even want to think about it anymore. You just go home, and just have the rest—you know, your life to deal with—and then you come back in the next day and you’re like, “Oh yeah, yeah—he died yesterday.” That’s about all you give yourself, so I find that that might be helpful. If there was something that sort of helped people figure out, like, a nice thing to do for themselves in the intense setting of—not even just the ICU, but sort of hospital social work in general. (Interviewee 15)

Probably just the only thing that we didn’t really talk about is sort of the work, the toll that it takes on us as the ICU social workers. I think that, even though we’re all, I think that, over time, I think there is a lot of stuff that goes on, has great impact. I don’t know what that impact is, and we all, I think, sort of deal with it in many different ways. As a younger person, I dealt with it one way, and now, in middle age, too, I think I deal with it in a different way. I think it’s intense stuff, and it has a life-changing effect, seeing people so ill and seeing things that people go through. I don’t think you ever completely understand the impact it has on all of us that do the work. It certainly changes our lives. I always joke around, I know more dead people than alive people. That certainly must have an impact, cuz friends of mine that don’t work in the field, when stuff comes up, unless they’ve had it in their own family, have never thought about end of life stuff. When we get in discussion about it, you can see that they’re right where some patients and families are. I eat, sleep, and dream it. (Interviewee 16)

As a result, many of the participants recommend having consistent supervision to discuss cases in the ICU and how they may affect the social work, therapeutic debriefing opportunities where all members of the ICU team can come together to discuss their reactions and emotions around cases, and opportunities for self-care:

A therapeutic debriefing program for the staff and then the caregivers involved in that particular patient demise. It didn't take off as well as we would have liked it to. There were three specific cases that I was able to implement that for staffing. Then the hospital—there was not a very huge amount of support. Maybe a year-and-a-half post our last effort with trying to offer these therapeutic debriefings, the hospital did, hospital-wide, develop its own program for care-giving support. That's a good thing. We started it, and it kind of fizzled out. Then at least the hospital initiated its own supportive program for the employees for traumatic events that may go on with their patient care. (Interviewee 13)

As a social worker, especially, we already have high stress jobs, and then we have this on top of it, and it can—there needs to be some source of support for that, I think, either as a group. Social workers kind of come together, and they debrief, so to speak, or something, but I do think it's really important to have some type of something in place to deal with that, as well. It's gonna make me more effective, as well as the shared experience if we have other social workers that are also kind of playing in that same role, and they may have a kind of tough situation, you can learn from the experience of the other social workers, as well. (Interviewee 14)

That could be—not that you could completely settle that in yourself, but I think any amount of personal counseling or supervision that allows you to identify that and figure out where you are, so that you can settle that when you approach situations with such intensity, so that you can remain relatively calm and nonjudgmental the best you can. I would say personal stuff that helps you examine your personal issues, from my point of view. (Interviewee 16)

Other Recommendations for Improvement in End-of-Life Care. Other

recommendations and hopes of improvement in the field are a designated palliative care team for the hospital, the ability to bring a hospice team into the ICU when a patient is going to expire there, improved and increased private space for families, and proactive communication to families:

We're not—we don't have the capability to do that (hospice in ICU) right now, but it's something that's in the works, and I think that that's gonna be really helpful for patients and for families, and ultimately for the physicians. (Interviewee 8)

I think that, for those patients that can't be moved and that that will be their place of death, I think having some more private space for families would be helpful for them. It's the environment of the unit that just doesn't lend itself to that, so I think that if there were maybe some—like a private family room or consultation room that was more available, that would probably be easier for families, be some comfort for families. (Interviewee 9)

One of the things they do in the ICU where I work which is great, they call the families twice a day. The nurse calls and gives them a report so to try keep down any anxiety or things that they have. Every person in the ICU, once they identify a family member or support person, that designated family person gets a phone call at 9:00 in the morning, like, between 9:00 and 10:00 in the morning, and then again at night between 9:00 and 10:00. They know to have their phone available for an update. (Interviewee 12)

Conversations. In addition three of the participants discussed the need for the culture around end-of-life discussions to occur earlier in patient's disease process. Often the ICU physicians and team are addressing goals of care with patients and families for the first time. This results in families feeling unprepared to have those conversations, or they may feel blind-sided. Earlier conversations may lead to less ICU admissions and less aggressive care with earlier implementation of DNR's:

I think, especially going into the future, we might be able to do a little bit more just as far as initiating discussions in a more timely fashion. (Interviewee 8)

I always feel like the discussion comes too late. I always feel like there should've been more discussion with patients and families, because what I've seen, even in difficult cases, it is the multiple discussions that eventually brings us to some, what appears to be a caring, loving, sensitive conclusion. I just wish the discussions may have started earlier on. (Interviewee 16)

They talk about hospice after they've totally exhausted and drained every aspect of the patient. When you know from day one, you just can tell. Let's talk about it, let's get them home, let's do palliative care. We have people here for weeks when it's inevitable. Then they go home, or they go across the street and they die within 72 hours. (Interviewee 6)

The Second Trauma. The final recommendation by one of the participants is to train staff on *The Second Trauma*. This is described as:

We even have a program that's called *The Second Trauma*, where we try to, where physicians are really, the whole point is that the first trauma is the trauma that's experienced. The second trauma is the hospitalization, or the breaking of bad news to loved one. For example, if you go into a, your husband dies in a car accident, and I'm a surgeon coming to tell you that news. I'm in a blood-soaked gown and I didn't change yet, or I have blood on my shoes. That's going to

impact that person's ability to cope and grieve. We feel that. The way that the person is told, if they believe the physician cared about them, that they cared about the loved one. (Interviewee 10)

There were many suggestions and beliefs on ways to improve the field of palliative care and end-of-life care. Many of the ideas were a designated ICU social worker, decreased caseloads, additional end-of-life resources, improved education on the role of the social worker, supervision, improved space for the families and educating all ICU staff on the second trauma. The findings showed a wide range of comfort level and practices of the ICU social worker. Some social workers take an active role on the ICU team and with end-of-life conversations, whereas others feel devalued and focus solely on discharge planning.

Limitations

This study had many limitations. To begin, the sample size was not diverse. The study was conducted in and around the area of Philadelphia, Pennsylvania. This sample area resulted from purposive and snowball sampling. Fifteen of the seventeen participants were female, and fourteen were Caucasian. As a qualitative study, the results are not generalizable, because of the design and because the participants were not randomly assigned. In addition, the sample size and location limits the generalizability and transferability of the study findings (Morrow, 2005). The study area was chosen based on an examination of the MSW/MSS programs in the area. However, if this study were to be done again, a broader review of MSW/MSS programs across the country could be completed, as well as recruitment to a broader area.

Although this was not a diverse sample, saturation was reached with the participants. Morrow (2005) states that there is not an exact number to fit a qualitative study, rather data should be collected until saturation is reached. In addition, the interviews were in-depth and the sample represents twelve hospitals in the Philadelphia area. Four of the hospitals were large city university teaching hospitals, two were city affiliated university hospitals, four suburban hospitals, and one cancer center hospital. This strengthens the study because a large percentage of the Philadelphia area hospitals were included in the sample.

Another significant limitation to this study is the threat to trustworthiness through respondent bias (Bowen, 2005). Social desirability is a concern because the participants may have answered the questions in a way he/she felt the researcher wanted to hear because this was an examination of their work (Rubin, 2000). The researcher attempted to minimize this by explaining how the information for each participant and his/her

hospital was de-identified and assuring that the questions were not used to judge how he/she performs his/her role.

Not all of the hospitals in the Philadelphia area were represented in this study. This is due to the recruitment process. If the manager or team leader at the other hospitals were not willing to have his/her social worker participate in the study, they would not connect the researcher to a potential participant, and/or many ICU social workers were not willing to be interviewed. ICU social work is a demanding profession for one's time and large caseloads, and as result many may not have been willing to dedicate their time to this study. This results in a sample of willing participants, who may have a similar interest in end-of-life care in the ICU. This can potentially skew the results, and not represent all perceptions on the topic.

Confirmability was another limitation to this study because the researcher was the instrument (Morrow, 2005). This subjected the interviews and analysis to researcher bias because the researcher had read the literature on the field prior to the interviews and is emotionally connected to the topic (Morrow, 2005). The probes utilized in the interview varied based on the participant and researcher. However, the research utilized the semi-structured interview, asking the primary questions to all the participants. In addition, the researcher engaged in bracketing and reflexivity. This is the process whereby the researcher made her biases known in order to set them aside while conducting the study and analyzing the data (Morrow, 2005).

