

Understanding the Roles of Social Workers in Palliative Care

Research Practicum Report
Submitted to the Faculty of Social Work
In Partial Fulfillment of the Requirements
For the Degree of
Master of Social Work

University of Regina
By Laura Amanda Hildebrand

Prince Albert, Saskatchewan
November, 2017

Copyright 2017. L.A. Hildebrand
All Rights Reserved

Abstract

Palliative care is an approach intended to improve the quality of life for individuals who have been diagnosed with an untreatable condition and pending death. Social workers are members of palliative care interdisciplinary teams who serve to improve the quality of life for palliative individuals. Frequently social workers have difficulty defining the roles they perform thus impacting their confidence levels as well as impacting team member knowledge of what social workers do. This research aims to understand the roles of social workers who provide palliative care services to individuals and family members. Data was collected through facilitation of two focus groups with registered social workers who have an interest in palliative care. The data revealed five roles the social workers perform including serving as members of interdisciplinary teams, case management, re-interpreter of the health care system, providing psychological support, and a system navigator. The data revealed social workers strongly value establishing therapeutic rapport with palliative individuals and their family members, which serves as a tool to effectively perform their roles. There were additional findings that emerged in the research that highlight identified strengths that social workers bring to palliative care including social workers' ability to establish therapeutic rapport, and knowledge that social workers have pertaining to palliative care and using self-reflective practice. This research further suggests that social workers are unique in their ability to adapt in their roles to meet the individual needs of each palliative individual.

Keywords: Social work, palliative care, end of life care, death and dying

Acknowledgments

I wish to extend my thanks to the Saskatchewan Hospice and Palliative Care Association for hosting me as a research student. Thank you to the social workers who participated in the research and took time from their busy lives, I couldn't have done it without you. Your passion and regard for palliative individuals and families is remarkable.

I would like to extend my gratitude to Academic Supervisor Bonnie Jeffery for sharing your wealth of knowledge, as well as for the patience you displayed throughout the research process. To Professional Associate Anna Maria, thank-you for shedding light on clinical practice in palliative care and for continuing to read my rambling e-mails. To Committee Member Nuelle Novik for your kind words and continued support. Karla Ethier, thank-you for editing paper after paper while using poetic slogans to keep my grammar in check, I'm lucky to call you my friend.

To my mom and dad who have cheered me on and helped my little family throughout this journey, thank-you! Mom you said "when you get your Master's I'm getting mine too!" Mom, we did it! A special thanks to my husband Josh for supporting my dreams to further my education and also for picking up the slack in our lives... at times I know there was a lot of it. Lastly, to my girls Kate and Brooke who have grown before my very eyes throughout my time in the MSW program, thank you for reminding me to slow down and enjoy the simple things in life. Now and always girls, dream big and follow your heart.

Table of Contents

Abstract.....	ii
Acknowledgments	iii
Introduction.....	1
Literature Review	2
1.1 Methodology of Literature Review	2
1.2 Founder of Palliative Care.....	4
1.3 Guiding Social Work Initiatives in Palliative Care	4
1.4 Social Work Competencies and Roles	7
1.5 Highlighted Barriers.....	11
1.5.1 Education as a barrier.	12
1.5.2 Barriers to providing palliative care services in hospital settings.	14
1.5.3 Barriers associated with palliative care services in home settings.	14
Methods.....	16
2.1 Participant Recruitment.....	16
2.2 Data Collection.....	17
2.3 Data Analysis	18
2.4 Ethical Considerations.....	19
2.5 Limitations	19
Findings.....	20
3.1 Roles of Social Workers in Palliative Care.....	20
3.1.1 Interdisciplinary team member.	21
3.1.2 Case management.	24
3.1.3 Re-interpreter of the health care system	25
3.1.4 Psychological support.....	27
3.1.5 System navigator.	30
3.2 Identified Strengths of Social Workers in Palliative Care	33
3.2.1 Therapeutic rapport.....	34
3.2.2 Knowledge.....	36
3.2.3 Self-reflective practice.....	39
Discussion.....	41
4.1 The Roles of Social Workers in Palliative Care.....	41

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

4.2 Therapeutic Rapport as a Tool	43
4.3 Discomfort with Death	44
4.4 Education and Knowledge	45
4.5 Palliative Care Services in the Home	46
4.6 Implications	47
Conclusion	48
References	50
Appendix A	55
Appendix B	56
Appendix C	57
Appendix D	58
Appendix E	61

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Introduction

Social workers are educated as generalists in practice working in an array of settings such as health care, education systems, non-government organizations, correction systems, and social services. Social workers strive to support individuals and families going through difficult times with a common goal of promoting social justice, advocating on behalf of vulnerable populations, and striving to empower those they work with (Hicks, 2006). Given that social workers provide services in numerous settings they must adapt their roles accordingly to support those they work with. This research study will focus directly on the roles of social workers who work with palliative individuals and families.

The term palliative is frequently used medically to describe “reducing the severity of a disease or condition without curing it” (Palliative, n.d). Palliative care can be described as a holistic approach that strives to improve palliative individuals’ quality of life by addressing physical, psychological, social and spiritual concerns (Cairns, Thompson & Wainwright, 2003). To provide individuals with palliative care services an interdisciplinary team approach is used.

Palliative care interdisciplinary teams are comprised of several health care professionals, primarily including social workers, physicians, and nurses. Social workers use several skills in relation to their work on interdisciplinary palliative care teams including advocacy, assessment, and case management (Bosma et al., 2010; Christ & Sormanti, 2000). Using these skills social workers are frequently the members on interdisciplinary palliative care teams to provide psychosocial care. Providing psychosocial care includes using appropriate language that promotes client centered care.

Within the field of palliative care and within the profession of social work, efforts are made to avoid referring to individuals as “patients” because the term removes people from their identity by focusing on the medical aspects of their care. Bosma et al. (2010) state that palliative

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

care and the profession of social work need to consider people in the full context of their lives. It is important in the profession of social work and the approach of palliative care that the personal values, experiences, and desires of palliative individuals be considered as they near the end of life. For the purpose of this paper, those receiving palliative care services will be referred to as individuals, people, and families.

The purpose of this qualitative research project was to hear from social workers who have an interest in palliative care. The voice of social workers in this study will provide an in depth understanding into the roles they perform to meet the needs of each unique palliative individual and their family members. It is important to understand the roles of social workers for two reasons. First, it will improve the confidence levels of social workers because they will be able to effectively communicate their roles within interdisciplinary teams. Second, social workers who clearly articulate their roles in palliative care will increase awareness on palliative care interdisciplinary team members, leading them to be more willing to seek the expertise of social workers. In turn, this will improve the quality of care provided to palliative individuals and their families.

The paper consists of four sections. First, a literature review will provide readers with insight into the roles of social workers in palliative care. Next the research methods will be discussed. Following this will be the findings of the study highlighting the roles social workers perform and the strengths and skills that social workers in palliative care demonstrate. Last, a discussion is provided.

Literature Review

1.1 Methodology of Literature Review

The literature included in this review was identified through a search of academic and grey literature. Peer reviewed publications published in the English language were searched in

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

selected electronic databases, namely; Cumulative Index to Nursing and Allied Health Literature (CINAHL), Social Services Abstracts, and Social Work Abstracts. The search focused on research articles with terms “palliative care” OR “end of life care” OR “death and dying” AND the terms “social work” OR “social work competencies.” Google Scholar was used to identify peer-reviewed grey literature of relevance. The reference pages of peer reviewed articles found were also searched to find additional sources that fit the criteria of the literature review.

Google Scholar was used to identify peer-reviewed grey literature of relevance such as dissertations, reports, and abstracts. In addition, a systematic review of the grey literature focused on websites relevant to Social Work and Palliative care. Websites included in the search were Canadian Hospice and Palliative Association, National Association of Social Work, World Health Organization, and Saint Christopher’s Hospice.

Inclusion criteria included: presentation of research findings, qualitative or quantitative research articles; reports reviewing palliative care summits, and overviews of social work and palliative care. The search was broadened to include information on social work curricula when it became evident that palliative care specific curricula were influential in strengthening social workers’ ability to work competently in palliative care.

This literature review will provide an overview on the development of social work within the field of palliative care and explore the roles of social workers within palliative care settings. The similarities between the approaches utilized within palliative care services and within social work as a profession will be reviewed. The roles social workers play on interdisciplinary palliative care teams, such as providing psychosocial care, will be highlighted followed by an overview of the value social workers place on working as a member of palliative care interdisciplinary teams. A discussion of the education that social workers receive in relation to

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

end of life care will follow. Lastly, barriers that impact social workers' ability to provide palliative care services, and barriers that impact palliative individuals in seeking palliative care services will be reviewed.

1.2 Founder of Palliative Care

Dame Cicely Saunders was a founding member of hospice care in 1967. Saunders began her career as a nurse, however, she also worked as a social worker and eventually became a physician (Harper, 2011). Saunders was inspired by cancer patient David Tasma whom she fell in love with in 1948. Together they dreamed of developing a home-like setting for terminally ill people (St Christopher's Hospice, 2016). Following Tasma's death, St Christopher's Hospice was opened in London by Saunders. The philosophy of this Hospice was focused on the importance of client centered care; Saunders once said "you matter because you are you and you matter till the last moment of your death" (St Christopher's Hospice, 2016, para. 5). Saunders' passion and knowledge continues to impact hospice and palliative care today. Her founding organization, St Christopher's Hospice, still continues to offer palliative care service to palliative individuals in London, England and also offers educational courses thorough webinars, sends end of life journal articles to subscribers, and hosts a variety of conferences pertaining to end of life issues.

1.3 Guiding Social Work Initiatives in Palliative Care

It is important to highlight events that have contributed to the evolution of social work in palliative care because the initiatives are frequently referenced in the literature. In 1994 the Open House Society funded *Project Death in America* (PDIA) when a group of clinicians, academics and activists recognized that dying people were not being provided with psychosocial and spiritual care at the end of life (Open Society Institute, 2003). The goal of PDIA was to

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

improve the quality of life of palliative individuals and their families by incorporating psychosocial and spiritual care into palliative care services.

A study by Christ and Sormanti (2000) explored social work student's level of preparedness to offer end of life care to palliative individuals. They found that neither physicians, nor nurses nor social workers were receiving adequate training in relation to end of life care. This study is essential as it influenced a new initiative within PDIA that focused on developing the Social Work Leadership Development Award Program that funded forty two social workers to lead projects in the areas of education, practice, and policy development in relation to end of life care (Altilio, Gardia & Otis-Green, 2008). Undoubtedly, the PDIA initiative was crucial to both palliative care as an approach and the roles social workers perform in palliative care for several reasons. First, PDIA created funding for social workers to conduct research in the area of curriculum development while emphasizing the role of social work within palliative care. Second, opportunities were provided for social workers to network and strategize ways to improve the role of social work in palliative care. Last, PDIA captured the importance of introducing psychosocial care as regular practice in palliative care.

