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Medical Social Worker Perception of Competence in Palliative Care Consultations

Katie Rubischko

St. Catherine University, katie.rubischko@gmail.com

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**Medical Social Worker Perception of Competence in
Palliative Care Consultations**

by

Katie Rubischko, LSW

MSW Clinical Research Paper

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

Master of Social Work

**Committee Members
Rajeon Moone, Ph.D., (Chair)
Natalia Haala, MSW
Melanie Hemmes, MSW**

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

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Introduction and Purpose Statement

Palliative care is customized care that meets the needs of patients experiencing a serious illness. Unlike hospice care, a patient does not need to have a limited life expectancy of less than six months and patients can continue curative treatments if desired. The goals of care are not exclusively focused on curative treatment. Instead, the prevailing emphasis with palliative care is to improve the quality of one's life physically, mentally and spiritually. The specific type of care a patient receives is dependent on the understanding of the illness, needs identified from the patient's perspective and the patient's goals of care.

Many hospitals have established Palliative Care Teams. These teams typically consist of trained palliative care physicians, nurses, chaplains and social workers. Social workers eligible for this level of a position typically require the additional credentials of an Advanced Certified Hospice and Palliative Care Social Worker (ACHP-SW). In order to obtain this licensure, a Master's Degree in Social Work is required. In addition, twenty CEUs related to hospice and palliative care, documentation of at least two years of supervised social work experience in hospice or palliative care, current license adherence to NASW Code of Ethics and NASW Standards for End of Life Care need to be secured (National Association of Social Workers {NASW}, 2015).

Medical social workers routinely work with patients and families that are dealing with acute or chronic life-limiting illnesses. These difficult situations often require knowledge and skills to help patients and their families navigate an already confusing medical system. Prior to the development of palliative care, patients were offered hospice services when they were

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facing life-limiting illnesses. However, in order to qualify, a physician was required to certify that the patient had a limited life expectancy of no more than six months. This excluded many patients that were struggling with chronic, debilitating illnesses that often left them in pain. With the creation of palliative care, patients were no longer required to be facing an imminent death or be opting out of curative treatments to receive symptom management.

Palliative care programming has grown exponentially. As a result, it can be challenging for the ACHP-social worker to see each and every consultation. Therefore, a generalist social worker could be asked to participate in palliative care consultations. Research findings reveal that many health care providers, including social workers, identify feeling unprepared when meeting with patients and families who either are or will be facing end-of-life. The purpose of this study is to investigate the relationship between training and the perceived level of competence of a generalist medical social worker who participates in palliative care consults. Findings from this study will help determine if training gaps exist and if so how that influences the delivery of palliative care consultations.

Literature Review

Background on Palliative Care

Palliative care is specialized care that can be customized to meet the needs of individuals suffering from serious illnesses. The focus of this care is to improve the quality of life of the patient, manage symptoms from the illness and provide needed emotional support to both the patient and their loved ones. Palliative care is tailored to meet the individual patients' needs by working in synergy with the primary treatment the patient is receiving (Devi, 2011). Eligibility is not dependent on life-expectancy, but rather the diagnoses of a serious illness which could encompass either an acute or chronic condition. Unlike hospice, a patient can continue to receive curative treatment and still participate in palliative care. Seeking palliative care isn't about giving up hope or hastening death, but rather a way to get the most appropriate care in the last stages of life (Tabuns, 2015). Palliative care teams aspire to improve communication between the patient, family and treatment team so that the priorities of care and future goals of the patient can be identified. Despite the success and growing number of palliative care teams being established in the United States, the State-by-State Report Card in 2015 revealed that for millions of Americans suffering with serious illness in the United States, palliative care remains inadequate. "One third of hospitals report no palliative care services of any kind, and access to palliative care in community settings (home, nursing home, assisted living) is limited for people who are not hospice eligible (actively dying)" (Center to Advance Palliative Care, 2015).

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Even though palliative care has been associated with higher quality of care and decreased healthcare costs, access to palliative care has been limited primarily to hospitals and patients' who are dying. Palliative care is commonly referred to as comfort care, supportive care and symptom management. Palliative care services can be confused with other subspecialties like hospice or pain management as both of these services can complement palliative care treatment plans.