Timing and location were another limitation to this study. Due to the time constraints of the participants, the researcher consented to meet at a location and time that was convenient and chosen by each participant. As a result, three of the interviews were

conducted in public settings. One was conducted in a hospital cafeteria, one at a restaurant near the participant's hospital, and one was conducted in the sitting area of the hospital's main entrance. This resulted in a shortened interview due to discomfort and distraction for both the researcher and participant, as well as a less in-depth understanding of each question.

In addition to location, interviewing participants during their workday resulted in less time available for the interview. Participants were still connected to their day via pagers and cell phones that occasionally went off during the interview. In addition, it took the interviewer a few minutes to build trust with the researcher as the interview process began and if the interview was taking longer than the participant anticipated, the interviewer noticed the participants attempt to rush through some of the questions. If the study is to be done in the future, the researcher should take a more active role in determining the location and time. If the researcher recruited the social worker through a manager or team leader, the researcher could potentially reserve conference room space with that supervisor to ensure privacy, and potentially interview the participant either before or after his/her day began/ended or on the weekend.

This study was a of a single data source (Morrow, 2005; Rubin, 2000). The participants were only interviewed one time. This lack of time with the participant limited the depth of understanding the researcher was able to obtain from them, as well as a lack of trust building with each participant (Morrow, 2005; Rubin, 2000). The researcher was unable to immerse herself in the setting to gain an understanding of the culture and context, which also takes away from the trust established between researcher and participant (Rubin, 2000). In addition, there was a lack of variety in the data gathered

(Rubin, 2000) because only one-on-one in-depth interviews were completed. If this study is to be replicated, the researcher could conduct group interviews in hospitals with more than one ICU social worker in conjunction with one-on-one in-depth interviews to gather more comprehensive data.

A final limitation to this study was that it only looked at the ICU social worker's perception on end-of-life care. However, end-of-life work in the ICU is provided by many disciplines, for example, physicians, nurses, nurse practitioners, ICU intensivists, and palliative care teams. Due to heavy caseloads, social workers are not always able to be present in the ICU at all times, relying on the other disciplines to consult with them as needed. However, without gaining an understanding of the perception of other disciplines the researcher is not able to glean a comprehensive understanding of end-of-life care in the ICU. Interviewing other disciplines can gain insight into how ICU social workers are perceived, how end-of-life care is perceived in the ICU, and potential opportunities for improvement in care in the ICU and improvement in interdisciplinary collaboration, education and teamwork.

Discussion

The purpose of this study was to gain an understanding of how ICU social workers perceive their role providing end-of-life care, the factors that aid or impede their ability to perform that role, and how their MSW education has influenced their practice. A semi-structured interview was used with all of the participants to gain an in-depth understanding of their role in the ICU and potential opportunities to change and improve the field of ICU social work.

The findings were organized and analyzed utilizing the ecological perspective. This framework was helpful at guiding and informing the findings. This research found that hospital social workers have independence throughout their role, as long as they meet the minimum requirements of discharge planning. This creates an opportunity for the social worker to become involved in aspects of the ICU that are not required, for example organizing and attending family meetings, or providing supportive counseling to a family during a code. Every social worker brings his/her own perspective, expertise and experience to the ICU and it was important to understand how practicing ICU social workers perceive their role in the ICU. In addition, it is imperative to understand how ICU social workers interact on the ICU team, with the families in the ICU, as well as within his/her department and hospital organization.

Microsystem

The microsystem represents the individual social worker in the ICU, including his/her educational experiences, his/her beliefs on ICU social work practice, and his/her personal values. The key findings from the research are that the majority of the participants identified various roles and skills necessary for ICU social work consistent with the literature (McCormick et al., 2007; McCormick et al., 2010; Hartman-Shea et

al., 2011). However, their role as discharge planner was seen as the primary role that takes up the majority of their time. The participants also identified their role as counselor as significant. Sitting with patients and families, listening to their stories and supporting them through this difficult time was highly valued and key to providing good end-of-life care.

In addition to providing support to patients and families, a few of the participants discussed their role as providing support to staff, consistent with the findings of McCormick et al. (2007). Other roles and skills identified by the participants that are consistent with the literature (McCormick et al., 2010, Hartman-Shea et al., 2011) is performing assessments, acting as the facilitator and liaison between the families and the medical team to improve communication, an advocate for the patient and family, as well as having the role of educator. The types of assessments varied for each participant. The participants who viewed their role as discharge planners discussed assessment as a means to identify the next of kin for decision making, and to assess the needs of the patient for discharge in order to identify the correct rehabilitation facility. However other participants discussed their assessments as tools to understand the family dynamics, to gain insight into how the family views end-of-life, and what their perception of the patient's prognosis may be. This was consistent with the literature (Delva et al., 2002; Hartman-Shea et al., 2011; Ross & Shelton, 2006), which identified the social work assessment as a key function of social workers in the ICU.

Through various roles the social worker has, their role as educator is central in improving communication and understanding in the ICU (Cagle & Kovacs, 2009; McCormick et al., 2010). The participants discussed their role as educator to encompass

educating the medical team on the patients and families wishes and family dynamics, educating the patients and families on medical terminology and options for care, as well as advance directive documents, and what patients and families could complete based on the legal parameters. These findings are consistent with the literature, (Hartman-Shea et al. 2011; McCormick et al., 2007; Rose & Shelton, 2006), who discussed the role social workers have in improving communication in the ICU.

The other key role that the participants identified as an important function is that of advocate. The participants all discussed the central importance self-determination and promoting patient autonomy has to their work, which is consistent with the work of McCormick (2011). The social workers discussed the importance of understanding the patient's wishes, and then partnering with them to promote those wishes with the patient's family and medical team. The participants identified different approaches to promoting patient autonomy. They described locating and presenting the patients' advance directive to the medical team, sitting with the patient and family to support the patient while they expressed their wishes to the family, helping the families to think back to a time the patient may have expressed their wishes if the patient is incapacitated, and also spending time with families to help support them grapple with their emotions in regards to making end-of-life decisions congruent with the patient's wishes. The role of patient advocate was a consistent response with many of the participants. Although the findings were not different from the literature, it was important to understand how the social workers perceive their role as advocate. The range of approaches identified by the participants signifies the different beliefs of the ICU social worker as advocate. This understanding of each perception provides insight into how the social worker perceives

their role, what actions they take, and how they liaise between the patients, families, and ICU team.

In addition, there have not been many continuing education programs available in end-of-life care in the ICU. Many of the participants rely on their department's in-services for continuing education training because they do not have the time or flexibility to go off site for trainings. However, there are many limitations to those in-services described by the participants. For example, the in-services rarely discuss end-of-life or are relevant to their work in the ICU, they are geared towards other disciplines, primarily nursing, or those that are on end-of-life are repetitive and offered only by hospice agencies. The participants expressed a desire to learn more on working on an interdisciplinary team, understanding children with grief and loss, running groups in the medical setting and understanding group dynamics, communication strategies, the legal aspects of end-of-life, self-care, end-of-life resources, bioethics, religion and loss, second trauma, medical information and technology, and initiating palliative care in the ICU. In addition to the topics desired, the topics that were beneficial to those participants who did attend a useful training were end-of-life communication strategies, grief and loss, self-care and self-awareness, bioethics, the second trauma, and end-of-life resources including the difference between palliative care and hospice care. These findings are important because there is limited literature and research on the impact of continuing education training for current social work practitioners. In Pennsylvania, medical social workers are not mandated to have their license. As a result, many are not required to get continuing education for credits towards their license. However, continued education is vital to maintain a practice that is informed by current research and that is diverse. ICU

social workers are exposed to a vast array of cases. The social worker may be working with a patient who is ill and undocumented, a patient who expires with no family or contacts, or with a family who brings their young children in to see a dying patient. It is imperative that social workers have access to continuing education that informs their practice.