In Canada in 2005, Health Canada's Palliative Care and End of Life Team tasked the Social Work Competencies of Palliative Education (SCOPE) project to conduct research to gain insight into social work competencies used in palliative care. The goal of the project was to improve social work curricula by articulating the roles of social workers in palliative care (Canadian Hospice and Palliative Care Association [CHPCA], 2016). A delphi study completed by Bosma et al. (2010) recognized the diverse roles of social workers in palliative care and highlighted eleven competencies social workers use within this specific field of practice including: advocacy, assessment, care delivery, care planning, community capacity building, confirmation, decision

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

making, education and research, information sharing, an interdisciplinary team approach, and self-reflective practice.

The studies by Christ and Somanti (2000) and Bosma et al. (2010) are important because the findings prompted PDIA in the United States and SCOPE in Canada. These two studies are similar in their focus on highlighting core competencies social workers rely on while working in palliative care and the intention of improving social work curricula. The focus in the studies are different because Christ and Somanti (2000) had a broader lens focusing on three categories; Master of Social Work (MSW) preparedness, post graduate training and the experiences of practicing social workers in Palliative Care. Bosma et al. (2010) focused primarily on defining social work competencies with the intention to define the roles of social work in palliative care to improve social work curricula.

The outcomes of both studies were used to organize conferences to discuss the future direction of social workers in palliative care. The social work leadership development program and PDIA worked together to arrange two separate summits in 2002 and 2005 in the United States. The key question participants were asked to think about was “What are anticipated challenges related to end of life and palliative care-within the policy, research, education, and practice domain of social work-that need to be addressed during the next decade?” (Christ & Blacker, 2011, p. 26). The outcome of the summits in the United States became a guiding source in the development of end of life standards for the National Association of Social Workers (NASW). On a smaller scale in Canada with a more focused intent, SCOPE met at Lakeland University in 2008. The goal of the gathering was to validate competencies social workers use while working in palliative care and to strategize ideas to implement them into practice settings and social work curricula (CHPCA, 2016). In 2009, the SCOPE project in Canada concluded by

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

developing and evaluating models of curricula to be implemented into undergraduate and graduate schools of social work across the country (CHPCA, 2016).

1.4 Social Work Competencies and Roles

The literature pertaining to social work and palliative care examined for this project consistently identified the struggle of social workers to define their roles and competencies while working in palliative care. Social workers providing end of life care to dying individuals and their families have felt uncertain of their roles in palliative care which has negatively impacted their ability to practice confidently (Bosma et al., 2010; Christ & Sormanti, 2000). Davidson (2016) argues that social work, as a profession, is not well defined, thus impacting social workers' abilities to strive for and achieve leadership roles on interdisciplinary palliative care teams. The literature revealed two existing explanations as to why social work roles and competencies lack definition. First, social work competencies and roles are misunderstood by members of the interdisciplinary team (Reigada, Ramos & Novellas, 2015). Second, social workers feel they are ill-prepared by their social work education because they are neither taught about end of life issues nor do they have experience in palliative care settings. Therefore, they feel uncomfortable claiming expertise in their practice (Gutheil & Heyman, 2011). Christ and Sormanti (2000) highlight two ways to improve social workers' ability to define their roles. One is to clarify competencies frequently used in palliative care, in part by highlighting the unique training social workers receive. The second way is to define the scope of standards and practice.

The literature offered insight into competencies social workers use in palliative care. Bosma et al. (2010) highlighted eleven core competencies used by social workers in palliative care: advocacy, assessment, care delivery, care planning, community capacity building, confirmation, decision making, education and research, information sharing, an interdisciplinary team

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

approach, and self-reflective practice. A few of the participants also reported that cultural competence is a core competency used in their regular practice (Bosma et al., 2010). Christ and Sormanti (2000) identified ten competencies in their study: supportive counseling, advocacy, symptom management, communication, bereavement, education, ethics, case management, decision making, and discharge management. Social workers depend on the competencies as discussed in these studies to effectively perform their roles in palliative care.

The similarity of values between palliative care and social work surfaced in the literature. Bosma et al. (2010) reflect on how the two philosophies coincide where “both palliative care and social work reflect philosophies of caring that considers individuals in the full context of their lives” (p. 79). Social workers apply family systems theory in their work which suggests that people cannot be understood in their lives without considering the influence of their families (Hicks, 2006). It is important to understand how individuals function within their family system in palliative care because family is so frequently involved at the end of life. Members of the family may have information about family medical history, and previous health experiences both positive and negative that may impact the palliative individual’s beliefs about comfort and medical care. Family members may also be influencing palliative individuals decisions based on their own previous experiences with health care. Decisions made by interdisciplinary teams, and ultimately the death of palliative individuals, impacts family members. It is for these reasons that social workers and palliative care interdisciplinary teams strategize to support the family members in addition to the palliative individual.

The philosophies of social work and palliative care empower and support palliative individuals by avoiding the term *patient* that is used in medical systems. Seeing people as individuals supports self-determination as they embark on their end of life journey. Christ and

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Blacker (2011) name key components that palliative care and social work have in common including; client self-determination, biopsychosocial models of care, family and social systems, cultural competence, and promotion of justice to challenge unequal medical treatment related to the socio-economic status, gender, or ethnicity of palliative individuals. The profession of social work and approach of palliative care practice both strive to promote equality in palliative care services intended to improve the quality of life for all individuals.

There is a substantial focus in the literature pertaining to the social worker's role on palliative care interdisciplinary teams. As highlighted previously, being an interdisciplinary team member was named as a core competency. The members of interdisciplinary palliative care teams most often are physicians, nurses, social workers, and less frequently are chaplains, occupational therapists, and physical therapists. When referring to interdisciplinary palliative care teams, Blacker and Deveau (2010) state "each team member must have a commitment to a common purpose and a deep respect and understanding of the roles and scopes of practice of the other team members" (p. 241). Respecting and supporting each discipline allows team members to work cohesively to provide the best care to palliative individuals and families. Palliative care teams are in part successful because they strive to meet regularly as a team in addition to meeting together with individuals and families. Regular contact allows information to flow, thus reducing repetitious conversations with individuals and families and ensuring that all team members have correct and up to date information to provide client centered care. While working on palliative care interdisciplinary teams, social workers are frequently the team member to provide psychosocial care to palliative individuals and their families.

Although it is noted that physicians, nurses and other palliative care interdisciplinary team members certainly can and do provide psychosocial care, social workers more frequently tend to

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

the psychosocial care needs of palliative individuals and families (Altilio, Otis-Green, Hedlund, & Finberg, 2012; Cadell, Johnston, Bosma & Wainright, 2010; Lawson, 2008; Reigada et al., 2015). Psychosocial care can be defined as a holistic approach that factors the spiritual, psychological, social, emotional, and physical needs of palliative individuals into practice (Cairns et al., 2003).

Additional roles social workers perform on interdisciplinary teams that is within their scope of practice are to facilitate family meetings, clarify information patients receive from other team members (particularly physicians and nurses), and assist with discharge planning when necessary (Lawson, 2008). Haxton and Boelk (2010) found that social workers are often expected to perform roles outside their usual scope of practice. In that study, less than half the respondents reported that their role was solely as social workers, other roles performed include bereavement counsellor (36.4%), coordinating and assigning tasks to volunteers who spend time in palliative care (9.8%), and program directors (4.4%) (Haxton & Boelk, 2010). The literature revealed that social workers value environments where palliative care interdisciplinary teams work together because a team approach provides the opportunity to provide mutual support, collaborate and share knowledge.

Studies by Bosma et al. (2010) and Miller et al. (2007) indicate social workers value working as interdisciplinary team members. Bosma et al. (2010) found that working as an interdisciplinary team member was highly valued among social workers. Miller et al. (2007) reported very similar findings where 94% of participants reported collaborating with team members as valuable. These studies clearly indicate that social workers find it essential to work and collaborate with team members. Sumser, Remke, Leimena, Altilio, and Otis-Green (2015) found that being a part of an interdisciplinary team is essential because it provides the

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

opportunity for education and growth. A study by Miller et al. (2007) examined the value of social work on interdisciplinary teams from a patient perspective rather than from the perspective of social workers or members of the interdisciplinary team. The study stated that social workers included on palliative interdisciplinary teams improved the overall quality of life for individuals with cancer.

Pain management is an important component to palliative care. Social workers have minimized and questioned their role in pain management, relying on other interdisciplinary team members to address it (Altilio et al., 2012). It is expected that medical professionals on the interdisciplinary team (physicians and nurses) will tend to the pain management needs of patients because it is a physical symptom. Although pain is a physical symptom, it is often unpleasant and therefore can impact a palliative individual's emotional well-being (Altilio et al., 2012). Ensuring that patients are comfortable requires conversations about pain management. Patients and families may have concerns and/or questions about pain management medications due to previous experiences or misunderstandings (Brandsen, 2008; Supiano & Berry, 2013). In situations such as these social workers use assessment tools to gather information on beliefs, values, cultural factors, and family history. Assessing patients' pain from a psychosocial perspective can shed light on a patient's perception of pain, family history, and support systems (Brandsen, 2008; Supiano & Berry, 2013). Understanding these areas increases the ability for interdisciplinary team members to provide client centered care while respecting patients' wishes about managing pain.

1.5 Highlighted Barriers

The literature revealed three barriers that impact either social workers' ability to provide end of life care or palliative individual's ability to seek adequate palliative care services. The first

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

barrier focuses directly on the lack of end of life knowledge social workers obtain through their generalist social work education thus impacting their ability to provide end of life care. The next barrier explores the hospital system impacting the ability of palliative individuals to receive client centered care. The last barrier will explore palliative individual's ability to receive adequate palliative care services in home settings.

1.5.1 Education as a barrier. Social workers are educated as generalists in practice learning an array of skills that can be applied to a number of different settings. There are both benefits and setbacks to social workers being generalists. One of the benefits is the flexibility social workers have to work in an array of settings including: health care settings, education settings, non-government organizations, and social services settings. One of the setbacks is because social workers are educated as generalists there is a lack of detailed training and knowledge in specific areas, such end of life care. However, it would be beneficial for social workers to have specific knowledge about end of life care incorporated into social work curricula. Death and dying is an inevitable and frequent occurrence therefore impacting the roles social workers perform within a large scope of settings. Throughout the literature, a common theme emerged reporting that social workers expressed concern that their education did not provide them with enough knowledge pertaining to end of life care. Sumser et al., (2015) found that only 46% of students felt prepared by their education to provide end of life care. Similarly, Gutheil and Heyman (2011) found that only 25% of social work students reported that end of life education was incorporated into their courses in the social work curriculum. Christ and Sormanti (2000) found that Master of Social Work (MSW) students reported receiving limited information on death and bereavement during their studies, with 65% of students reporting their knowledge base in relation to death and dying was unsatisfactory.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Project Death in America (PDIA) recognized that social workers feel ill prepared to provide palliative care services and recommended that social work curricula begin to specialize in end of life care. Smith College School for Social Work and the University of Iowa were two of the Universities who received funding from PDIA. Both host graduate programs that offer end of life education on self-dignity of patients, interventions at the end of life, spiritual care, and cultural competence (Berzoff, 2003; Murty, Sanders & Stendland, 2015). MSW students at the University of Iowa have the option to enroll in the End of Life Care program or complete the courses as electives. After funding from PDIA ceased, the University of Iowa decided to provide financial support to continue with the program. Such a decision shows the value, impact and importance of end of life care. The University has been working on recruitment and retention of students in the End of Life Care program, by 2014 only 34 students successfully completed the program (Murty et al., 2015). The low rate of students successfully completing the program indicates that only a small percentage of social workers entering the field are specialized in offering end of life care. Although the program may be a good solution for a select number of MSW students, options such as integrating end of life issues into current curricula or altering the curriculum to include a mandatory end of life class may increase the knowledge base of more social work students. Agencies hiring social workers frequently hire bachelor level social workers to fill positions in the field of palliative care. Therefore, excluding bachelor degree social workers from end of life curriculum is problematic.