Scope of Services

Pain management services are typically provided by a physician that has training in diagnosing and treating various types of pain. The pain experienced by a patient may be the result of acute or chronic pain. It may also be a result of surgery, injury or other illnesses like shingles. In contrast, palliative care services are only considered when patients are suffering from serious or life-limiting illnesses. Integrating pain management with palliative care can improve the quality of life of patients experiencing pain symptoms. One of the principle functions of palliative care is the prevention and control of distressing symptoms. Freeing sick people, emancipating them from pain and unendurable symptoms is one of the conditions that sick people need the most. This allows them to live their remaining time as fully as possible (Zentralbl, 1998). Pain management teams are routinely involved with patients receiving palliative care. Foley et al found that 20% of patients receiving palliative care services required three switches of their medication before an effective dose was found (Foley, 2000).

Hospice care is another ancillary service that can overlap with palliative care. Hospice care is paid for by Medicare, Medicaid in most states, the Department of Veterans Affairs, most private insurance plans, HMOs, and other managed care organizations (American Cancer

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Society, 2014). Many patients that participate in palliative care consultations have life-limiting illnesses. If a physician identifies that an illness is terminal and they suspect death could occur within six months or less, hospice services can be considered. A patient enrolling in hospice services cannot participate in curative treatments for their underlying disease. Hospice care is designed to provide supportive care outside of the hospital. This care can be provided in the home, a long-term care facility or a residential hospice. By enrolling in hospice, a patient waives their rights to Medicare services associated with the treatment of their terminal condition. As outlined by Medicare, a patient receiving hospice is eligible for the following services:

- Doctor services
- Nursing care
- Medical equipment
- Medical supplies
- Prescription drugs
- Hospice aide and homemaker services
- Physical and occupational therapy
- Speech-language pathology services
- Social work services
- Dietary counseling
- Grief and loss counseling
- Short-term inpatient care (for pain and symptom management)
- Short-term respite care

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- Any other Medicare-covered services needed to manage your terminal illness and related conditions, as recommended by your hospice team

On the other hand, Medicare will not cover:

- Treatments intended to cure a terminal illness and/or related condition
- Prescription drugs (except for symptom control and pain relief)
- Care from any provider that wasn't set up by the hospice medical team
- Room and board
- Care in an emergency room, inpatient facility care, or ambulance transportation

Unlike palliative care, hospice care is regulated by benefit periods. A physician must certify that a patient has a limited life-expectancy of less than six months. If a patient lives past this benefit period, a hospice medical director would need to recertify a patient for their terminal illness in order for the patient to receive continued hospice benefits.

Challenges in providing palliative care are not only dependent on availability. Doctors describe finding it difficult to initiate referrals to palliative care in a timely matter. Some factors they identify include being unsure of the disease process, possibility of periods of remission, inadequate communication skills, lack of knowledge about palliative care, lack of support, time and lack of team accessibility (Devi, 2011).

Interest continues to grow to expand palliative care programming. Barriers to the access of palliative care include workforce, research and payment models linked to quality measures. The Center to Advance Palliative Care (CAPC) is encouraging federal policy actions to

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overcome these barriers. They suggest as Center for Medicare and Medicaid Innovation (CMMI) is selecting and piloting new care models they ensure palliative care is a component of care, quality measurement and payments for those with serious illness. In addition, the Centers for Medicare and Medicaid Services (CMS) is being encouraged to include palliative care measures in all relevant quality and value-based programs, such as Medicare-sponsored Accountable Care Organization measures, the Five Star Quality Rating System for Medicare Advantage plans and CMS facility-based quality reporting and incentive programs. According to CAPC, the promotion of regulatory and accreditation requirements and payment linked to value and availability of valid reliable measures are necessary to redress inconsistencies in access and quality of palliative care services associated with geographic location, health systems and ownership, among other variables.