Another key finding is how the participant's master's program has impacted their current practice. Some of the participants were able to take an elective course geared towards end-of-life. However, consistent with the current literature (Berzoff, Dane & Cait, 2005; Csikai & Raymer, 2005; McCormick et al., 2010), the participants discussed different course content for the elective course. The topics were: understanding one's own experience with loss and how that influences one's practice, a discussion on grief and loss utilizing Kubler-Ross's stages of grief, and understanding the cultural differences and beliefs around loss. It is important to note that many participants were dissatisfied with their programs. Some noted how infrequent the elective was offered, some did not have any end-of-life electives at their program, and others discussed the lack of integration of end-of-life in their core courses, such as Human Behavior Across the Lifespan.

In addition to the coursework, the participant's internship experience also shaped their learning experience. Just over half the participants had an internship that was in a medical setting. For those participants, the experience helped prepare them for their work in a medical setting. However, only a few participants had internship experiences centered around end-of-life care. The benefits they found were learning the culture of the hospital, working in a fast-paced environment, discharge planning, and crisis

management. Only two of the participants identified a supportive supervisor as key to their learning. For the majority, the exposure to the environment was the greatest experience for their educational preparation.

The limited continuing education opportunities and inconsistency and gaps in MSW programs lead to inconsistency in the field. This resulted in different approaches and comfort levels to ICU social work practice. Some of the participants took an active role in end-of-life care in the ICU, whereas others deferred to other providers to explain and educate patients and families on treatment options. There needs to be a cultural change to incorporate end-of-life care into the educational opportunities for social workers.

Mesosystem

The mesosystem is the social worker's interaction with the ICU team or families in the ICU. A key finding under the mesosystem is that of the role of the social worker on or with the ICU team. Many of the social workers did not feel a part of the ICU team. These participants noted a lack of time spent in the ICU on a regular basis, lack of consults to provide support to patients and families, inappropriate consults that were focused on discharge planning when it was evident that the patient and family needed psychosocial support, poor communication with the team members, which resulted in social workers not being aware of family meetings and goals of care conversations, as well as a poor understanding of the role of the social worker. This was evident when the ICU team consulted a hospice team directly to provide support to a dying patient and their family, rather than utilizing the ICU social worker to provide that support and to refer to the appropriate hospice agency.

Inadequate teamwork is a symptom of a problem within the system. Presence and visibility in the ICU is important for social workers to become a member of the team. One way to interact with the team is to attend the ICU rounds. However, for many of the social workers, time constraints and heavy caseloads limited their availability for those rounds. Even as many social workers felt pulled in many different directions, those that reported more success working with the members of the ICU team found that a proactive approach to finding cases in the ICU was successful. Those participants sought out the ICU physicians and nurses to discuss the cases in the ICU who may need social work involvement. This approach also resulted in relationship building, as the social workers listened to the staff, they could support them in the work that they were doing, as well as discuss approaches to care moving forward and could educate the nurses and physicians on how the social worker can help with each case. This approach resulted in success for many of the social workers.

A result of limited involvement with the team is a lack of participation in family conferences. Family conferences are an effective interdisciplinary method for providing clear and accurate information in a supportive way for families (Curtis & Vincent, 2010; Fineberg, 2005; Werner et al., 2004). The participants who discussed their experience on the team as positive and collaborative also discussed their role with family conferences as significant. The social worker often would initiate, organize and facilitate the family conferences. However, not all of the participants discussed a similar role with family conferences. For those that discussed a negative culture around ICU interdisciplinary collaboration, they were not included in family conferences, or family conferences were not done in the ICU unless under extreme crisis situations. The participants who have a

negative experience with collaboration and family meetings also reported feeling overstretched and pushed to focus on discharge planning. They did not have significant time available to spend developing relationships in the ICU and reaching out to families to provide ongoing support.

The participants discussed a need for further education in the ICU to teach the staff the skill set of the social worker and what he/she can bring to a case. The social workers that are proactive integrate education into their daily interactions with staff. This is an effective method in the ICU. It does not require taking time out of one's day to lecture on the role and importance of social work, and is a natural and non-threatening way to educate and reinforce the role of the ICU social worker.

The three trauma social workers that were interviewed for this study discussed their work with the ICU team as collaborative, supportive and effective. Some of the keys to success identified were a need to see every patient within 24 hours of admission, daily interdisciplinary team rounds, case consultation with the team members and a recognition and respect of the different roles that each member fulfilled on the team. This approach to ICU care is an exemplary mode of care. Two of the social workers were at large city university hospitals and one was at a small tertiary hospital. However, each reported similar successes in the ICU.

Exosystem

The exosystem represents the social worker's interaction with the system they work under, such as his/her department and the hospital. In this study many of the participants identified role and boundary issues with their nurse case-manager counterparts in their department. The participants identified issues around role definition

and role boundary, problems being managed by a nurse manager, and feeling unappreciated and devalued. It is important to understand the factors that foster a negative environment for the social workers. The factors the social workers identified are a focus on discharge planning, a lack of understanding of the role and skill set of the social worker, and heavy caseloads. These problems within the department impact how the social worker interfaces with the ICU team. As they are pressured to focus on discharge planning and are given a caseload that is unmanageable, the social worker will feel overwhelmed when the ICU team needs him/her for a family meeting or to spend time with a family to provide support. As many participants noted, cases in the ICU are time consuming. A family meeting can last for one to two hours and if the social worker is helping a family through a withdrawal of care, the social worker may be needed for an entire afternoon. However, there is limited infrastructure in place in the institutions with a negative approach to ICU social work to support the ICU social worker.

There were significant differences between the participants in a negative environment compared to those who reported a positive departmental view to their role in the ICU. The departments that had a positive view had supportive managers and supervisors who recognized the time demand and need for a social worker in the ICU. At many of those institutions the social worker was only assigned to the ICUs. The social worker felt comfortable discussing those difficult cases with his/her supervisor, processing their reactions to the case, and brainstorming ways to move forward with the case.

The other key factor was the colleague support that the ICU social worker relied on and valued. This was one of the major factors that aid the social worker in providing

end-of-life care in the ICU. The participants discussed the significant impact supportive colleagues had on their ability to provide good end-of-life care. Some co-workers would hold their pager if there was a family meeting, others would provide peer debriefing after a difficult case, and others would come together monthly for case presentations.

However, not all the participants reported colleague support. For a few of the participants, the ICU as part of a caseload was viewed as easy because it does not have many discharges, but for others their colleagues did not have the time to help them because of large workloads, or because end-of-life care was not a valued part of the social workers role. This was due to the focus of the social workers being on discharge planning. As the literature reports, with technological advances, patients are living longer and death is becoming more complicated (Christ & Sormanti, 1999). There needs to be increased presence and availability of the social worker in the ICU to help with providing comprehensive care to the patients and families and an understanding in the social work field that cases in the ICU are complex and require a great deal of time and devotion.

Macrosystem

The macrosystem represents the influences of factors on an individual, such as societal norms and beliefs on end-of-life care or one's religious views on end-of-life care. Understanding how one's view on end-of-life decisions and societal norms impacts on end-of-life decision making is important for social work practitioners. The participants identified a key consult they receive is around crisis management; helping the ICU team when there is a conflict with care. Often in the ICU, the team is faced with conflicting beliefs around end-of-life care due to personal beliefs on what is the "right" decision (Barclay et al., 2007; Carlet et al., 2003; Curtis, 2005; Laroche et al., 2009). For almost

all of the social workers, they identified the need to be aware of their own beliefs, in order to not allow those beliefs to impact and guide how they provide end-of-life care.

The social worker's training promoting self-determination is integral, however they also need training on ethical decision making. Grady et al. (2008) found that only 57% of their respondents, nurses and social workers, had ethics education. "Ethics education and training can help healthcare practitioners develop confidence in their decisions, as well as the confidence and know-how to take appropriate action and tap into available resources when needed" (Grady et al., 2008, p. 6).

The participants in this study also had a varied approach to working with families with different views and beliefs on end-of-life care. Some of the participants took an active role and were on the ethics committee at their hospital. They utilized interventions such as education, support, ongoing communication and family meetings as effective methods in working with families. Other interventions included working through the ethical dilemma as a team, processing each other's reactions to the case, and possible methods for moving forward, as well as consulting the ethics committee for an outside support and opinion on the case. However, not all the participants reported taking an active role in working through difficult cases, which is a deficit in the field.