The University of Regina at the undergraduate level offers a course on “Death and Dying”, with a focus on how individuals, families, and professionals are affected by the death and dying process. A graduate social work course on “End of Life Issues” reviews issues pertaining to end of life surrounding cultural and personal perspectives while reviewing the roles of social workers

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

in health care and research (University of Regina, 2017). These two courses appear to be beneficial as they allow students the opportunity to explore the role of social workers in palliative care, however, because the classes are offered periodically only a select number of students are able to enroll in the classes. Overall a gap continues to exist in relation to social work students receiving end of life care knowledge.

1.5.2 Barriers to providing palliative care services in hospital settings. Lawson (2008) found that decisions related to the care of palliative individuals are frequently determined by cost factors and emergency medical situations. Lawson (2008) provided the following example, “Medical teams arrived unannounced, transporters arrive to take the patient for a CT scan or MRI, and all are asked to adapt and accommodate to professionals and institutional demands” (p. 7). The hospital was described as “our house” meaning that palliative individuals are prioritized by the demands of the hospital which results in patients having little control over the care received (Lawson, 2008, p.7). Limited information and research pertaining to barriers or challenges that exist in hospital and home care settings surfaced in the literature. Social workers providing services in hospital settings where decisions may be based on finances are faced with ethical dilemmas that jeopardize their ability to practice morally and ethically. Further research is required to understand constraints that impact social workers’ ability to function within their defined roles within hospital and home care settings.

1.5.3 Barriers associated with palliative care services in home settings. A gap in the literature was found pertaining to clients’ self-determination to receive palliative services in their home. A review of the literature reveals that 70% of Americans say they want to die at home but only 25% of the population is able to do so (Berzoff, 2003). Two studies discussed existing barriers for palliative individuals to die in their homes, with one study focusing specifically on

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

providing services to rural palliative care patients. Christ and Sormanti (2000) found that end of life care in homes is accompanied by little home-based support. A respondent in their study reported: “patients bounce from home to hospital to home to hospice because families are unprepared and cannot find community support other than minimal visitation in the home” (pp. 92-93). On the contrary, Haxton and Boelk (2010) found that rural people receiving palliative care services were more self-sufficient than those in urban settings. They explained this may be due to the independent way of life that rural people have adapted to. Haxton and Boelk (2010) identified distance as one of the challenges to providing services to rural palliative care individuals. Travelling to the homes of rural individuals was identified as time consuming and costly. Social work participants in the Haxton and Boelk (2010) study reported additional barriers such as difficulty accessing community based services (ie., home delivered meals), coordinating transportation, and accessing information on health and social service programs. Limited support from health care providers and services may create isolation for both palliative individuals and their families. Social workers providing palliative services in rural areas reported a sense of isolation when working in rural settings (Christ & Sormanti, 2000). Lawson (2008) noted two benefits of palliative individuals receiving services in their home as having some control in the decisions made about their care and feeling comfortable in their own home.

Recommendations that may improve the quality of life for palliative individuals and their caregivers are offering home based services which include: increased services to monitor and administer pain relief medication, a regular rotation of consistent staff who provide in home care and specialize in palliative care services, and respite options for family members to avoid caregiver fatigue.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

The literature review revealed the roles of social workers in palliative care have been influenced by Dame Sicely Saunders and events such as PDIA and SCOPE. Social workers struggle to define their roles within palliative care which may impact their confidence levels and interdisciplinary team members' ability to articulate what social workers contribute to palliative care interdisciplinary teams. The literature revealed that the values in the profession of social work and the approach of palliative care align by respecting and encouraging palliative individuals' rights to self-determination. Lastly, the literature review identified barriers that social workers or palliative individuals may experience.

Methods

In this section I will discuss the methods used to carry out this qualitative research study and will discuss: participant recruitment, data collection, data analysis, ethical considerations, and study limitations.

I chose a qualitative research method to explore the self-perceived role of social workers who deliver palliative care services (Thyer, 2015). The goal of this qualitative research study is to understand the perceived role of social workers in palliative care to improve the confidence levels of social workers and to increase awareness on palliative care interdisciplinary teams leading them to be more willing to seek consultation and services of social workers.

2.1 Participant Recruitment

Prior to recruiting participants for the research, approval for the study was granted by the University of Regina Ethics Board (Appendix A). Recruitment occurred in two ways. First, the Saskatchewan Association of Social Work (SASW) was contacted and agreed to send a recruitment script (Appendix B) via email to registered social workers in Prince Albert and Saskatoon. The recruitment script requested that those who have an interest in palliative care contact me via e-mail or telephone. The second form of recruitment was snowball sampling.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

When the opportunity presented itself, my Professional Associate and I approached social workers with whom we were familiar through the SASW, SHPCA, and University of Regina Social Work program. When face to face opportunities presented fellow social workers were approached, information was verbally provided to them following a script (Appendix C) that provided information about the research project.

Participants were recruited without difficulty for the first focus group which was held in Prince Albert. Seven participants confirmed their attendance and six attended. Recruiting participants proved to be challenging for the second focus group that was held in Saskatoon. Three of the five participants cancelled on the day the focus group was set to take place. Therefore, the focus group was cancelled hours prior to the scheduled time. That same week the ethics application was amended and approved to include participants who had an education in social work but were not registered social workers (RSW). No further participants were found despite the amendment therefore only registered social workers were included in the study. Four participants were confirmed for the second focus group, however, only two participants attended. A combined total of eight social workers participated in the two focus groups

2.2 Data Collection

A focus group guide was created that consisted of four primary questions with several sub questions (Appendix D). The focus group guide prepared me to collect data related to the roles of social workers in palliative care but also allowed the flexibility required to discover emerging information (Krueger, 1994). The focus groups were audio recorded with the permission of the participants and later transcribed verbatim in order to eliminate the possibility of errors and biases (Creswell, 2013).

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Upon arrival at the focus groups, participants were provided with a consent form (Appendix E) and given time to review it and ask any questions. Participants were informed that the focus group was voluntary and that they could leave at any time. The project was of minimal risk to the participants but to ensure well-being of the participants a list of counseling resources were provided for both Prince Albert and Saskatoon focus group events. Participants signed the consent form and were also provided with a copy of the signed consent form for their own records.

2.3 Data Analysis

Data analysis included reviewing the data collected from the transcribed interviews (Creswell, 2013). Following transcription, the transcripts were read several times to familiarize myself with the data. During analysis, two rounds of coding occurred. During the first round of coding, I examined the data for actions, interactions, and compared for similarities and differences (Strauss & Corbin, 1998). As I was completing the first round of coding I read the transcripts line by line asking myself “what does this mean?” Memos were noted in the margins “that captured short phrases, ideas, or key concepts” (Creswell, 2013, p. 183). As the data was conceptualized, themes related to the knowledge that social workers require to work in palliative care and specific roles they perform in palliative care began to emerge.

During the second level of coding I began to label the themes that emerged and place them into categories. Labeled categories are important because they resemble the phenomenon that the participants have shared (Strauss & Corbin, 1998). I found this level of coding particularly challenging. I found it both tedious and necessary to make sure that I understood the meaning of the categories from the first round to ensure I was accurately capturing the information shared by

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

the participants. During the second round of coding the responses of the participants were transforming from the narratives of the participants into themes.

2.4 Ethical Considerations

Prior to the research project an ethics application was submitted to the University of Regina Ethics Board and approved on February 11, 2017 (Appendix A).

One of the focus groups was held in the community of Prince Albert where I am employed as a social worker. Pre-existing relationships were taken into consideration and discussed with my Academic Supervisor. To my observation, no relationships that indicated a power differential presented themselves. I believe that pre-existing relationships are important to note, however, may also be considered an advantage because a trust relationship is built prior to the time of the focus groups.

To protect the identity of the social work participants pseudonyms are used throughout the paper when referencing quotes. Additionally, identifying information such as names of agencies have been omitted to protect the confidentiality of the participants.

Lastly, I am a social worker registered with the Saskatchewan Association of Social workers (SASW) and as such, it is my responsibility to adhere to ethics as laid out by the Canadian Association of Social workers (CASW). The *Code of Ethics* (CASW, 2005) guides me to follow values and principles outlined by the Association to ensure that I make good judgments and decisions while conducting research.

2.5 Limitations

A limitation of the study was the small sample size of the second focus group. The goal was to identify five to seven participants, and this number of participants was chosen to allow

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

participants to have turns to share their perspective but also to allow the flow of conversation (Krueger, 1994). Only two participants were in attendance for the second focus group.

Another limitation to note is that participants in attendance were recruited on the basis that they have an interest in palliative care. Social work participants had a broad range of knowledge, with experience in a number of health care agencies but not necessarily direct experience in providing in palliative care services.

Findings

The findings will be divided into two sections. First, the roles that social workers perform in palliative care including serving as an interdisciplinary team member, case management, re-interpret of the medical process, providing psychological support, and system navigator will be reviewed. As each role is identified the tasks within the role will be presented. Second, the strengths and skills that social workers contribute within their roles of palliative care will be discussed including the ability to establish therapeutic rapport, specific knowledge social workers have obtained to successfully perform their roles, and the use of self-reflective practice.

3.1 Roles of Social Workers in Palliative Care

Five roles social workers perform within palliative care emerged from the data. The roles include being an interdisciplinary team member, case management, re-interpret of the medical process, providing psychological support, and system navigator. Within each role the social workers reported performing several tasks to effectively meet the needs of palliative individuals and their family members. These tasks will be highlighted as subthemes when discussing each role.

The personal needs of palliative individuals and their families varies considerably depending on their comfort with death and dying, support provided within the family system, personal experiences, and medical needs. To effectively meet each palliative individual's needs social

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

workers carefully assess their needs and tailor their roles and interventions accordingly.

Although there is considerable variation in the roles performed, the roles are consistent in that they are intended to ease the uncertainty and confusion associated with death and dying and the health care system.

3.1.1 Interdisciplinary team member. Social work participants in this research project noted that palliative care interdisciplinary teams are comprised of a number of disciplines including social workers, physicians, nurses, pharmacists, dieticians, spiritual care leaders, physical therapists, and speech language pathologists. The most frequently referenced palliative care interdisciplinary team members were social workers, physicians and nurses. During one of the focus groups, social work participant Darlene stated palliative individuals and their family members also serve as members of the interdisciplinary team when discussing their care. I agree that palliative individuals and their families become part of the interdisciplinary teams. Being an interdisciplinary team member requires collaborating and sharing information with palliative individuals and their families to provide the best care possible.