While continual efforts are being made to make palliative care a subspecialty in the hospital setting, many hospitals are not exclusively using this team for consultations. The demand for palliative care is rising exponentially with the surge of elderly patients suffering from chronic conditions or serious illnesses. As a result many Palliative Care Teams, if they exist, are unable to meet the influx of the referrals they receive (Archer, Bali, Hay & Stewart, 2015). In turn, health care professionals, particularly hospital based social workers, need to have a comfort level and base knowledge of palliative care programing to effectively meet the needs of their patients and families suffering from life-limiting or chronic, serious illnesses. Advanced Certified Hospice and Palliative Care Social Workers (ACHP-SW) are typically called in to consult on more complex cases, lending their expertise and ensuring optimal care is being provided. In theory, optimal care should be provided regardless of the credentials of the social worker. The

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challenge that exists in many healthcare settings is there is often only one social worker assigned to a Palliative Care Team. With increasing referrals, it is nearly impossible for them to see every patient they receive a consult on. Therefore, some of these referrals may be absorbed by social workers who have a generalist background. A generalist practice embraces a wide range of practice skills with multiple client systems and is guided by social work ethics and an anti-oppressive framework (Larkin 2013). Simply put, generalist social workers may be involved in consultations with little or no palliative care training.

Curie identified that many health care staff report feeling unprepared and unsupported with very little “real life” experience of providing end of life care (Curie, 2015). “Figures obtained by IMT ahead of a major palliative care conference in the RCPI showed that 70 percent of staff had not had any palliative care training in the past two years and 66 percent of healthcare assistants and 42 percent of nurses did not feel they were competent to address death and dying with patients” (Kelly, 2012, p. 6). This study revealed that the gap in palliative care training needs is not exclusive to the social work role. Physicians, nurses, chaplains and even physical therapists revealed their concerns with feeling they lack core competencies in this field of work. Specific and ongoing palliative care training needs to be offered not only to social work staff but all health care professionals who participate in these consultations to prevent inequalities in care. Hospital administration staff can act as gatekeepers to influencing the efficacy of palliative care training on the job and to the advancement of competency.

Palliative Care Training

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Palliative care training has been shown to increase clinician's competence and comfort with participating in end of life discussions. McCormick (2007) found in a pre-post study that social worker's working on the ICU increased their satisfaction with meeting family needs and reported more total social worker activities after being trained in the principals of palliative care. Due to palliative care being a young specialty, there is a lack of an established evidence base that can be used for designing palliative care trials. Unclear standards for "best care" practice, ethical issues when conducting trials and the overlap with other specialties like hospice make researching this service difficult (Aziz et al., 2004).

There is a fair amount of research identifying physician and nurses roles in palliative care. However, there was limited data specific to social work training needs and core competencies in palliative care. Often these studies concentrated more on the financial or emotional benefits of palliative care.

Additional research needs to be conducted to determine if competencies in medical school curricula is effective in increasing competency in certain health care fields. The challenges with identifying palliative care training needs is there is limited research identifying what gaps exist. This could easily be dependent on the demographic population being served, the professionals comfort level with end of life issues, personal versus professional exposure to palliative care cases, employer continuing education allowances and hospitals expectations for competencies in palliative care.

Challenges social workers encounter is the fact that undergraduate and graduate level training is not specialized. When social workers complete undergraduate or a graduate level

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schooling, they are prepared to be generalists. While they may have opportunities to explore particular interests they have, they are not required to learn about palliative care. Many of these students in fact will never be required to participate in palliative care consultations. Palliative care education in postgraduate medical schools remains sparse as well. Clinical exposure to end of life and chronic illnesses is most often learned on the job. This makes it challenging to not only prepare social workers but other health care professionals in this field. Individual employees will have different exposure and comfort levels with end of life issues. Given that real life scenarios cannot easily be simulated in an educational environment, tailored palliative care training should be considered.

Employers are often more aware of the risk of compassion fatigue and its symptoms than they are of palliative care core competencies. Employers recognize that staff that are frequently engaged with patients and families at the end of an illness experience physical, emotional and mental exhaustion. They also can experience a reduced sense of meaning in work, burnout and become less efficient in their work which can directly impact length of stay and ultimately cost the hospital money. Secondary effects of palliative care training may include reducing compassion fatigue symptoms of employees and increasing employee satisfaction rates.