The participants were asked to discuss ways they felt the field of palliative care social work could be improved. What was found was the importance of having a designated ICU social worker. This could result in increased time in the ICU to develop relationships with the staff, more time to spend providing support and facilitating end-of-life care to patients and families, as well as the opportunity to organize and run support groups. The social worker would have the opportunity to begin other initiatives in the

ICU that would result in increased patient and family satisfaction, as well as satisfaction for the staff. These interventions would include initiating discharge planning for those patients who will survive the ICU stay, increased education for the staff to understand the role and potential of the social worker and developing increased end-of-life resources.

Another key improvement recommended by the participants is increased supervision and peer debriefing. Caring for a patient who is going through the dying process emotionally impacts those involved. Self-care is important for social workers, as well as the other providers in the ICU. Compassion fatigue and burn-out are real risks for those in organizations where there is little control of the workload (Maltzman, 2011). It is important to recognize the impact this work has on those involved. Improved interdisciplinary collaboration and respect can aid in decreasing the risks for compassion fatigue and burn out as well as a supportive department. This finding is significant because there is a lack of research on the impact of ICU work on social workers. If social workers are not getting adequate support and do not know how to take care of themselves, the care they are able to provide will diminish.

Implications for Clinical Practice and MSW Education

Implications for Education

The results of this study highlight the need for further investigation into the development and integration of end-of-life care into the MSW programs. There is an urgent need for increased education on end-of-life care in MSW programs as well as continuing education training opportunities (Bomba et al., 2011; Morrissey, 2005).

Forrest & Derrick (2010) find social work education to be the best place for interdisciplinary learning because social work focuses on strengths based perspective of “starting where the patient is”, they value teamwork and relationship building, and focus on communication. The continuing education training and MSW programs need to incorporate working with patients and families at end-of-life, how to work on an interdisciplinary team, how to facilitate family conferences, ethics at end-of-life, and overall medical social work (Fineberg, 2005; Grady et al., 2008). Fineberg (2005) found that the social work students who received training on interdisciplinary family conferences were successful because it increased their confidence, gave new approaches, and increased their understanding of each disciplines role.

Social work education has evolved in the last few years. It now is offering concentrations, such as working with the aging, school social work, and health and mental with the emphasis on mental health. However, there is a need to develop a concentration on medical social work. Social workers in the ICU and in the medical field are faced with many challenges, for example they must learn the hospital environment, work on an interdisciplinary team, provide support and counseling, understand and work with insurance companies, and understand and refer to the various resources around discharge, such as rehabilitation facilities, hospice facilities and home care agencies. The

skills social workers need to learn are strong clinical skills, relationship building skills, understanding family dynamics, empathy, listening skills, patience, good communication, organizational skills, understanding of environment, self-awareness, knowledge of resources and laws, investigative skills, and end-of-life ethics.

Continuing education training opportunities are important to improve the practice of social workers. The reality is it's always difficult for hospital social workers to leave the hospital for training. This study found that continuing education programs on end-of-life are usually only offered by hospice companies who give the same lecture. There needs to be further research into how that can be improved. Investigators need to look at ways to make continuing education training accessible in order for more social workers to have equal opportunities to enhance their learning. This could potentially be done through the use of local expert who can go on-site to the hospital to provide continuing education to the staff. The social workers can receive CEU's at the completion of the training. It is also important that hospitals create opportunities for social workers to go off site for trainings as well as bring innovative programs on site. In the state of Pennsylvania, medical social workers do not have to be licensed to work in the hospital. As a result, many social workers may not be actively seeking out continuing education programs to obtain the units needed to maintain their license. Easily accessible and interesting education programs may capture more medical social workers to maintain a discipline that is up to date on the latest research in the field.

Implications for Practice

There is a great deal of diversity among how social workers provide end-of-life care. In this study for example, some participants discussed a comfort level with talking

to families about touching the patient or discussing the spiritual beliefs of the patient and family when delivering end-of-life care. However, the participants had a varied level of comfort providing end-of-life care. McCormick (2010) found that with palliative care training, the interventions of the social workers improved. More research is needed to provide palliative care training to practicing social workers as well as to MSW students. The goal being to decrease the inconsistency throughout the field of ICU social work and increase social worker's comfort level with providing end-of-life care.

Hartman-Shea et al. (2011) discuss the need to develop guidelines for social work in critical care settings. Some potential for those guidelines include: an assessment of every ICU patient within 72 hours of admission, within this assessment would be to ask about advance directives, wishes and goals of care, as well as determine the next of kin/health care proxy. Delva et al. (2002) also noted the need for social work to focus, within the first 72 hours, on assessment, providing information, providing emotional support and helping to solve practical problems. Further research is needed to develop a framework for ICU social workers to improve the care delivered.

Social workers are taking a more active role in the development and identification of advance directives in the hospitals and Wittenberg-Lyles et al. (2008) stress the importance social work has on helping patients and families with advance directives. Many participants reported receiving consults throughout the hospital whenever a patient requests the completion of an advance directive. However the comfort level around educating the patients on the content of the material and having the time and ability to help them complete the document varied throughout the participants. Many of the social workers reported a discomfort with educating patients and families on the content and

meaning of the documents. They reported referring those patients to their medical provider for further clarification and completion. However, other social workers felt it was important that they first assess the patient's ability to complete the document, help the patient understand the document in lay-man's terms, and would take the time to go through the document page by page. Further research is needed to uncover where the discomfort stems from, methods to decrease that discomfort, and recommendations for how social workers should incorporate advance directives into their practice.

This research found a need for supervision, peer support, and peer debriefing when working within the ICU. Peer support was the major factor that aids the participants in this study to perform better, to feel supported, and to process their reactions of difficult cases. In the ICU social workers are faced with moral dilemmas, dying patients, and crises that affect them emotionally. However, there is a gap in hospitals between those who foster an environment of peer support and who offer supervision and those who do not. An investigation and study is needed to understand how ICU work affects social workers and other practitioners, how they practice self-care, and methods to integrate and bring supervision and peer debriefing to them.

Hartman-Shea et al. (2011) discussed the role post-traumatic stress disorder (PTSD) has on many families after an ICU stay. It was found that families would have benefited from counseling during that stay. More research needs to look at the benefits of a designated ICU social worker. All the participants discussed the need for more time and a smaller caseload in order to improve the care they provide in the ICU. In addition, many identified the need for a designated ICU social worker to improve the field. Further research needs to be conducted to measure the satisfaction rates of patients,

family and ICU staff that have a dedicated ICU social worker, an evaluation of the positive impacts that designated social worker brings to the ICU.

Further Research

Interdisciplinary team work in the ICU has been linked to family satisfaction with care (Campbell & Guzman, 2003). However this research highlighted the different experiences social workers have with members of the ICU team. Some participants felt there was no interdisciplinary team in the ICU, only individuals working separately to provide care to the patients and families, whereas others felt well integrated into the ICU team. More research is needed to understand how the two can relate more constructively. There needs to be a better understanding how to define the role of the social worker in the ICU, how the team functions, and strategies to improve how they work together and provide care.

There is a growing trend to incorporate a palliative care team into the ICU, although not all physicians are willing to work with them. Many of the participants in this study discussed the role of his/her hospital's palliative care team in relation to end-of-life care in the ICU. However, there was inconsistency with how the palliative care team is utilized, what the ICU social worker's role becomes when with palliative care team is involved, and how the ICU social worker interacts with the various members of the palliative care team. Social workers still need to provide and be able to provide end-of-life care in ICU. They cannot always rely on the palliative care team or palliative care social worker to take on the role of supporter and facilitator. As seen in the research, many institutions do not have a palliative care team and of those that do, many are a single physician or a small team for the entire hospital. Further research needs to look at

how the palliative care team and palliative care social worker can best work with the ICU team and ICU social worker, as well as look at the implications of having a proactive palliative care team on the medical/surgical floors to initiate goals of care conversations before a patient is emergently admitted to the ICU. Questions such as, how would the ICU social worker and palliative care social worker share cases, who would be responsible for the needs of the patients and families as they arise, could earlier conversations decrease ICU admissions, would those conversations be linked to earlier implementation of a DNR, which decreases the use of futile aggressive care? ICU social workers cannot rely on the palliative care team to take over all psychosocial needs of patients and families in the ICU. Further research is needed to look at those factors and the implications for admissions to the ICU and end-of-life care in the ICU.