Although challenges of being a palliative care interdisciplinary team member were noted, a few of the participants reflected positively on the work and relationships that result from being a team member. Megan noted, “I think the palliative care teams work miracles with what they do”. Another social work participant referred to the value of collaborating with team members and appreciating the philosophical differences between disciplines. Lastly, one of the participants shared her belief that due to working as a team member a deep respect had formed among the team members as professionals and as people. Within the role of interdisciplinary team member the social workers perform four main tasks: liaison, assessments, advocating, and providing education.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Liaison. Acting as a liaison between members of the interdisciplinary team and palliative individuals and families was seen as a necessary task to enhance psychosocial care. Social work participants reported acting as messengers relaying information about the palliative individual's care or collecting required information from palliative individuals about their desires for end of life care, or concerns. Participants mentioned challenges related to serving as a liaison between interdisciplinary team members and palliative individuals.

One social work participant shared her experience of navigating dual relationships when acting as a liaison. She shared her experience of witnessing palliative individuals and their families being upset with physicians or nurses from the interdisciplinary team. As a result, she observed hesitation on behalf of the individuals and families to trust her. The participant suspected it was because they viewed her as a representative of the team. She found it necessary to honor her role as an interdisciplinary team member while working to support the family. Honoring her role as interdisciplinary team member was important because of the valued relationship she established with members of the interdisciplinary team.

Assessment. A few of the social work participants shared their role of collecting information from palliative individuals and families to complete an assessment in relation to the needs of palliative individuals. One social work participant shared her experience of attending morning rounds with the interdisciplinary team to check in with palliative individuals. During rounds she shared her role in asking questions about palliative individuals' well-being to assess if psychosocial needs had changed.

Advocating. A number of the participants shared their experience of palliative individuals and families voices not being heard by members of the interdisciplinary team. Darlene recognized that advocating on behalf of palliative individuals could be intimidating. She

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

reported, “It’s not easy to stand up to a nursing team or the doctors.” The social work participants shared their perspective that “standing up” to nurses and doctors is a difficult role but necessary to meet the needs of palliative individuals.

Many of the participants noted their observation that members of the interdisciplinary team were not direct when telling people they are palliative or when discussing options for palliative care. Participants attributed the lack of discussion about palliative care to discomfort with discussing death. A few of the participants reported their role of advocating on behalf of palliative individuals for direct open communication about quality of life as their health deteriorated and for discussing options for end of life care.

Educating. A few of the social work participants spoke about their role in educating interdisciplinary team members about psychosocial care, cultural awareness, and family systems theory. They provided examples of educating team members on the history of First Nations people in Saskatchewan and how they are impacted by colonization. Megan shared an example of educating team members on reasons why particular individuals and families present with emotions related to anger:

You hear of the story of the angry patient, the angry family, the disgruntled, the combative, the non-compliant. You use all this negative language around it. They feel as social workers we can help put the positive spin on those things, and/or help the rest of the interdisciplinary team understand all the reasons why a person is “combative” or “non-compliant”.

Social workers improve relationships and patient satisfaction between interdisciplinary team members and palliative individuals and families by providing education on family systems theory and cultural awareness.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

3.1.2 Case management. Most of the social work participants identified strongly with being a case manager on palliative care interdisciplinary teams. Case management was frequently described as organizing information collected from fellow interdisciplinary team members and arranging details related to the care of palliative individuals. Megan shared her co-workers' perspective of case management:

One of my co-workers refers to social work in an endearing way- the junk drawer of (name of agency). So we encompass all of the things that you don't know where to go, you don't know where to put it, you don't know where to find it, you don't know where to get it and so social work can be sort of that catch for all.

Several of the participants reported they were familiar with details related to palliative individuals' care and therefore prioritized organizing required paperwork and meetings to keep members of the interdisciplinary team up to date. Within the role of case management three tasks were identified: assessment, coordination, and facilitating.

Assessment. Several of the social work participants reported using assessment as a tool within case management. Social workers assess the psychosocial needs and consider whether additional care from interdisciplinary team members is required. As the health of the palliative individual declines the social worker assesses the changing needs of the palliative individual and the family members. Assessments were completed by asking questions of a variety of people including the palliative individual, family members, and members of the interdisciplinary team.

Coordination. Demonstrating case management was viewed as essential to avoid several professionals approaching palliative individuals and family members to collect the same or similar information. Jaycee describes case management as coordinating with interdisciplinary team members to ensure the family does not experience what she describes as chaos that

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

sometimes occurs in the health care system. She said, “We make sure it’s going well for that family and it’s chaos from that side and that family has no idea”. It was interpreted that “chaos from that side” meant the busy pace of the hospital setting.

Facilitation. A few of the social work participants reported facilitating meetings with only the interdisciplinary team members and at times a combination of the interdisciplinary team and the palliative individuals and their family members. The meeting had multiple purposes including sharing of information, coordinating services, answering questions palliative individuals and their families may have related to care, and discussing comfort measures.

3.1.3 Re-interpreter of the health care system. Many of the social work participants identified one of their roles to “re-interpret” the health care system when working with individuals and families. Participants noted that the health care system is often confusing to palliative individuals and their families. Often medical language is used to explain diagnosis or instructions for care. Several of the social work participants viewed themselves as the “non-medical” interdisciplinary team member and highlighted that often individuals and families also viewed them as the “non-medical” professional. Megan explained why her role as a social worker was not one of a medical nature: “...our role isn’t to fix or to cure or to treat”. Megan viewed being identified as a “non-medical” professional as a strength because she did not feel the pressure to provide medical intervention. This was also beneficial because individuals and families did not have that expectation of her to offer divine intervention that individuals and families might expect from physicians and sometimes fantasize about at the end of life.

Several participants shared their experience of becoming desensitized to the medicalized health system. One example shared by a social work participant was noticing that she was beginning to use medical terminology. Upon recognizing that she was using the terminology,

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

she reminded herself that people outside of the health care system, including herself at one time, are not familiar with medical language. Within the role of re-interpreter of the health care system three tasks were identified: advocating, assessment, and facilitating and sharing information.

Advocating. Some of the social work participants identified that part of re-interpreting the palliative process is being able to advocate on behalf of clients and families. They explained that frequently, unfamiliar medical terminology is used to explain important components about diagnosis or caring for medical needs. The social workers reportedly observed that individuals and families are sometimes uncomfortable to ask professionals to explain what is being said or might not know to inquire further with questions. Social workers recognized the need to advocate on behalf of individuals and families to ensure they are understanding physician's explanations, but also to remind members of the interdisciplinary team that medical terms and acronyms need to be explained using lay language. Megan shared that it is not always easy to "stand up" to nurses and doctors but that it is necessary: "... they have a nurse who writes out the notes in the consultation settings, she writes things like BID and TID and I'll say to her 'If I don't know what that means and there is no nurse in the family I can guarantee no one knows what that means. I need you to write that out the long way'". Advocating for understandable language serves to reduce frustration and confusion for palliative individuals and family members.

Assessment. Some of the social work participants reported assessing if palliative families and individuals understand the medical information that is being presented to them. A few methods of assessment mentioned were reading body language, asking questions to inquire if they understood, and on some occasions being able to "feel it out" which is the social worker

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

listening to their intuition based on answers provided by assessment. Jaycee explained how she assesses if a palliative individual understood information received from physicians and nurses and also assessing if the physician had in fact been direct telling people they are palliative:

Did he talk to you about what is going on?Okay so the doctor didn't indicate that the palliative care team will start to follow you. Do you know what that means? Did the doctor explain that to you?

Assessing by way of asking questions is imperative to de-medicalizing the health care system. The participants shared several examples of palliative individuals being either embarrassed to ask questions, or distraught in their thoughts and therefore unsure what to ask. Assessing if palliative individuals are comprehending the information or in fact receiving information from physicians about their palliative diagnosis removes future confusion and can also provide a measure of comfort.

Facilitating and sharing information. A few of the social workers shared examples of facilitating meetings. Typically, those in attendance would be the interdisciplinary team members, palliative individuals, and family members. The social work participants reported acting as a liaison in meetings between family and professionals ensuring that individuals and families understand their diagnosis and the end of life treatment plan. During meetings, information is shared to answer questions and clarify information. While facilitating meetings some social workers reported translating medical terminology in lay terms.

3.1.4 Psychological support. The importance of providing psychological support was identified as a key role for social workers by participants. Psychological support can be described as discussing the mental and emotional needs of palliative individuals and their families and exploring options to ensure their needs are met. Examples of psychological support

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

include, but are not limited to, providing opportunities to discuss fears or concerns related to dying, facilitating conversations between family members to discuss their vision of how their palliative individual will be cared for as they near death, and listening to the narratives of palliative individuals and family members as they reflect on their life and journey in palliative care. Participants emphasized the importance of providing psychological support to palliative individuals and also provided insight about the difficulty of pinpointing the tasks within the role due to the range of needs of each individual. The following tasks were identified as: counseling, and educating and informing.

Counseling. The participants agreed that providing psychological support includes counseling. Important attributes of counseling include making assessments of psychological needs, and listening and validating.

When engaging in counseling, participants reported they begin by assessing the needs of palliative individuals by asking questions. Jaycee provided an example of asking, “is there something more that we can do? Is there something that would make you feel easier about this situation or time?” Counseling also involves reading non-verbal cues. Palliative individuals and their families may be uncomfortable to voice their psychological needs but their body language may provide some insight. One participant provided an example of working with a family who was not in a place of acceptance or understanding that their family member was dying. The social work participant observed that the palliative individual understood their diagnosis but was trying to support their family member who was in denial that the individual was dying. Jaycee said, “You can tell by their facial expression; their body language. They understand. They know what’s happening.” The ability to identify the meaning of the non-verbal cues allows social workers the opportunity to provide psychological support.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Many of the participants reported that counseling frequently entails simply listening to palliative individuals and their family members and validating their feelings. One participant reported that, in some cases, palliative individuals try to stay strong for family members, therefore avoid talking with their family about death. Talking with a social worker provides palliative individuals the opportunity to release emotions or explore fears associated with death or leaving family members behind. During these times it is the role of the social worker to listen, and provide support.

Educating and informing. Many of the social work participants identified that they provide psychological support by providing education. They noted that palliative individuals who are not educated about provisions of palliative care or informed of their medical condition suffer psychologically because they have fear associated with the unknown. Many of the participants shared stories of interdisciplinary team members being uncomfortable talking about death. As a result, it was the perception of the participants that individuals and families were not clearly informed they are being deemed palliative or provided education about what the provisions of palliative care include. Several of the social work participants stated that palliative care diagnoses are frequently explained by discussing the provincial drug care coverage that offers pain management medication. In other words, people were told they were deemed “palliative” in order to receive improved pain medication free of charge. The participants felt that this allowed doctors to avoid informing palliative individuals they are dying. Megan shared her experience of an individual referring to palliative care as the “P” word because it was a scary word to say. The participants saw it as necessary to educate palliative individuals on the provisions of palliative care. Megan explained,

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

...I use the P word all the time. It's not a bad word, it's not a dirty word. I see it as support services to be able to support a patient or person sooner rather than later. The sooner you can get the support services in, the better quality of life we see patients and families have for a much longer period of time.