Lack of education and training in palliative care is not specifically a social work issue. It appears to affect other health care disciplines as well. The challenge that arises is the fact that ongoing palliative care training is not required by the Board of Social Work or hospitals themselves. However, there are expectations that a social worker in a hospital setting will have

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knowledge of the program, navigate patients and families through these discussions and coordinate safe discharge plans. It becomes the employee's responsibility to identify his or her own incompetency and feel comfortable enough to alert appropriate management for additional support and training.

Research conducted by Monette (2012) suggested that most Canadians died in primary care despite communicating their interest in dying at home. He found that little research explored if competencies in palliative care were being met in medical school curricula. He recognized post-graduation palliative care education had been sparse in his findings. Kelly (2012) echoed those findings by recognizing that nearly 70% of health care staff had not had any palliative care training in the past two years and nearly 42% of the staff reported not feeling competent addressing death and dying with their patients.

Simon and fellow colleagues recognized that professionals providing palliative care consultation are most effective when they are able to emulate their own authenticity and are able to maintain a high level of perceptiveness. They stressed the importance of including core attitude training in palliative care education. These core attitudes would include: personal characteristics, experience of care and competence in care (Simon et al., 2009).

As palliative care continues to grow to meet the expanding needs of patients suffering from acute or chronic illnesses, the social work role in advance care planning will continue to evolve. With hospital social workers being the primary mental health professionals providing support to individuals and their families facing end of life and or advanced illnesses, it will be imperative that these professionals have the specialization and training to adequately meet the

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needs of this population. As palliative care is relatively new, it is important for hospital based social workers to have proper training to provide bio-psychological assessments in order to support patients and families experiencing the challenges of advanced illness. Identifying research opportunities that could further develop their role and efficiency in palliative care will be equally important. Best care practices will need to be identified and researched to provide an evidence base going forward. This study will examine the relationship between palliative care training in generalist social workers working in health care and their perceived competence in providing palliative care consultations. Results of this research could ultimately provide guidance in establishing social work core competencies in palliative care training.

Conceptual Framework

The framework used for examining competency in palliative care included Competence Framework, Family Systems Theory and Gold Standard Framework.

Competence Framework

A competence framework requires the identification of each individual social work competency that is needed to perform palliative care consultation in health care settings. Themes considered in this examination included identifying education and training needs, measuring competency, general skills and program knowledge, patient experience and aspects of professional interaction.

Family Systems Theory

Family members can be dependent on each other. As a result, this can influence not only how the patient copes with his or her illness but how the family chooses to confront it. The Family Systems Theory explored how the disease of the patient and the family's daily life were interconnected. Research in palliative care has been typically limited to the perspectives of one family member. Clinicians are often faced with managing complex family dynamics when working in palliative care. As a result, social workers need to have knowledge and tools to handle complex family dynamics which in turn can improve confidence in the social workers clinical abilities.

Gold Standard Framework

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The goal of examining a Gold Standard Framework in palliative care is to develop a practice based system that will improve the delivery and quality of palliative care. This will increase confidence in staff providing this service and improve team work, coordination of services and communication. To achieve the goals of a Gold Standard Framework, 7 C's of palliative care need to be examined (Amass, 2006).

Gold Standards Framework in Palliative Care 7 C's of Palliative Care

1. Communication
2. Coordination
3. Control of symptoms
4. Continuity
5. Continued Learning
6. Career support
7. Care in the dying phase

Methods

Research Design

Qualitative research methodology was used to capture the perceived training needs of social workers conducting palliative care consultation. This required interviewing social workers that work in health care settings and have direct practice with palliative care.

Qualitative research was applied to this particular study as randomized controlled trials in palliative care would pose ethical, moral and practical issues.

Grounded theory was used in this study. Grounded theory is defined as a set of rigorous research procedures leading to the emergence of conceptual categories. These concepts/categories are related to each other as a theoretical explanation of the action that continually resolves the main concern of the participants in a substantive area (Glaser & Strauss, 1967). The question, “Do Medical Social Workers Feel Competent Providing Palliative Care?” was explored. Selected health care professionals, which included eight medical social workers, were interviewed to analyze their views and experiences with palliative care. The goal of this study was to determine if any training gaps exist and if so what competencies are not being met.