The participants in this study who work on the trauma service discussed an approach to ICU work that was collaborative and comprehensive. Certification of trauma centers is strict and there is set criteria that the institution must adhere to. The social worker completes an assessment on every patient and there are formal and informal team meetings. Research is needed on the exact variables that make this a successful approach and how to infuse those variables into the ICU to create consistency and satisfaction with interdisciplinary approach to end-of-life care.

Conclusion

This study highlighted the many roles social workers have in the ICU, which include discharge planners, investigators, counselors and liaisons. The factors that influence their work is the training they received in their master's program and from continuing education, their ability to collaborate and integrate themselves onto the ICU team, as well as the culture of their department.

This study has added to the existing research through identifying areas for further learning, as well as gaining a comprehensive understanding of the roles and skills practicing ICU social workers feel are necessary for the work, which provides a framework for developing continuing education programs and courses in MSW programs. It is important to understand the social worker in his/her environment (Bomba et al., 2011) and this study uncovered the factors that aid and impede the work of the ICU social worker.

Further investigation is needed to examine ways to improve MSW programs to better prepare social workers for their role in the ICU and methods to promote themselves in an environment of medical personnel. There also needs to be more drive to take on leadership positions in hospital social work and nurse case-management departments. As palliative care begins to evolve, social workers need to be on the frontlines providing the care, and in administrative roles affecting policy. However, this study has provided the building blocks needed to begin to develop a medical social work concentration in MSW programs.

References

- Abbott, K., Sago, J., Breen, C., Abernethy, A. & Tulsky, J. (2001). Families looking back: One year after discussion of withdrawal or withholding of life-sustaining support. *Critical Care Med*, 29, 197-201.
- Abramson, M. (1985). The autonomy-paternalism dilemma in social work practice. *Social Casework: The Journal of Contemporary Social Work*, 387-393.
- Ahrens, J., Yancey, V., & Kollef, M. (2003). Improving family communications at the end of life: Implications for length of stay in the intensive care unit and resource use. *American Journal of Critical Care*, 12(4), 317-323.
- Altilio, T. (2011). Palliative sedation: A view through the kaleidoscope. In T. Altilio & S. Otis-Green (Ed.), *Oxford textbook of palliative social work*. (pp. 661-669). New York: Oxford University Press.
- Aronson, J. (1994). A pragmatic view of thematic analysis. *The Qualitative Report*, 2(1), 1-3.
- Bailey, J., Sabbagh, M., Loisell, C., Boileau, J., & McVey, L. (2009). Supporting families in the ICU: A descriptive correlational study of informational support, anxiety, and satisfaction with care. *Intensive and Critical Care Nursing*, 26, 114-122.
- Barclay, J., Blackhall, L., & Tulsky, J. (2007). Communication strategies and cultural issues in the delivery of bad news. *Journal of Palliative Medicine*, 10(4), 958-977.
- Bartlett, H. (1975). Ida M. Cannon: Pioneer in medical social work. *Social Service Review*, 49(2), 208-229.
- Beder, J. (2006). *Hospital social work: The interface of medicine and caring*. New York: Routledge.

- Berzoff, J., Dane, B. & Cait, C.A. (2005). Innovative models for developing post-masters curriculum in end-of-life care. *Journal of Teaching in Social Work, 25*(3/4), 63-88.
- Biestek, F. and Gehrig, C. (1978). *Client self-determination in social work: A fifty-year history*. Chicago, Illinois: Loyola University Press.
- Blondeau, D., Valois, P., Keyerslingk, E., Hebert, M., & Lavoie, M. (1998). Comparison of patients' and health care professionals' attitudes towards advance directives. *Journal of Medical Ethics, 24*, 328-335.
- Bomba, P., Morrissey, M., & Leven, D. (2010). Key role of social work in effective communication and conflict resolution process: Medical orders for life-sustaining treatment (MOLST) program in New York and shared medical decision making at the end of life. *Journal of Social Work in End-of-Life & Palliative Care, 7*, 56-82.
- Bowen, G. A. (2005). Preparing a qualitative research-based dissertation: Lessons learned. *The Qualitative Report, 10*(2), 208-222.
- Broffebrenner, U. (1994). Ecological models of human development. In *International Encyclopedia of Education*, Vol. 3, 2nd Ed. Oxford: Elsevier. Reprinted in: Gauvin, M. & Cole, M. (Eds.), *Readings on the development of children*, 2nd Ed. (1993, p 37-43). NY: Freeman.
- Browning, A. (2008). Empowering family members in end-of-life care decision making in the intensive care unit. *Dimensions of Critical Care Nursing, 28*(1), 1-23.
- Bryn Mawr University. (2012). Bryn mawr college graduate school of social work and social research course guide 2011-2012. Retrieved October 5, 2012 from <http://www.brynmawr.edu/socialwork/documents/CourseGuideGSSWSR.pdf>

- Buckey, J. & Abell, N. (2009). Factors affecting life-sustaining treatment decisions by health care surrogates and proxies: Assessing benefits and barriers. *Social Work in Health Care, 48*, 386-401.
- Burford, C. (1981). Social work why it's needed in intensive care units. *Texas Hospitals, 11-13*.
- Cagle, J. & Kovacs, P. (2009). Education: A complex and empowering social work intervention at the end of life. *Health & Social Work, 34(1)*, 17-27.
- Campbell, M. & Guzman, J. (2003). Impact of proactive approach to improve end-of-life care in medical ICU. *CHEST Online, 123*, 266-271.
- Carlet, J., Thijs, L, Antonelli, M., Cassell, J, Cox, P., Hill, N., Hinds, C., Pimental, J. Connor, S., Egan, K., Kwilosz, D., Larson, D. & Reese, D. (2002). Interdisciplinary approaches to assisting with end-of-life care and decision making. *American Behavioral Scientist, 46*, 340-356.
- Carlet, J., Thijs, L, Antonelli, M., Cassell, J, Cox, P., Hill, N., Hinds, C., Pimental, J. Reinhart, K., & Thompson, B. (2003). Challenges in end-of-life care in the ICU: Statement of the 5th international consensus conference in critical care. *Intensive Care Med, 30*, 770-784.
- Chachkes, E. & Foster, Z. (2004). Taking charge: Social work leadership in end-of-life care. In J. Berzoff & P. R. Silverman (Eds.), *Living with dying: A handbook for end-of-life healthcare practitioners* (pp. 825-837). New York: Columbia University Press.
- Chan, R. & Webster, J. (2010). End-of-life care pathways for improving outcomes in caring for the dying (review). *The Cochrane Library, 1*, 1-15.

- Christ, G. & Sormanti, M. (1999). Advancing social work practice in end-of-life care. *Social Work in Health Care, 30*(2), 81-99.
- Clarke, E., Curtis, R., Luce, J., Levy, M., Danis, M., Nelson, J., & Solomon, M. (2003). Quality indicators for end-of-life care in the intensive care unit. *Critical Care Medicine, 31*(9), 2255-2262.
- Connor, S., Egan, K., Kwilosz, D., Larson, D. & Reese, D. (2002). Interdisciplinary approaches to assisting with end-of-life care and decision making. *American Behavioral Scientist, 46*, 340-356.
- Csikai, E. L. (2006). Bereaved hospice caregivers' perceptions of the end-of-life care communication process and the involvement of health care professionals. *Journal of Palliative Care, 9*(6), 1300-1309.
- Csikai, E. L. & Bass, K. (2000). Health care social workers' views of ethical issues, practice, and policy in end-of-life care. *Social Work in Health Care, 32*(2), 1-22.
- Csikai, E. L. & Raymer, M. (2005). Social workers' educational needs in end-of-life care. *Social Work in Health Care, 41*(1), 53-72.
- Curtis, R. (2005). Interventions to improve care during withdrawal of life-sustaining treatments. *Journal of Palliative Medicine, 8*, 116-131.
- Curtis, R., Engleberg, R., Wenrich, M, Shannon, S., Treece, P., & Rubenfeld, G. (2005). Missed opportunities during family conferences about end-of-life care in the intensive care unit. *American Journal of Respiratory and Critical Care Medicine, 171*, 844-849.
- Curtis, R., Patrick, D., Engelberg, R., Norris, K, Asp, C. & Byock I. (2001). A measure