Jaycee shared an example of informing an individual they were palliative. Jaycee identified that although it is hard to tell people they are dying they need information to process what is happening to them. Jaycee stated "there's been times where I have told someone that they are palliative and.... knowing what to say in that moment and how to explain that, because that's a scary word and people have no clue what that means". Properly informing and educating palliative individuals about their diagnosis and provisions of care is a method of supporting people's psychological well-being. Well informed individuals may have a better opportunity to process what is happening to them or prepare themselves or family members for impending death.

3.1.5 System navigator. Several of the social work participants identified one of their roles as helping palliative individuals and their families navigate the health care systems. Health care systems often consist of a number of facilities including hospitals, physicians' offices, and clinics. These facilities are often scattered throughout cities within the province that palliative individuals are unfamiliar with. Navigating health care facilities may be as simple as directing people where to park, providing directions to the closest accommodations, and directing people to the cafeteria. Participants observed that palliative individuals and families are often travelling from rural or northern areas and have not been exposed to the health care facilities. A palliative care diagnosis coupled with an unfamiliarity of health care systems was noted to be overwhelming.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Participants shared their observation that health care professionals become accustomed to their busy roles and no longer view health care systems and facilities through the fresh lens of the palliative individuals. Megan noted that palliative individuals and families “don’t know what to do. They don’t know who to ask. They don’t know where to turn to.” Participants reported that navigating the health care system was important, in part, due to their own personal experiences. Several participants reported at one time the health care system was once unfamiliar territory to them, which they remember to be intimidating. Several of the participants explained their perception that palliative individuals and families, like themselves at one time, may feel intimidated, lost, confused, and scared while trying to understand the medical system. The social workers therefore recognize that individuals and families need to be supported while they navigate the system. There are three tasks included in being the system navigator: assessment, making referrals or “being the link”, and facilitating.

Assessment. The importance of making assessments pertaining to how familiar palliative individuals are with support and resources available to them was a theme that emerged from the data. Assessments are made by both listening and asking questions. Social work participants highlighted how important it is to listen to palliative individuals as they share their story. As they listened, the social workers made assessments pertaining to what services and resources may ease the responsibilities of family members and improve the quality of life for the palliative individuals. At times, assessing people’s need requires prompting by asking questions. Amber shared her concern that palliative individuals and families may not know what questions to ask. In reference to palliative individuals and families and their specific needs she stated, “lots of people are just too upset or shy to verbalize that.” Social workers making assessments is beneficial so they can link palliative individuals and their families to available services.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Making referrals or “being the link”. The majority of the participants referred to “being the link” which was often referred to as making referrals. Participants reported that being the link meant connecting palliative individuals to services and resources that will improve the palliative individual’s quality of life. Following assessment, the participants reported that they shared their knowledge with palliative individuals to discuss resources available and worked to connect palliative individuals by referring them to resources that best suit their individual needs. One participant shared a personal story of her husband being diagnosed with an untreatable diagnosis and navigating the health care system. Reflecting back, she reported that although both she and her husband had backgrounds in social work, but neither of them were familiar with services that were beneficial for palliative individuals. She viewed the role of social workers to link palliative individuals and families to resources that offer assistance.

Facilitating. The data revealed that one of the roles of social workers is to help palliative individuals navigate health care systems by facilitating conversations about end of life care. Social work participants shared their experiences of exploring options such as taking loved ones home to die, or end of life care provided in a hospital setting or long term facility. The social work participants noted that although these conversations are sometimes uncomfortable for palliative individuals and families, facilitating these conversations alleviates stress and reduces uncertainty. While performing the task of facilitation social work participants explained they rely on knowledge they have obtained such as the services available that enhance palliative care, knowledge of the dying process, and effective communication techniques.

In addition to participants identifying the roles social workers perform in palliative care, they also identified very important skills that social workers bring to palliative care because of their education as generalist practitioners.

3.2 Identified Strengths of Social Workers in Palliative Care

In addition to the roles social workers perform in palliative care further information surfaced in the data that focused on the strengths and skills of social workers who provide palliative care services. Strengths and skills that surfaced in the data include: social workers' ability to develop therapeutic rapport, knowledge about different theories and approaches, and the use of self-reflective practice.

The theme of therapeutic rapport provides insight into the value social workers place on therapeutic relationships that are formed with individuals, families, and team members. The social work participants established therapeutic rapport by showing compassion, being present in conversations, and showing small acts of kindness. The therapeutic rapport developed with individuals and families seemed to strike a personal chord reflecting the personal values of the social workers. Nearly every participant discussed the importance of therapeutic rapport. As participants took turns discussing the importance fellow participants nodded their head in agreement. Several of the participants took time to share stories about the personal connections they formed with dying individuals and families. Participants also emphasized that therapeutic rapport is a tool used in practice. Once therapeutic rapport is established, the relationship acts as a bridge to perform their roles.

Social workers providing palliative care services need to develop a specific knowledge base. Knowledge required to perform their roles effectively were highlighted by the social work participants and included knowledge about: family systems theory, cultural awareness, death and dying, grief and loss, medical terminology, and health care systems. Knowledge was obtained by social workers through their social work education, conferences, personal and professional experiences, interdisciplinary team members, and fellow social work colleagues.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

The last theme that emerged is using self-reflective practice as a tool to guide social workers, both professionally and personally. Self-reflective practice is a combination of four dimensions that include personal experiences, bias, mentorship and support, and self-care. Self-reflective practice was frequently referred to by participants as “keeping in check” with themselves. The participants identified that because death is inevitable, they have personal experiences that reflect the way in which they practice. They viewed their personal experience as a strength and reported that this experience acts as a guide to provide genuine care to others.

3.2.1 Therapeutic rapport. I have used the term therapeutic rapport to describe the connection and relationship built between the social workers and palliative individuals and families. The social workers spoke frequently and passionately about the importance of building therapeutic rapport with palliative individuals and families. Participants highlighted the importance of social workers being empathetic, respectful, non-judgmental, honest, supportive, genuine, and present in conversations. A factor that was brought forth by participants was that building therapeutic rapport often takes time. Social work participant Eleanor stated “Relationships take time and energy. They just don’t happen”. Jaycee described her experience of building therapeutic rapport with a man who was eventually transferred from the hospital she worked in to a larger city center where he died. Jaycee reported the man was resistant to accept services from a social worker, however, she assessed that psychosocial care might be beneficial to the man and spent time establishing therapeutic rapport. Jaycee spoke passionately about the therapeutic rapport she established:

We built a really good relationship. He was there maybe a week. I went through home care with him and what things might look like, what to expect for him and his wife..... at the end, it’s about that relationship building..... and anyways at the end of the whole hospital stay I

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

told him who to call if he needed help and he said “can I just call you?” and I said “ya you can” which I shouldn’t have said, and he gave me a hug and a kiss on the cheek and said good-bye. And then a week later he died in Saskatoon. Tell me I didn’t help him.

Building therapeutic rapport undeniably impacts both the social workers and those they are working. Once trust and respect is established in the relationship, therapeutic rapport aids as tool to enhance the services that are offered. Palliative individuals and families felt more comfortable to discuss advance care directives (directives for end of life medical care), psychological needs, and concerns or questions about medical care. Social workers acknowledged that they are known to be the interdisciplinary team member to establish therapeutic rapport. Compassion, being present in conversations, and supporting clients were deemed as imperative to building therapeutic rapport.

The importance of social workers showing *compassion* to palliative individuals and their families surfaced in the research. Compassion can be defined as “a feeling of deep sympathy and sorrow for another who is stricken by misfortune, accompanied by a strong desire to alleviate suffering” (Compassion, n.d). Eleanor said “the people I knew who worked in palliative care have been extremely compassionate, caring, patient first oriented”. Social work participants reported that showing compassion was met with gratitude from those they were working with.

Being present was described by Eleanor as, “your ability to listen and pay attention to what family members are saying, and the individuals as well. What they want and really listening...” Being present while engaging in conversations was noted by several participants to be a challenging task. One participant reflected on a scenario when she was talking to a family and suddenly noticed a physician in the background whom she needed to talk to before he left the

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

unit. She further reflected that she lost her train of thought in the conversation which interfered with establishing therapeutic rapport. Jaycee stated “you have to be there and really care about what you’re doing”.

Some of the social work participants shared examples of *small acts of kindness* that can increase the level of comfort for families and aid in establishing therapeutic rapport. One social worker provided an example of rolling in a coffee cart to the room of a palliative individual so the family members could stay with their loved one.

3.2.2 Knowledge. Originally when preparing for the research project and facilitating the focus groups, I chose the word competency in an effort to capture information the social workers required to perform their roles in palliative care. When conducting the first focus group participants did not respond to the question. I think this is partially due to the fact the question was unclear and participants were unsure of what I was asking for when I used the word competency. During the second focus group, the word competency was defined to participants as “the ability to do something successfully or efficiently.” In retrospect, the question may still have been unclear to participants. When one participant referred to the knowledge required to work in palliative care, other participants appeared to grasp the concept and were able to provide knowledge in specific areas that enhances their roles. Rather than using the word competency in the findings the term knowledge has been chosen to more accurately reflect the focus group discussion.

Participants highlighted that having knowledge in particular areas allows them to act in their roles while providing palliative care services. Participants highlighted social workers’ need to have knowledge of family systems theory, death and dying, grief and loss, medical terminology and medical systems and facilities.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

The participants identified that they obtained knowledge pertaining to *family systems theory* from their social work education. Family systems theory can be explained as viewing an individual's way of being by examining the relationships, interactions, and dynamics within the family (Hicks, 2006). Knowledge of family systems theory allows social workers to understand the different roles family members play and emotions that are evoked when navigating the palliative process. In relation to family dynamics and emotions, social work participant Eleanor stated "So there are often conflicts, so difference of opinions amongst family members and social workers can really help alleviate that or at least direct it so it's not negatively impacting the patient at the moment". In the scenario described above, family conflict can create an uncomfortable dynamic for members of the palliative care interdisciplinary team to navigate. Social workers familiar with family systems theory have insight pertaining to how the family group and palliative individuals are impacted because the theory takes into consideration the dynamics of the family. Therefore, according to family systems theory, family dynamics including arguments and confrontation impacts the well-being of palliative individuals.

Social workers identified that knowledge about the *process of death and dying* is essential to their roles in working with palliative individuals and their families. The participants identified they have witnessed discomfort in discussing death by both members of the interdisciplinary team and the palliative individuals and family members they work with. The social workers identified the importance of sharing their knowledge of the dying process with dying individuals and their families. Sharing this knowledge may reduce fear about the unknown final stages of death as well as normalize some of the signs that individuals and families may observe.