Sample

Medical social workers that have regular exposure (see at least two patients facing end of life or experiencing acute or chronic life illnesses a month) were sought for participation in this study. Eight medical social workers participated in an hour long, private interview with the researcher. Participants were identified by using publicly available contact information on

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websites for medical social work departments, along with snow-ball sampling. Fifteen emails were sent by the researcher to medical social workers identified by this process.

The response from these emails generated six in-person interviews. The remaining two interviews were sought through snowball-sampling from participants who had already completed their interviews. Two interviewed respondents identified an individual they each thought would be a good candidate for this research study based on these social worker's years of experience and frequency interacting with patients suffering from acute or chronic illnesses. These two social workers were subsequently sent an email inviting them to participate in this study. Both of these individuals responded to the researcher and completed an hour long interview like the previous six respondents.

The respondents from this research consisted of one LICSW (Licensed Clinical Social Worker), three MSW (Master Social Workers) and four LSW (Licensed Social Workers) trained social workers. The LICSW educated social worker had ten years of health care experience working in both skilled nursing home settings and a hospital. The three MSW social workers had two, six and eight years of health care experience retrospectively. The participant with two years of experience had worked solely in a hospital setting. However, her work experience included employment at two separate hospitals that were affiliated with two separate health care systems. The individual with six years of experience had worked five years in a hospital setting before transferring to a clinic setting where she is currently employed. Neither of these settings are affiliated with one another. The third MSW prepared social worker had eight years of experience working in both hospital and hospice settings. These settings were not located

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within the same state. The remaining participants, which included four LSW prepared social workers, acknowledged having had eight, fifteen, seventeen and eighteen years of health care experience retrospectively. The social workers with seventeen and eighteen years of experience had worked the majority of their careers in a hospital setting. They identified less than two years of their work experience was located within a skilled nursing home setting. The social worker with fifteen years of experience had also identified working in a hospital setting the majority of her career. She acknowledged additional experience in non-medical settings. The final participant with eight years of experience had worked five years in a long-term care facility, one year in a hospital setting and two years in a clinic setting. All eight of these participants were female and had no palliative care training in post-secondary school. The eight participants work within the same metropolitan community, but are separated by three counties. They range in age from 28 to 63 years old. Seven of the eight participants have exclusive work experience in the same state. Only one participant's career in social work includes employment history in two different states.

Projection of Human Subjects

St. Catherine University Institutional Review Board (IRB) approval was secured before any research was conducted. All interviews were conducted in a private office to ensure privacy and allow participant flexibility. No personal information was used that could identify the individuals participating in this research study. In addition, all data collected from the interviews are being stored in a secured environment and will be destroyed by June 1st, 2016. A

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Letter of Consent was reviewed with each participant before they signed on to the study (See Appendix A for Letter of Consent).

Data Collection Instrument and Process

Thirteen open-ended questions were created (See Appendix B for interview schedule). These questions were used to collect data during the face-to-face interviews. Semi-structured interviews were conducted with eight social workers that work in healthcare. These interviews were recorded, transcribed and supported by the researcher's field notes. Participant observation was recorded in field notes as well. Immersing in the data, the researcher used Grounded Theory to identify codes relevant to the study. Grounded Theory is defined as a set of rigorous research procedures that lead to the emergence of conceptual categories or codes (Glaser & Strauss, 1967). Once this researcher identified codes they were grouped into subsequent themes.

Data Analysis Plan

All interviews were transcribed by the researcher and have accompanied field notes. The researcher sought codes and themes using a master coding log. These codes and themes assisted the researcher in endorsing or disputing the literature review. Texts from the interviews were read as a whole and then again code by code before developing themes were established. Data was analyzed for themes using constant comparative analysis. This allowed the researcher to develop concepts from the data and analyze the results at the same time. These themes were grouped into categories. Constant comparative methodology incorporates four stages: (1) comparing incidents applicable to each category, (2) integrating categories and

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their properties, (3) delimiting the theory, and (4) writing the theory” (Glazer & Strauss, 1967, p. 105).