- of the quality of dying and death: initial validation using after-death interviews with family members. *Journal of Pain and Symptom Management*, 24, 17-31.
- Curtis, R. & Vincent, J.L. (2010). Ethics and end-of-life care for adults in the intensive care unit. *Critical Care* 2(376), 1347-1353.
- Delva, D., Vanoost, S., Bijttebier, P., Lauwers, P., & Wilmer, A. (2002). Needs and feelings of anxiety of relatives of patients hospitalized in intensive care units: Implication for social work. *Social Work in Health Care*, 35(4), 21-40.
- Dubus, N. (2010). Who cares for the caregivers? Why medical social workers belong on end-of-life care teams. *Social Work in Health Care*, 49, 603-617.
- Emanuel, E. (1987). A communal vision of care for incompetent patients. *The Hastings Center Report*, 17(5), 15-20.
- Emanuel, E. & Emanuel, L. (1989). Living wills: Past, present, and future. *The Journal of Clinical Ethics*, 9-17.
- Encyclopedia of Social Work (2012). Health care social work, 1-6. Retrieved from <http://www.oxfordnaswsocialwork.com/LOGIN?sessionid=5819c7270c1facf3c4de9397ad4ac6c4&authstatuscode=400>.
- Fereday, J. & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), 1-11.
- Fineberg, I. (2005). Preparing professionals for family conferences in palliative care: Evaluation results of an interdisciplinary approach. *Journal of Palliative Care*, 8(4), 857-866.
- Forrest, C. & Derrick, C. (2010). Interdisciplinary education in end-of-life care: Creating

- new opportunities for social work, nursing, and clinical pastoral education students. *Journal of Social Work in End-of-Life & Palliative Care*, 6, 91-116.
- Freedberg, S. (1989). Self-determination: Historical perspectives and effects on current practice. *Social Work*, 33-38.
- Germain, C. B. (1981). The ecological approach to people-environment transactions. *Social Casework*, 62(6), 323-331.
- Gilligan, C. (1993). *In a different voice: Psychological theory and women's development*. Cambridge, MA: Harvard University Press.
- Gitterman, A. & Germain, C. B. (1976). Social work practice: A life model. *Social Service Review*, 50, 601-610.
- Goldsmith, J., Wittenberg-Lyles, E., Rodriguez, D., & Sanchez-Reilly, S. (2010). Interdisciplinary geriatric and palliative care team narratives: Collaboration practices and barriers. *Qualitative Health Research*, 20(1), 93-104.
- Grady, C., Danis, M., Soeken, K. L., O'Donnell, P., Taylor, C., Farrar, A., Ulrich, C. M. (2008). Does ethics education influence the moral action of practicing nurses and social workers? *Am J Bioeth* 8(4), 4-11.
- Gries, C., Curtis, R., Wall, R. & Engelberg, R. (2008). Family member satisfaction with end-of-life decision-making in the intensive care unit. *Chest*, 3, 704-712.
- Harper, B. C. (2011). Palliative social work: An historical perspective. In T. Altilio & S. Otis-Green (Eds.), *Oxford textbook of palliative social work* (pp. 11-20). New York: Oxford University Press.
- Hartman-Shea, K., Hahn, A., Kraus, J., Cordts, G. & Sevransky, J. (2011). The role of the

- social worker in the adult critical care unit: A systematic review of the literature. *Social Work in Health Care*, 50, 143-157.
- Heyland, D. & Tranmer, J. (2001). Measuring family satisfaction with care in the intensive care unit: The development of a questionnaire and preliminary results. *Journal of Critical Care*, 16, 142-149.
- Heyland, D., Rucker, G., Dodeck, P., Kutsogiannis, D., Konopad, E., Cook, D., Peters, S., Tranmer, J. & O'Callaghan, C. (2002). Family satisfaction with care in the intensive care unit: Results of a multiple center study. *Critical Care Med*, 30, 1413-1418.
- Heyman, J. & Gutheil, I. (2006). Social Work Involvement in End of Life Planning. *Journal of Gerontological Social Work*, 47(3/4), 47-61.
- Higgins, P. C. (2011). Guess who's coming to dinner? The emerging identify of palliative social workers. In T. Altilio & S. Otis-Green (Eds.), *Oxford textbook of palliative social work* (pp. 31- 42). New York: Oxford University Press.
- In Social Work Speaks: NASW's policy statements. (2006). 6th Ed, 46-49. Abstract retrieved from <http://www.socialworkers.org/resources/abstracts/abstracts/client.asp>
- Judd, R. & Sheffield, S. (2009). Hospital social work: Contemporary roles and professional activities. *Social Work in Health Care*, 49, 856-871.
- Kane, M., Houston-Vega, M. Tan, P.P., & Hawkins, W. (2002). Investigating factor structure of an instrument to measure social work students' preparedness for managed care environments. *Social Work in Health Care*, 35(4), 41-55.
- Kramer, B. J., Boelk, A., & Auer, C. (2006). Family conflict at the end of life: Lessons

- learned in a model program for vulnerable adults. *Journal of Palliative Care*, 9(3), 791-801.
- Kramer, B. J., Christ, G. H., Kern-Klug, M., & Francoeur, R. B. (2005). A national agenda for social work research in palliative and end-of-life care. *Journal of Palliative Medicine*, 8(2), 418-431.
- Larochelle, M., Rodriguez, K. Arnold, R., & Barnato, A. (2009). Hospital staff attributions of the causes of physician variance in end-of-life treatment intensity. *Palliative Medicine*, 23, 460-470.
- Mackelprang, R. W. & Machelprang, R. D. (2005). Historical and contemporary issues in end-of-life decisions: Implications for social work. *Social Work*, 50(4), 315-324.
- Maltzman, S. (2011). An organizational self-care model: Practical suggestions for development and implementation. *The Counseling Psychologist*, 39(2), 303-319.
- Mann, J., Durgin, J., & Atwood, J. (1977). The social worker on the critical care team. *Supervisor Nurse*, 62-68.
- McAdam, J. & Puntillo, K. (2009). Symptoms experienced by family members of patients in intensive care units. *American Journal of Critical Care*, 18, 200-209.
- McAdam, J., Dracup, K., White, D., Fontaine, D., & Puntillo, K. (2010). Symptom experiences of family members of intensive care unit patients at high risk of dying. *Critical Care Medicine*, 38(4), 1078-1085.
- McCormick, A. (2011). Palliative social work in the intensive care unit. In T. Altilio & S. Otis-Green (Eds.), *Oxford textbook of palliative social work* (pp. 53-62). New York: Oxford University Press.
- McCormick, A., Curtis, R., Stowell-Weiss, P., Toms, C. & Engelberg, R. (2010).

- Improving social work in intensive care unit palliative care: Results of a quality improvement intervention. *Journal of Palliative Medicine*, 13(3), 297-304.
- McCormick, A., Engelberg, R., & Curtis, R. (2007). Social workers in palliative care: Assessing activities and barriers in the intensive care unit. *Journal of Palliative Care Medicine*, 10, 929-937.
- Miller, J., Frost, M., Rummans, T., Huschka, M., Atherton, P., Brown, P., Gamble, G., Richardson, J., Hanson, J., Sloan, J., & Clark, M. (2007). Role of a medical social worker in improving quality of life for patients with advanced cancer with a structured multidisciplinary intervention. *Journal of Psychosocial Oncology*, 25(4), 105-119.
- Mills, J., Bonner, A. & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods*, 5(1), 1-10.
- Mizrahi, T. (1992). The direction of patients' rights in the 1990s: Proceed with caution. *Health & Social Work*, 17(4), 246-252.
- Morrissey, M. (2005). Role of social workers as central health care professionals in advance care and end of life planning, and end of life decision making. *Journal of Pastoral Counseling*, 28-46.
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52(2), 250-260.
- Nadicksbernd, J. J., Thornberry, K., & von Gunten, C. F. (2011). Social work and physician collaboration in palliative care. . In T. Altilio & S. Otis-Green (Ed.), *Oxford textbook of palliative social work* (pp. 471-476). New York: Oxford University Press.