Some of the participants referred to the importance of having *knowledge about grief and loss*. It was noted as important to share their knowledge about the grieving process with families who

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

may be experiencing grief prior to the death of their loved one. Social work participant Nora reported, “So explaining the grief cycle and explaining the fact that you can be grieving before your loved one is even deceased”.

Being *familiar with the health care facilities and resources* in the community was deemed essential. Knowledge in these areas is required to aid in navigating the system. One social worker provided an example of a time that she provided information about where a family she was working with could go and eat, and location of the nearest lodging for the family to stay. Several social workers emphasized that small details about food and accommodations are not highlighted areas when discussing care for palliative individuals. Sharing knowledge in these areas was seen as necessary and frequently brought forth appreciation from individuals and families on the receiving end.

Some participants mentioned that details about the palliative individual’s health, procedures, and care was described by physicians and nurses using *medical terminology* that people did not understand. Social workers shared their experiences of learning the medical terms by being exposed to the language during meetings with the palliative care interdisciplinary team and researching the meaning of terms. Social work participant Amy stated, “I remember I would take hours to learn the terms and ya know, I’d have to look it up on my computer”. Several of the social work participants reported that becoming familiar with medical terminology took both time and patience to learn. Social workers serve as a liaison between health care professionals and palliative individuals and family members to ensure medical terminology is understood.

Several participants underlined the importance of having *knowledge and respect for the culture* of individuals and families who are receiving palliative care services. Bosma et al. (2010) conducted a research study identifying core competencies used by palliative care social

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

workers. Several of the participants in the study requested that cultural awareness be identified as a core competency. Similarly, during the focus groups held for the purpose of this study social work participants identified strongly with the importance of cultural awareness. The social work participants spoke of Saskatchewan having a diverse population with several diverse cultures. Some of the social workers shared their experience of working with First Nations families and appreciated the knowledge that was shared through their education and experiences of working with First Nations families in the past. I found the manner in which the social workers approached the value of cultural knowledge to be both respectful and thoughtful. They were able to highlight cultural awareness they learned about, but most importantly they acknowledged that cultures outside of their own are unfamiliar to them. The participants referred to the importance of being respectful and open to families' cultural values and supporting cultural practices related to the end of life process, particularly during situations that are unknown or unfamiliar

3.2.3 Self-reflective practice. The social work participants frequently referenced taking time throughout their day to “check in” with themselves, which is an example of self-reflective practice. Self-reflective practice meant a variety of things to the participants depending on their personal experiences, their way of showing emotions, and the way they practice self-care. Self-reflective practice is impacted by the following factors: personal experiences, biases, mentorship and support, self-care, and knowledge.

Being cognizant of *personal experiences and biases* was viewed as important by the social work participants. Many of the participants discussed the reality that because death is inevitable, they have had personal experiences related to the death of a loved one. When referring to death as a personal loss, Amy noted “unfortunately we have to go through it but it really helps to see

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

what the other side is and how families could be experiencing things”. Those who spoke of personal losses identified that there could be triggers associated with working with palliative individuals and families but overall viewed their personal experiences with death as a strength to help them with providing services to others.

A few of the participants discussed taking into consideration *personal biases* they have due to their own values. Being aware of biases was noted as important in order to avoid transferring what they personally believe is best, and focusing on the individual needs of the palliative family and individual. Participants also noted the risk of interdisciplinary team members imposing their personal biases on both social workers and palliative individuals. The participants reported it is necessary to be aware of the biases of other team members and approach palliative individuals and families open mindedly.

Several of the participants noted being *mentored and supported* by social work colleagues and interdisciplinary team members. A few of the participants noted when beginning in palliative care they felt tearful and emotional at times when joyous things were occurring. Upon reflection, they observed the impacts of being immersed in work which was described as “tough” and “sad”. Social work participants viewed debriefing and consulting with colleagues as a necessity to continue practicing in good physical and mental health.

The majority of participants noted *self-care* as essential when working in the area of palliative care. Self-care meant different things to different participants. One participant noted that she needed to give herself permission to be emotional because that is who she is as a person. Another reported that she needed to rely on her personal supports after a difficult day. Another participant discussed striving to find a balance between work and home life. One social work participant discussed the importance of reflecting on the times at work when she felt she was

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

successful and made a difference. After there was a positive shift in a conversation with a family, Megan noted "... you can see it, you can feel it (pause) and that is the most rewarding part of my job right there, absolutely is to be able to help do that". Reflecting on positive experiences was a method the participant used to practice self-care.

Overall, the findings revealed the five highlighted roles of social workers which were followed by strengths and skills that social workers bring to palliative care.

Discussion

This discussion is separated into six sections. The first section will focus on the variability of social workers' roles within palliative care and their role as interdisciplinary team members. Next therapeutic rapport as a tool will be explored, discussing the risks and benefits it has on social workers professionally. The following section will explore health care professionals' and society's discomfort with death. The findings from this study suggest that members of the interdisciplinary team and society in general have a discomfort with death, which in turn affects the roles social workers perform in palliative care. The next section discusses the connection between education and knowledge and explores where social workers in palliative care can obtain their knowledge. The gaps in services provided to palliative individuals dying in their home and social workers' responsibility to merge this gap will be discussed followed by the final section that discusses implications for social work practice.

4.1 The Roles of Social Workers in Palliative Care

The findings identified five main roles performed by social workers in palliative care being: interdisciplinary team member, case management, re-interpreting the medical process, providing psychological support, and system navigator. An observation based on the findings was the variability in the demands of each palliative individual and family member. Due to the variability in the needs it is difficult to pinpoint exactly what social workers' roles may be on a

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

daily basis. It became clear that social workers are adaptable within their roles while striving to meet the unique needs of each palliative individual they provide services to. The roles as outlined in the study are presented as observations of the findings also recognizing that social worker are flexible and adapt in the roles they perform, therefore, roles may be extended or additional roles may be performed other than highlighted in the study. Davidson (2016) revealed that social workers struggle to define their roles in palliative care, it is possible social workers struggle to define their roles given the substantial variance in the demands of their work and the flexibility displayed within their roles. Further, social workers who have difficulty defining their roles may impact on the perceived importance of their roles within their palliative care interdisciplinary teams.

Several of the social work participants acknowledged that they have observed a “hierarchy” structure within health care and palliative care interdisciplinary teams. They noted a pecking order, which has physicians near the top and social workers at the bottom. Darlene shared her perception of social workers’ position within health care stating, “I think in health care there is a real hierarchy, sometimes what we bring to the table is not always as valued.” While discussing the observed hierarchy, one social work participant asked in a teasing manner if in fact the tape recorder was recording. The response of the participants leads me to believe that there is hesitation to disclose information about the hierarchy. I question if the participants were fearful of repercussions or if it is possible that the social work participants feel insecure in their roles due to their perception of being at the bottom of the pecking order therefore do not challenge the hierarchy.

4.2 Therapeutic Rapport as a Tool

Therapeutic rapport or what the participants referred to as “building relationships” was an area of discussion frequently brought forth by participants. The time, energy, and importance of establishing therapeutic rapport was an aspect described as central to the work that social workers do in palliative care. Rapport influences the roles social workers perform, the knowledge social workers obtain, and self-reflective practice. Social workers engaging in rapport have the potential to establish personal connections with palliative individuals and their family members which may impact social workers on a personal level.

Social workers in this study recognized that establishing therapeutic rapport is a tool to aid in performing their roles. Once therapeutic rapport is established palliative individuals and their family members are more susceptible to open up to the social workers and share information that is often required to provide medical care. It is also more likely that palliative individuals will voice concerns and highlight their needs. Although therapeutic rapport is undeniably an effective tool in practice, it also has potential to evolve beyond the realm of rapport becoming a connection that impacts social workers on a personal level. There are both pros and cons associated to social workers establishing therapeutic rapport.

A risk associated with establishing therapeutic rapport or personal connections is social workers placing an onus on themselves to ensure all the palliative individuals they are working with have all their medical and psychosocial needs met. These tasks may not be realistic or attainable therefore increasing the risk of social workers feeling inadequate in their roles. Participants in the study were not oblivious to the fact that creating rapport has the potential to affect them on a personal level. The findings indicated that in an effort to be proactive in taking care of their own well-being social workers engage in self-reflective practice. Lastly, the

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

findings revealed that social workers have pride associated with their ability to establish therapeutic rapport and highlighted that rapport has the ability to enhance the services they provide to palliative individual and their families.

4.3 Discomfort with Death

I asked the participants about barriers to providing palliative care services. I expected participants to share information about working within financial constraints, and working under the supervision of a manager from a different discipline. While some of these barriers briefly surfaced, working with interdisciplinary team members and palliative individuals who display discomfort when discussing death and palliative care was repeatedly brought to light. The participants attribute interdisciplinary team members discomfort with discussing palliative care and death to the larger picture of death being “taboo” and an “uncomfortable” area of discussion in society. In addition, the language used by health care professionals may have different meanings to different people. For example, the term “palliative” may be deciphered as a type of care they will be receiving or as news that they are nearing death. The term “palliative” may be chosen by health care professionals because of their discomfort with death therefore avoiding telling individuals “you are dying”.

The participants suggested that because death is a topic that creates discomfort, health care professionals have difficulty telling people they are dying or will be followed by palliative care teams. Coberly (2003) suggests that nurses and doctors have feelings of incompetence when they are not able to improve patient’s health; therefore it interferes with their ability to effectively communicate details pertaining to dying to palliative individuals. Regardless of the reasons for the discomfort, avoiding the topic of death interferes with palliative individual’s right to information about their care. In addition, avoiding the topic of dying perpetuates fear and

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

misunderstanding. One of the principles of palliative care named by the Canadian Hospice and Palliative Care Association (2013) clearly states that a person has the right “to choose to be informed about his/her disease, its meaning and implications, available therapeutic options, and their potential benefits, risks, and burdens, and alternatives” (p. 13). Avoiding the language and topic of death interferes with individual’s right to be informed. Discomfort discussing death and palliative care as an approach impacts the roles social workers perform.

Social workers have a responsibility to continue to challenge discomfort with death that impacts palliative individuals’ care, and to support palliative individuals who are impacted by society’s discomfort with death. Several of the roles social workers perform are impacted by discomfort of death being: interdisciplinary team member, re-interpreter of the system, and providing psychological support. Examples of social workers tailoring their roles to challenge discomfort with death are: social workers making assessments to inquire if palliative individuals are receiving all the information required about dying or receiving a palliative diagnosis, advocating palliative individual’s right to information about dying and their palliative diagnosis, encouraging interdisciplinary team members to be honest in their delivery of information about death, and educating palliative individuals about provisions of palliative care and what to expect physically and mentally as death approaches. Much of the information required for social workers to perform their roles in challenging discomfort with death is obtained from knowledge gained from experience, fellow colleagues, and members of the interdisciplinary team.