Results and Findings

Findings

This research study was designed to explore the perceived competence of medical social workers performing palliative care consultations. This researcher sought to identify if training gaps in palliative care exist and if so how this affects a social worker's comfort level providing palliative care consultation. Fifteen emails were sent out to social workers that were identified by using publicly available contact information on websites for medical social work departments. These emails produced six responses from social workers identifying interest in participating in this research study. The remaining two respondents were secured through snow-ball sampling.

Once the eight interviews were finalized, the researcher consolidated participant's responses. These answers were organized into categories and carefully studied. General themes were identified by key words or phrases stated during these interviews. Each of these phrases or key words were placed into sub-categories where further analysis identified emerging themes. Five of these themes were subsequently identified by the researcher. These themes included: confusion of how palliative care and hospice are different, resistance to receiving palliative care, comfort with addressing end of life or difficult conversations, differences in the delivery system of palliative care between hospital and community settings and lack of formal professional education in palliative care. These themes were examined further to identify if similarities and differences existed amongst the participant's responses. The results of these findings are described below and were used in consideration for evaluating

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Medical Social Worker's perception of their competence in providing palliative care consultations.

Confusion of how palliative care and hospice are different

All eight respondents identified struggling at times with communicating the differences between palliative care and hospice. They acknowledged that they have all heard the words used interchangeably by other health care professionals. One respondent stated, "A lot of people say palliative care is hospice". While another respondent was quoted saying, "Families don't know the word palliative care, people may not understand what it means but when you explain what it is people have a sense of relief when they realize it's not end of life". A third social worker admitted she commonly uses the word hospice in her definition of palliative care because there is a base understanding of what the word already means. She told the researcher, "I say palliative care shares a really similar emphasis to hospice, it really is about making the patient as comfortable as they can be". While a fourth social worker claimed, "Families don't know the word palliative care so when I've explained it to patients and families I include the word comfort care".

A concern raised by six of the eight participants was the notion that fear was evoked when the word hospice was brought up during a conversation. One respondent shared the sentiment, "The word hospice alone scares everyone! They think oh my God I'm dying!"

Resistance to receiving palliative care

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Several components to resisting palliative care emerged during this research. The primary issue surrounded patients and families believing that receiving palliative care would mean they are giving up or were no longer interested in aggressive, curable treatments. Seven of the eight respondents shared the experience of working with patients or families who were not ready to face their prognosis and subsequently declined palliative care services. One respondent stated, “The family can serve as a barrier if they are not willing to consider the possibility of death or complete recovery”. Another social worker was quoted saying, “I would say if families aren’t ready for their loved one to die and they are in that denial phase, they won’t even let palliative care get involved”. While a third social worker supported this theory saying, “People sometimes think palliative care means they’re giving up. There is a lack of education. People view palliative care as hospice”.

Another significant consideration to the resistance of palliative care included the lack of financial support or incentive for patients to enroll. Four social workers claimed having difficulty coordinating palliative care in a skilled nursing facility because patients would not have Medicare coverage for their placement. In turn, they would be required to pay out of pocket for their stay. By pursuing short-term rehabilitation under their Medicare benefit they would most often not incur private expenses unless their placement was extended beyond the benefit period or permanent residency needed to be secured. Three social workers identified that they commonly experienced patients pursuing aggressive treatments, like physical therapy, despite their interest in symptom management which may have been best supported by a therapy free treatment plan. Again suggesting the financial benefit of participating in therapy outweighed the misfortune of incurring exorbitant expenses by not partaking in therapy.

Comfort with addressing end of life or difficult conversations

All eight participants of this research study identified that having conversations about palliative care or hospice with patients and families was difficult for them. Six of these social workers identified that trained palliative care professionals were more comfortable talking about these issues than most primary care physicians or even themselves. One respondent claimed, “The palliative care team is more comfortable having these discussions than I am”. A reason two social workers prefer to have someone from palliative care present during these types of meetings. Another social worker expressed, “Having difficult conversations with families can be challenging. I don’t think schools prepare us for those difficult conversations”. A core competency of providing palliative care identified by four of the respondents included the ability to be comfortable talking to patients and their families about end of life. “Having the innate tools like being compassionate and having the ability to hear where others are coming from and being able to support that place is important”.