- National Association of Social Workers. (2008). Code of ethics of the national association of social workers.
- Norlin, J. M., Chess, W. A., Dale, O., & Smith, R. (2003). A social systems perspective: The foundations for social systems theory. In Quinlan (Ed.). *Human behavior and the social environment: Social systems theory, 4th Edition* (pp. 25-52). Massachusetts: Allyn and Bacon.
- O'Mahoney, S., McHenry, J., Blank, A., Snow, D., Karakas, S., Santoro, G., Selwyn, P., & Kvetan, V. (2010). Preliminary report of the integration of a palliative care team into an intensive care unit. *Palliative Medicine, 24*(2), 154-165.
- Palos, G. R. (2011). Social work research agenda in palliative and end-of-life care. In T. Attilio & S. Otis-Green (Eds.). *Oxford textbook of palliative social work* (pp. 719-733). New York: Oxford University Press.
- Patrick, D., Engelberg, R., & Curtis, R. (2001). Evaluating the quality of dying and death. *Journal of Pain and Symptom Management, 22*, 717-726.
- Pollio, D. (2006). The art of evidence-based practice. *Research on Social Work Practice, 16*(2), 224-232.
- Quill, T. (2000). Initiating end-of-life discussions with seriously ill patients: Addressing the “elephant in the room”. *JAMA, 284*(19), 2502-2507.
- Rabow, M., Hauser, J. & Adams, J. (2004). Supporting family caregivers at the end of life “they don’t know what they don’t know”. *JAMA, 291*(4), 483-491.
- Rady, M. & Johnson, D. (2004). Admission to intensive care unit at the end-of-life: Is it an informed decision? *Palliative Medicine, 18*, 705-711.
- Reid, W. (2002). Knowledge for direct social work practice: An analysis of trends. *Social*

- Service Review*, 6-33.
- Roer-Strier, D. & Rosenthal, M. K. (2001). Socialization in changing cultural contexts: A search for images of the “adaptive adult”. *Social Work*, 46(2), 215-228.
- Rose, S. & Shelton, W. (2006). The role of social work in the ICU: Reducing family distress and facilitating end-of-life decision-making. *Journal of Social Work in End-of-Life & Palliative Care*, 2(2), 3-23.
- Rothman, J., Smith, W., Jakashima, J. Paterson, M. A., & Mustin, J. (1996). Client self-determination and professional intervention: Striking a balance. *Social Work* 41(4), 396-405.
- Rothman, J. (1989). Client self-determination: Untangling the knot. *The Social Service Review*, 63(4), 598-612.
- Rubin, A. (2000). Standards of rigor in qualitative inquiry. *Research on Social Work Practice*, 2, 173-178.
- Rubin, A. & Babbie, E. (Eds.). (2011). *Research Methods for Social Work*. Belmont, CA. Brooks/Cole, Cengage Learning.
- Siew, K. (2004). The last hours and days of life: A biopsychosocial-spiritual model of care. *Asia Pacific Family Medicine*, 4, 1-3.
- Silverman, P. R. (2004). Dying and bereavement in historical perspective. In Berzoff & Silverman (Eds.). *Living with dying: A handbook for end-of-life healthcare practitioners* (pp. 128-149). New York: Columbia University Press.
- Soskis, C. & Kerson, T. (1992). The patient self determination act: Opportunity knocks again. *Social Work in Health Care*, 16(4), 1-18.
- Stein, G. & Sherman, P. (2005). Promoting effective social work policy in end-of-life and

- palliative care. *Journal of Palliative Medicine*, 8(6), 1271-1281.
- Stricker, K., Kimberger, O., Schmidlin, K., Zwahlen, M., Mohr, U., & Rothen, H. (2008). Family satisfaction in the intensive care unit: What makes the difference? *Intensive Care Medicine*, 35, 2051-2059.
- Studdert, D., Mello, M., Burns, J., Puopolo, A., Galper, B., Truog, R., & Brennan, T. (2002). Conflict in the care of patients with prolonged stay in the ICU: Types, sources, and predictors. *Intensive Care Medicine*, 29, 1489-1497.
- Sullivan, M. (2003). Hope and hopelessness at the end of life. *American Journal of Geriatric Psychiatry*, 11(4), 393-405.
- Sullivan, M., Muskin, P., Feldman, S., & Haase, E. (2004). Effects of religiosity on patients' perceptions of do-not-resuscitate status. *Psychosomatics*, 45(2), 119-128.
- Temple University. (2012). Courses. Retrieved October 5, 2012 from http://www.temple.edu/gradcourses/socadm/gsc_d05401.htm
- Tilden, L., Williams, B., Tucker, R., MacLennan, P., & Ritchie, C. (2009). Surgeons' attitudes and practices in the utilization of palliative and supportive care services for patients with a sudden advanced illness. *Journal of Palliative Medicine*, 12(11), 1037-1042.
- Truog, R., Campbell, M., Curtis, R., Haas, C., Luce, J., Rubenfeld, G., Rushton, C., & Kaufman, D. (2008). Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine. *Critical Care Medicine*, 36(3), 953-963.
- University of Pennsylvania. (2012). MSW program course description. Retrieved October 5, 2012 from <http://www.sp2.upenn.edu/programs/msw/courses.html>

- Unger, M. (2002). A deeper, more social ecological social work practice. *Social Service Review, 76*(3), 480-497.
- Weick, A. & Pope, L. (1988). Knowing what's best: A new look at self-determination. *Social Casework: The Journal of Contemporary Social Work, 10-16*.
- Weiss-Gal, I. (2008). The person-in-environment approach: Professional ideology and practice of social workers in Israel. *Social Work, 53*(1), 65-75.
- Werner, P., Carmel, S., & Ziedenberg, H. (2004). Nurses' and social workers' attitudes and beliefs about and involvement in life-sustaining treatment decisions. *Health & Social Work 29*(1), 27-35.
- Wesley, C. (1996). Social work and end-of-life decisions: Self-determination and the common good. *Health & Social Work, 21*(2), 115-122.
- West Chester University. (2012). Graduate catalog 2012-2013. Retrieved October 5, 2012 From http://www.wcupa.edu/_information/official.documents/graduate.catalog/socwkg.htm#courses
- Widener University. (2012). Center for social work education 2012 graduate catalog. Retrieved October 5, 2012 from http://www.widener.edu/academics/catalogs/_docs/current/SW12Cat.pdf#page=14
- Wittenberg-Lyles, E., Villagran, M. M., & Hajek, C. (2008). The impact of communication, attitudes, and acculturation on advance directives decision-making. *Journal of Ethnic & Cultural Diversity in Social Work 17*(4), 349-364.
- Young, L. & Iverson, R. (1984). Intensive Care: The social worker's role. *Critical Care Medicine, 178-179*

Zastro, C. H. & Kirst-Ashman, K. K. (2004). Theoretical perspectives on human behavior and the social environment. In Gebo & Micheleana (Eds.). *Understanding human behavior and the social environment: 6th Edition* (pp. 1-19). California: Books/Cole-Thomson Learning.

Appendix 1.

Demographic Information

Interview Number:

Date:

Time:

Location:

1. What is your race?
2. What is your gender?
3. What are your religious beliefs?
4. What is your age?
5. How long have you had your master's degree and which degree is it?
6. How long have you worked as a hospital social worker?
7. How long have you been working as the ICU social worker at your hospital?
8. What is your assignment?
9. What proportion of your work is focused around end-of-life care?
10. How long have you worked on this unit?
11. Have you worked on other units in the hospital?
12. What percentage of your time is devoted to the ICU?

Interview Guide

Introduction of Focus of the Study

The purpose of this study is to understand your perception of your role as the ICU social worker providing end-of-life care. You were recruited for this study because of your role as the social worker in the ICU. The focus of the questions will be on your role as the ICU social worker, factors that aid or impede your role, and your educational experience regarding end-of-life care in your MSW program. Everything you say during the interview is confidential.