4.4 Education and Knowledge

The literature revealed that social workers feel ill equipped by their education to provide palliative care services (Christ & Sormanti, 2000; Gutheil & Heyman, 2011; Sumser et al., 2015). Although this study does not provide details about social workers feeling ill equipped by

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

their education it does provide information indicating that social workers obtain their knowledge pertaining to palliative care from sources outside of their formal professional education. One exception is family systems theory, which social workers identified that they obtained from social work curricula. Identified learning sources are members of the interdisciplinary team, social work colleagues and peers, conferences, experience obtained from being on the job, and personal experiences.

Because social workers are employed in a diverse range of settings, tailoring social work curricula specifically to end of life care may not be a feasible option. The University of Regina does offer courses at the undergraduate and graduate level that focus on end of life information. Social workers entering specific fields such as palliative care have a responsibility to obtain additional and required knowledge about their chosen field of work such as palliative care. In addition, some of the responsibility lies with the employer, such as health regions, to create learning opportunities for social workers and members of the palliative care interdisciplinary team members to enhance their knowledge of end of life care.

4.5 Palliative Care Services in the Home

Palliative individuals and their family members (who often become caregivers) are exposed to insurmountable barriers that can lead people to die in hospitals despite their desire to die in their home. Berzoff (2003) reported that 70% of Americans say they want to die at home but only 25% of the population is able to do so. Findings from this study identify that social workers did not have experience in providing palliative care services in the homes of palliative individuals. One social worker briefly addressed the gap in services in regards to availability of social work services in the homes of palliative individuals. She noted that in the Prince Albert Parkland Health region a single social worker provides palliative care home services for the entire health

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Region. In the city of Saskatoon she reported there are only two social workers who work directly with home palliative care services. The lack of services has a potential to create feelings of isolation for palliative individuals and their family members. Haxton and Boelk (2010) and Christ and Sormanti (2010) identified challenges that palliative individuals and their families face when choosing to die at home including feeling isolated in their homes, receiving limited support from health care providers, and difficulty accessing community based services.

Social workers have a responsibility to address the gap that persists between dying individuals' desire to die at home with dignity and the reasons why they are either unable or unwilling to do so as the end of life approaches. It is our duty as registered social workers to adhere to the Canadian Association of Social Work (CASW) Code of Ethics where *Value 1* clearly states "Social worker's uphold each person's right to self-determination, consistent with that person's capacity and with the rights of others" (CASW, 2005. p. 4). Social workers have a responsibility to promote individuals' self-determination to die with dignity in their homes. To fully appreciate, understand, and address implications of supporting palliative individuals' desire to die in their homes, more research is needed to gather information from palliative individuals and their caregivers.

4.6 Implications

The findings from this study will contribute to the ability of social workers to articulate the roles they perform in palliative care. These roles are built on a framework that is established by developing therapeutic rapport which often begins by listening, showing empathy, and viewing people for who they are as individuals rather than as patients. The participants identified that establishing rapport allows palliative individuals and families to talk and ask questions more

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

freely, therefore increasing the quality of care. For this reason, social workers need to establish an environment where therapeutic rapport is accepted and encouraged.

Historically, social workers have struggled to define their roles within palliative care services. Social workers who confidently provide insight to interdisciplinary team members and palliative individuals about their roles will reach a broader range of palliative individuals. It is important for social workers to educate interdisciplinary team members as well as palliative individuals and their families on the roles they perform.

Palliative care is misunderstood and frequently used as an end of life tool. The philosophy of palliative care is intended to improve the quality of care upon diagnosis of an untreatable diagnosis. The social work participants shared their perceptions of society and health care professionals being uncomfortable with death, hence creating a barrier to address constraints related to palliative care. Social workers have an obligation to challenge discomfort of death by advocating on behalf of palliative individuals and their families and educating society about palliative care as an approach.

Conclusion

I began this research study by reviewing the literature about the competencies social workers rely on and the roles which they perform in palliative care. The lack of defined social work roles can have a domino effect, where members of the interdisciplinary team have difficulty identifying the roles of social workers and therefore are not informing palliative individuals and families of the services social workers can offer. The aim of this qualitative research study was to understand the roles of social workers in palliative care to increase the confidence levels of social workers in palliative care as well as for social workers to have the ability to inform members of palliative care interdisciplinary teams of their roles so they are more likely to seek the expertise of social workers. My findings revealed that social workers perform five roles in

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

palliative care, and outlines specialized skills and knowledge that social workers bring to palliative care.

The importance of establishing therapeutic rapport with palliative individuals and their family members was highlighted as a central component for effective social work practice. Therapeutic rapport allows social workers to maneuver effectively within in their roles which were highlighted as interdisciplinary team member, psychosocial care, de-medicalizing the palliative process, navigating health care systems and facilities, and case management. It was found that social workers relied on knowledge obtained from their education, interdisciplinary team members, and experiences to support palliative individuals and their families. The social work participants shared their experiences of improving within their roles as their knowledge base expanded. Lastly, the participants shed light on using self-reflective practice, which was often referred to as “checking in” with themselves. Using self-reflective practice served the purpose of ensuring that their own emotional needs were cared for.

The findings of this study add to the research that defines social work roles in palliative care as well as highlighting the importance of social workers spending time establishing therapeutic rapport. Additionally, this qualitative research study provided social work participants an opportunity to share their perspectives on the roles they see as being essential in palliative care services.

References

- Altilio, T., Gardia, G., & Otis-Green, S. (2008). Social work practice in palliative and end-of-life-care: A report from the Summit. *Journal of Social Work in End-of-Life & Palliative Care*, 3(4) 68-86. doi10.1080/1552425802003513
- Altilio, T., Otis-Green, S., Hedlund, S., & Finberg, C. (2012). Pain management and palliative care. In S. Gehlert & Browne, T. *Handbook of health social work*. 2nd ed. (pp. 590-626). Hoboken, NJ: John Wiley & Sons, Inc
- Berzoff, J. (2003). Introduction: Special issue on end-of-life care Smith College studies in social work (June 2003). *Smith Studies in Social Work*. 73, 259-271. doi: 10.1080/00377310309517658
- Blacker, S., & Deveau, C. (2010). Social work and inter-professional collaboration in palliative care. *Progress in Palliative Care* 18, 237-243. doi:10.1179/096992610X12624290977141
- Bosma, H., Johnston, M., Cadwell, S., Wainwright, W., Ngairer, A., Feron, ...Nelson, F. (2010). Creating social work competencies for practice in hospice palliative care. *Palliative Medicine*, 24(1), 79-87. doi:10.1177/0269216309346596
- Brandsen, C. K. (2008). Social work and end-of-life care. *Journal of Social Work in End-of-Life & Palliative Care*, 1, 45-70. doi: 10.1300/J457v01n02_05
- Cadell, S., Johnston, M., Bosma, H., & Wainwright, W. (2010). An overview of contemporary social work practice in palliative care. *Progress in Palliative Care*, 205-211. doi: 10.1179/096992610X12775428636700
- Cairns, M., Thompson, M., & Wainwright, W. (2003). *Transitions: In dying and bereavement. A psychosocial guide for hospice and palliative care*. Baltimore, MD: Health Professionals Press.

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Canadian Hospice and Palliative Care Association. (2013). A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Retrieved from

<http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf>

Canadian Hospice and Palliative Care Association. (2016). Retrieved from

<http://www.chpca.net/projects-and-advocacy/projects/scope.aspx>

Canadian Association of Social workers. (2005) *Code of Ethics*. Retrieved from

<http://www.casw-acts.ca/en/what-social-work/casw-code-ethics/code-ethics>.

Christ, G., & Blacker, S. (2011). Defining social work's role and leadership contributions in palliative care. In T. Altilio, & S. Otis Green, *Oxford text book of palliative social work* (pp. 21-30). New York, NY: Oxford University Press.

Christ, G. H., & Sormanti, M. (2000). Advancing social work practice in end-of-life-care. *Social Work in Health Care*, 30(2), 81-99. doi: 10.1300/J01v30n02_05

Coberly, M. (2003) *Sacred passage: How to provide fearless, compassionate care for the dying*. Boston, MA: Shambhala Publications.

Compassion [Def. 1]. (n.d). In *Dictionary.com*. Retrieved from

<http://www.dictionary.com/browse/compassion?s=t>

Creswell, J. (2013). *Qualitative inquiry and research design: choosing among five approaches*.

(3rd ed.). Thousand Oaks, CA: Sage.

Davidson, J. (2016). Does the culture of modern day palliative care social work leave room for leadership? *Journal of Social Work*, 30(2), 203-218. doi:

10.1080/02650533.2016.1168385

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Gutheil, I.A., & Heyman, J. C., (2011). A social work perspective: Attitudes towards end-of-life planning. *Social Work in Health Care*, 50, 763-774.

Doi:10.1080/00981389.2011.595479.

Harper, C. H. (2011). Palliative social work: An historical perspective. In T. Altilio, & S. Otis Green, *Oxford text book of palliative social work* (pp. 11-20). New York, NY: Oxford University Press.

Haxton, J.E., & Boelk, A. Z. (2010). Serving families on the frontline: Challenges and creative solutions in rural hospice social work. *Social Work in Health Care*, 49, 526-550. doi: 10.1080/00981381003648422

Hicks, S. (2006). *Social work in Canada: An introduction (2nd ed)*. Toronto, ON: Thompson Educational Publishing, Inc.

Krueger, R.A. (1994). *Focus group: A practical guide for applied research (2nd ed.)*. Thousand Oaks, CA: SAGE publications.

Lawson, R. (2008). Home and hospital; hospice and palliative care. *Journal of Social Work in End-of-Life & Palliative Care*. 3, 3-17. doi: 10.1300/J457v03n01_02

Miller, J., Frost, M H., Rummans, T. A., Huschka, M., Atherton, P., Brown, P., ... Gamble, G. (2007). Role of a medical social worker in improving quality of life for patients with advanced cancer with a structured multidisciplinary intervention. *Journal of Oncology*. 25, 105-119 doi: 10.1300/J077v25n04_07

Murty, S. A., Sanders, S., & Stendland, M. (2015). End-of-life care as a field of practice in the social work curriculum. *Journal of Social Work in End-of-Life & Palliative Care*. 11(1), 11-26. doi: 10.1080/15524256.2015.1021071

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

Open Society Institute. (2003). *Project death in America: January 2001 to December 2003*

report of activities. Retrieved from

https://www.opensocietyfoundations.org/sites/default/files/a_complete_7.pdf

Palliative. (n.d). In *Merriam Webster* online. Retrieved from <https://www.merriam-webster.com/dictionary/palliative>.

Reigada, C., Ramos, P., & Novellas, R. (2015). The social work competencies in a palliative care: A case study. *BAOJ Palliative Medicine*, 1(3), 2-6. Retrieved from

<https://www.researchgate.net/publication/289988484>

St Christopher's Hospice. (2016, November). *History of Dame Sicely Saunders*. Retrieved from.

<http://www.stchristophers.org.uk/about/history>

Strauss. A., & Corbin. J (1998). *Basic qualitative research: Techniques and procedures for developing grounded theory* (2nd edition). Thousand Oaks, CA: Sage publications.

Sumser, B., Remke, S., Leimena, M., Altilio, T., & Otis-Green, S. (2015). The serendipitous survey: A look at primary and specialist palliative social work practice, preparation, and competence. *Journal of Palliative Medicine*, 18(10), 881-883.

doi:10.1089/jpm.2015.0022

Supiano, K, P., & Berry, P.H. (2013). Developing interdisciplinary skills and professional confidence in palliative care social work students. *Journal of Social Work Education*. 49, 387-396. doi: 10.1080/10437797.2013.796851

Thyer, A.B. (2015). The scientific value of qualitative research for social work. *Qualitative Social Work*, 15(1), 115-129. doi: 10.1177/1473325011433928.

University of Regina. (2017, May) *Faculty of Social Work*, Retrieved from

<https://www.uregina.ca/socialwork/courses-descriptions.html>

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

*Appendix A***University of Regina Ethics Board Approval**

University
of Regina

*Research Ethics Board
Certificate of Approval*

PRINCIPAL INVESTIGATOR
Laura Hildebrand

DEPARTMENT
Social Work

REB#
2017-011

SUPERVISOR:
Dr. Bonnie Jeffery

TITLE
Defining Social Work Roles in Palliative Care

APPROVED ON:
February 7, 2017

RENEWAL DATE:
February 7, 2018

APPROVAL OF:
Application for Behavioural Research Ethics Review
E-Mail Recruitment Script
Focus Group Recruitment Script
Focus Group Consent Form
Focus Group Guide
Support Services List

Full Board Meeting

Delegated Review

The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: <http://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/forms1/ethics-forms.html>.



Dr. Katherine Robinson
Chair, Research Ethics Board

Please send all correspondence to:

Research Office
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775 Fax: (306) 585-4893
research.ethics@uregina.ca

*Appendix B***Focus Group E-mail Recruitment Script****Defining Social work Roles in Palliative Care****E-Mail RECRUITMENT SCRIPT**

This E-Mail is being sent on behalf of Master of Social Work student Laura Hildebrand, RSW.

I would like to invite you to participate in a research project, Defining Social Work Roles in Palliative Care. This study is a research project being conducted by University of Regina Master Social Work student Laura Hildebrand under the supervision of Dr. Bonnie Jeffery. The goal of this study is to gain knowledge of Social Work competencies in Palliative Care in an effort to support social workers to define their roles and improve confidence in their ability to provide Palliative Care to dying patients and their families.

If you are a social worker who has an interest in Palliative Care, I would like to invite you to participate in a focus group to share your perspective of social work competencies in Palliative Care, working as an inter-disciplinarian team members, and experience with education about end of life care. Participation in this research project will include a focus group that will take 60 to 90 minutes. Focus groups will be held in Saskatoon and Prince Albert. Your participation is appreciated and completely voluntary.

This project has been approved by the University of Regina ethics Board on [date]. If you have any questions concerning the research project or would like to participate please contact me at (306)960-2874 or hildeb2L@uregina.ca

Warm regards,

Laura Hildebrand

*Appendix C***Focus Group Recruitment Script****Defining Social work Roles in Palliative Care****RECRUITMENT SCRIPT**

You are invited to participate in a research project, Defining Social Work Roles in Palliative Care. This study is a research project being conducted by University of Regina Master Social Work student Laura Hildebrand under the supervision of Dr. Bonnie Jeffery. The goal of this study is to gain knowledge of social work competencies in Palliative Care in an effort to support social workers to define their roles and improve confidence in their ability to provide Palliative Care to dying patients and their families.

As a social worker who has interest in Palliative Care, we would like to have you participate in a focus group to share your perspective of social work competencies in Palliative Care, working as an inter-disciplinarian team members, and experience with education about end of life care. Participation in this research project will include a focus group with will take 60 to 90 minutes. Your participation is appreciated and completely voluntary. Does this study sound like something you would be interested in participating in?

[IF YES CONTINUE READING, IF NO THANK THEM FOR THEIR TIME]

[IF YES] With your permission, I would like to ask for your full name and telephone number so you can be reached to arrange a focus group.

[IF YES, READ ADDITIONAL INFORMATION BELOW]

ADDITIONAL INFORMATION

This project has been approved by the University of Regina ethics Board on [date]. If you have any questions concerning the research project, please feel free to ask at any point; questions regarding this project or your privacy rights as a participant should be directed to Laura Hildebrand University of Regina research student at (306)960-2874, research supervisor Dr. Bonnie Jeffery at (306)953-5311 or the Research ethics Office at the University of Regina (306)585-4775 whom you may call collect.

*Appendix D***Focus Group Guide**

Study Title: Defining Social Work Roles in Palliative Care

1) Introduction:

Hello everyone. Welcome. My name is Laura Hildebrand, I'm the moderator for today's focus group discussion. Helping me today is [INSERT NAME OF NOTE TAKER].

We appreciate you taking time to participate in today's session. The aim of this focus group is to examine social workers' roles and competencies in Palliative Care. The goal of this study is to gain knowledge of social work competencies in Palliative Care in an effort to support social workers to define their roles and improve confidence in their ability to provide Palliative Care to dying patients and their families. This study is being conducted in part to fulfill the requirements of the University of Regina graduate Social Work degree. The hosting agency for the project is the Saskatchewan Hospice and Palliative Care Association (SHPCA). The research is overseen by academic supervisor Dr. Bonnie Jeffery.

Before we get started I want to review some of the information and go over general guidelines for our group's discussion.

Confidentiality: As we mentioned when explaining your consent forms, please respect the confidentiality of the other members of the group by not disclosing the contents of this discussion outside of the group, and be aware that others may not respect your confidentiality. We may use direct quotes in our study's results but all information that might identify you will be removed. We want to emphasize that it is very important that you maintain the confidentiality of what is said by others during the discussion. Please understand that if you withdraw from the focus group, it may not be possible to remove your data from the discussion given that the focus group is a group conversation, where each participant contributes to a contextual whole.

Audio-taping: This session is being audio-taped so that we can write an accurate report about the issues raised during the discussion.

Voluntary participation: Your participation in this focus group is entirely voluntary. You do not have to speak about any topic that you do not wish to discuss.

General guidelines:

1. Only one person should talk at a time
2. Avoid side conversations with your neighbors

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

3. If you have a cell phone, please turn it off or put it on vibrate. If you have to take a call, I would just ask that you step outside the room.
4. Please remember to be respectful of others' opinions, and we want to emphasize that all points of view are welcomed.
5. Finally, a note on my role. I'm here to ask questions and guide the discussion, I am here to listen and learn from you.

Opening Introductions

Please introduce yourself by telling everyone your first name and a little about yourself.

Focus Group Questions

- 1) What competencies do social workers use when working with palliative patients and families?
 - What are social workers roles/tasks when providing end of life care to palliative patients and families?
 - In what type of settings do social workers become involved in providing services to Palliative Care patients and families?
 - How do social workers support palliative patients and their families?
 - What are your views on cultural competence within Palliative Care?
- 2) How do social workers contribute to inter-disciplinary Palliative Care teams?
 - What are social workers roles/tasks as interdisciplinary team members?
 - What makes social workers special on Palliative Care teams?
 - How are palliative patients impacted from receiving care from an inter-disciplinarian team?
 - What are some of the benefits of social workers working as inter-disciplinarian team members?
 - What challenges may social workers face when working as an inter-disciplinarian team member?
- 3) Are social workers adequately prepared to provide end of life care following completion of the bachelor of social work program?
 - How do social work programs prepare students to work with end of life issues?
 - What improvements could be made to social work curriculums to provide end of life care knowledge?
 - What other types of education opportunities are available for social workers to learn about end of life issues?
- 4) What are some of the challenges for social workers to provide Palliative Care?
 - What are some of the barriers social workers may face when providing end of life care to palliative patients?
 - What is easy or difficult for social workers providing end of life care?

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

- How are social workers supported or deterred by supervisors to apply social work competencies working with palliative patients and their families?
- How are social workers impacted when their supervisors are from disciplines outside of social work?

*Appendix E***Focus Group Consent Form**

Study Title: Defining Social Work Roles in Palliative Care

Research Student: Laura Hildebrand

Hildeb2L@uregina.ca

(306)960-2874

Academic Supervisor: Bonnie Jeffery

(306)953-5311

Bonnie.Jeffery@uregina.ca

Note Taker: Karla Ethier or Anna Maria Buhr

Consent Form

Organization: University of Regina

You are invited to participate in a research project, Defining Social Work Roles in Palliative Care. Please read this form carefully, and feel free to ask any questions you might have. This study is a research project being conducted by University of Regina student Laura Hildebrand enrolled in the Social Work graduate program, under the supervision of Dr. Bonnie Jeffery. The goal of this study is to gain knowledge of social work competencies in Palliative Care in an effort to support social workers to define their roles and improve confidence in their ability to provide Palliative Care to dying patients and their families.

The focus group will take approximately 60 to 90 minutes to complete. The focus group will include 5 to 7 participants including yourself. Laura Hildebrand will be the moderator of the focus group with note taker Karla Ethier or Anna Maria Buhr present. Please respect the confidentiality of the other members of the group by not disclosing the content of this discussion outside the group, and be aware that others may not respect your confidentiality. The focus group will be being audio-taped so that an accurate report can be written about the issues raised during the discussion. The digital audio tapes will be stored on password protected computers, the research data will be stored in locked filing cabinets. Original focus group data and any other documentation will be securely stored for six years, after which time it will be destroyed.

There is no risk anticipated in the study. If you find the nature of the questions has raised concerns or caused any sort of distress, please contact the agencies listed on the resource page provided to you. Benefits in participating in the focus group includes the opportunity to share your perspective on Social Work competencies in Palliative Care, ability to network with Social Workers who share an interest in Palliative Care, and time that can be used as continuing education hours as required for SASW registration.

Your participation is appreciated and completely voluntary. You do not have to answer any question and you may decide to stop your participation in the focus group at any time. Please understand that if you withdraw from the focus group, it may not be possible to remove your data

UNDERSTANDING THE ROLES OF SOCIAL WORKERS IN PALLIATIVE

from the discussion given that the focus group is a group conversation, where each participant contributes to a contextual whole. Data analysis will begin one week following the focus group, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw information.

Direct quotes may be used in the report on the results of the study but all information that might identify you will be removed. Once the project has been completed and approved by the University of Regina the final report can be found at <http://ourspace.uregina.ca/> under the Faculty of Social Work link. If you have any questions concerning the research project, please feel free to ask at any point; questions regarding this project and your privacy rights as a participant should be directed to Laura Hildebrand University of Regina research student at (306)960-2874, research supervisor Dr. Bonnie Jeffery at (306)953-5311 or the Research Ethics Office at (306)585-4775. This study has been approved on ethical grounds by the University of Regina Behavioral Research Ethics Board on [date to be inserted].

Consent to Participate

I have read and understood the contents of this consent form and agree to participate in this focus group and this study: _____ Yes _____ No

I have received a copy of the consent form for my files: _____ Yes _____ No

I agree to have my focus group audio taped: _____ Yes _____ No

Participant Name (**print**) _____

Participant Signature _____ Date _____

Research signature _____ Date _____

Potential Participant Name

Phone number