1. Microsystem: The social worker's role in ICU and educational experience
 - a. How would you describe how end-of-life care in the ICU is managed?
 - b. How do you perceive your role providing end-of-life care in the ICU?
 - c. What skills are needed for an ICU social worker to participate in end-of-life care?
 - d. Have there been any continuing education programs that have helped you with your role in end-of-life care?
 - i. Probe: If yes, what were they and how did they help you?
 - ii. Probe: What was it about them that influenced your practice?
 - e. What topic or area of interest would you be interested in learning more about for your continuing education?
 - i. Probe: What topics may be useful to improve your understanding of how to provide end-of-life care?
 - f. Were there any courses in your MSW program that help you in your work with end-of-life care?
 - i. Probe: What were they?
 - ii. Probe: How have they influenced your practice?
 - iii. Probe: What kind of coursework do you wish you had in your MSW education to prepare you for the work you do now?
 - iv. Probe: Did your MSW internship experience prepare you for your current position?
2. Mesosystem: The social worker and ICU Team
 - a. What is your experience working on the ICU interdisciplinary team?
 - b. What is your role on the interdisciplinary ICU team?
 - i. Probe: Who do you work with primarily on the ICU team?
 - ii. Probe: How do you feel about the interaction between the different medical providers?
 - iii. Probe: Tell me about the communication between you and the physicians, nurses, and other members of the medical team

- iv. Probe: Give me an example of how you work with the physician on the team.
 - c. How do you initially get involved with an end-of-life case?
 - i. Probe: Do you get a referral from other providers? If so, who and how?
 - d. Are you comfortable being the first provider to initiate an end-of-life conversation? If so, do you feel supported by your ICU team members in initiating that end-of-life conversation?
 - e. What is your involvement with advance directives?
 - i. Probe: Who initiates conversations about advance directives?
 - f. Are you involved in relaying information on advance directives to patients and families in the ICU?
 - i. Probe: Can you explain how you provide the information on advance directives to patients and families?
 - ii. Probe: Who talks to the patients and families about what a code is and looks like?
 - g. Are you involved in family conferences?
 - i. Probe: If yes, what is your involvement?
 - ii. Probe: Can you take me through how a family meeting is organized and run in your ICU?
 - iii. Probe: What would you change in your role with family conferences for you to be more effective?
- 3. Exosystem: The social worker, their department and the hospital
 - a. How does your department view your role with providing end-of-life care?
 - b. What are the factors in your department that impede your ability to provide end-of-life care?
 - c. What are the factors in your department that aid your ability to provide end-of-life care?
- 4. Macrosystem: Specialized Questions
 - a. How do you work with a case when the patient's wishes or goals are in contrast with the family members' or medical team's wishes for care?
 - b. How do your values or world view impact how you provide end-of-life care?
 - i. Probe: How do you work with patients whose religious views contrast your own?
 - ii. Probe: How do you work with patients and families whose religious views affect their decisions on end-of-life care?
 - c. How do you manage ethical dilemmas regarding end-of-life care?
 - i. Probe: Do you take an active role?
 - ii. Probe: How would you improve the management of ethical dilemmas in the ICU?
- 5. Debrief: Satisfaction with care in the ICU
 - a. How satisfied are you with how end-of-life care is managed in your ICU?
 - i. Probe: If you could change how you deliver care, what would those changes be?
 - ii. Probe: How confident are you providing end-of-life care?

- b. Do you feel your skills are fully utilized?
- c. How do you think the field of palliative care social work could be improved?
- d. Is there anything that I should have asked that you would like to discuss regarding end-of-life care in the ICU?

Appendix 2.

Title of the Research Study: How do social workers in the ICU perceive their role in providing end-of-life care? What factors impede or help them in carrying out this role in end-of-life care and is social work education a contributing component?

Protocol Number:

Principal Investigator: Joretha Bourjolly, 215-898-5524, jerri@sp2.upenn.edu

Co-Principal Investigator: Allison Gonzalez, 508-735-8550, allison.klugman@gmail.com

You are being asked to take part in a research study. This is not a form of treatment or therapy. It is not supposed to detect a disease or find something wrong. Your participation is voluntary which means you can choose whether or not to participate. If you decide to participate or not to participate there will be no loss of benefits to which you are otherwise entitled. Before you make a decision you will need to know the purpose of the study, the possible risks and benefits of being in the study and what you will have to do if decide to participate. The research team is going to talk with you about the study and give you this consent document to read. You do not have to make a decision now; you can take the consent document home and share it with friends, family doctor and family.

If you do not understand what you are reading, do not sign it. Please ask the researcher to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to sign this form and a copy will be given to you. Keep this form, in it you will find contact information and answers to questions about the study. You may ask to have this form read to you.

What is the purpose of the study?

The purpose of the study is to learn more about the social worker's role in the ICU in providing end-of-life care.

- This study is the dissertation research. The goal of the study is to determine the common practices of ICU social workers performing end-of-life care. The goal of this study is to understand the perception of ICU social workers regarding their role providing end-of-life care and the factors that impede or facilitate that role.

Why was I asked to participate in the study?

You are being asked to join this study because you are an ICU social worker.

- You have been selected for this study because you are currently assigned to an ICU in a hospital and have worked in the ICU for one year or more.

How long will I be in the study? How many other people will be in the study?

The study will take place over a period of one year. This means on one day we will ask you to spend 1-2 hours in an interview.

You will be one of 12-25 people in the study.

Where will the study take place?

You will be asked to come to an agreed upon meeting room at or near your hospital.

The researcher will meet you at a pre-determined location close to your job. This space will be a private area, with minimal noise, and where you will feel comfortable to discuss and answer all questions without fear of being overheard.

What will I be asked to do?

- You will be asked to meet with the researcher for a tape recorded interview that will last up to 90 minutes. There will only be one meeting, and throughout that meeting you will be asked questions regarding your role as the ICU social worker providing end-of-life care to patients and families.

What are the risks?

- There are no anticipated risks to you, all information will remain confidential. Your name will be removed from the interview and a number will be assigned.

How will I benefit from the study?

There is no direct benefit to you. However, your participation could help us understand the best practices for end-of-life care by social workers in the ICU, which can benefit you indirectly. In the future, this may help other people to provide “best-care” practices in the ICU.

What other choices do I have?

Your alternative to being in the study is to not be in the study.

What happens if I do not choose to join the research study?

You may choose to join the study or you may choose not to join the study. Your participation is voluntary.

There is no penalty if you choose not to join the research study. You will lose no benefits or advantages that are now coming to you, or would come to you in the future.

When is the study over? Can I leave the study before it ends?

The study is expected to end after all participants have completed all interviews and all the information has been collected. The study may be stopped without your consent for the following reasons:

- The PI feels it is best for your safety and/or health-you will be informed of the reasons why.
- You have not followed the study instructions
- The PI or the Office of Regulatory Affairs at the University of Pennsylvania can stop the study anytime

You have the right to drop out of the research study at anytime during your participation. There is no penalty or loss of benefits to which you are otherwise entitled if you decide to do so. Withdrawal will not interfere with your future care.

If you no longer wish to be in the research study, please contact Allison Gonzalez, at 508-735-8550 and take the following steps:

- State that you do not want your interview used in the research.

How will confidentiality be maintained and my privacy be protected?

The research team will make every effort to keep all the information you tell us during the study strictly confidential, as required by law. The Institutional Review Board (IRB) at the University of Pennsylvania is responsible for protecting the rights and welfare of research volunteers like you. Any documents you sign, where you can be identified by name will be kept in a locked drawer in the researcher's home office. These documents will be kept confidential. All the documents will be destroyed when the study is over. The methods of this study are qualitative, utilizing thematic analysis to review and analyze the data.

- Only the researchers in this study will have access to the information gathered for the study. The file created for you will not contain your name, a code number will be used. All interviews will be audio recorded. The recordings will have your name removed to ensure that your information remains confidential.
- The files will be stored in a locked cabinet in the researcher's home. Only the researcher will have access to the information with your name and code number. All information reviewed by the dissertation committee will be de-identified and will only have a code number attached.
- The interviews will be transcribed by a reputable transcription service. The interviews will be sent to the service without any identifying information; each

interview will be assigned a number. The transcription service will keep all interview information confidential.

Will I be paid for being in this study?

You will be compensated for your time with a \$30 gift card.

Please note that if you receive more than \$600.00 compensation in one year for participation in research studies at the University of Pennsylvania, you must provide an Individual Tax Identification Number or Social Security Number for tax purposes.

Who can I call with questions, complaints or if I'm concerned about my rights as a research subject?

If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you should speak with the Principal Investigator listed on page one of this form. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs with any question, concerns or complaints at the University of Pennsylvania by calling (215) 898-2614.

When you sign this document, you are agreeing to take part in this research study. If you have any questions or there is something you do not understand, please ask. You will receive a copy of this consent document.

Signature of Subject _____

Print Name of Subject _____

Date

Signature of Investigator _____

Print Name of Investigator _____

Date