Differences in the delivery system of palliative care between hospital and community settings

One of the most predominant themes identified in this research was the identification that seven of the eight social workers interviewed strongly suggested that palliative care looks different in hospital and community settings. All eight respondents could identify a process for hospital palliative care consultation. However, seven of the eight social workers expressed not having a complete understanding of how palliative care is supported in the community. This was reinforced by a respondent stating, “How palliative care plays out, outside of the hospital and what the interaction looks like is unclear to me”. Another social worker supported this

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sentiment by saying, “I can’t tell what they are even working on, what the focus is? How are we then supposed to work together?” While there appears to be a defined process for palliative care consultation in the hospital setting, there is confusion surrounding the process of initiating community palliative care. In addition, there is a lack of clarity surrounding the working relationship between the primary care team and a community palliative care provider. Another respondent who participated in this research stated, “Palliative care in the community seems to be a little bit different than in the hospital because you are not working as close together, yet you are trying to focus on what the goals of care are”. A LSW social worker with eighteen years of health care experience was quoted saying, “Having some understanding of the focus of palliative care outside of the hospital would be helpful”. Another respondent alluded to recognizing that palliative care consultations were taking place in skilled nursing homes by physicians that have experience with addressing palliative care. This topic was not explored further as it was brought to the researcher’s attention late in the interview process, well after the majority of the interviews were completed. A clinic social worker in this research study emphasized that a lot of trained healthcare staff don’t realize palliative care is even offered in the community. She added that extensive education should be focused toward identifying this community service given the potential to capture a broader population of patients that aren’t requiring hospitalizations.

There was a consensus in this research that hospital-based palliative care was more clearly defined and used more frequently than community palliative care. The two clinic-based social workers who participated in this research were employed within the same health system but practiced in separate clinics. They both were able to identify the community palliative care

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program supported by their organization. However, they both recognized feeling disconnected from the palliative care team and experienced a lack of communication or means to electronically track patient's plans of care or visits despite this system affiliation. In contrast, the hospital social worker that was employed within the same health system acknowledged having direct communication with the palliative care team when initiating referrals from the hospital. The variance in these two roles needs to be considered. On one hand, the hospital-based social worker has the ability to offer the community palliative care team insight to a patient's current situation, particularly if there is no present relationship between the two parties. Communicating goals of care, current treatment options and identifying any barriers could enhance a patient's overall palliative care experience. Once the patient discharges from a hospital, the relationship between the hospital social worker and the patient ends. The social worker working alongside the primary health physician, on the other hand, has an ongoing relationship with the patient in the clinic and is expected to be a point person in coordinating the patient's treatment in the community. Without having ample communication with outside providers, like palliative care, a patient runs the risk of being burdened with recalling these details, locating contacts and providing proof of care themselves.

Lack of formal professional education in palliative care

The last theme identified in this research study was the recognition that not one of the eight social workers interviewed had any formal professional education in palliative care during their post-secondary schooling. One of the MSW prepared social workers interviewed stated, "There really isn't any training in school about palliative care. There were some conversations

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around bereavement but not really any medical focused education outside of mental health disorders and treatment”. All eight social workers identified receiving palliative care training while on the job. Another MSW prepared social worker with eight years of health care experience claimed that one of the biggest gaps to understanding palliative care is coming out of college without a good understanding of what palliative care even is. She acknowledged that she hadn’t even heard the term palliative care until starting her first job in a hospital.

Along with the recommendations for social workers to receive post-secondary education in palliative care, over half of the interviewed social workers expressed a need or interest in seeking more disease-specific education. Two respondents identified that nurses had broader access to this type of training. However, they identified that this type of education could help social workers identify potential palliative care recipients as well as allow them to gain a broader understanding of future needs of patients experiencing acute or chronic illnesses. By having this repertoire of information, these social workers expressed they would feel more comfortable advocating for palliative care consultations in situations that may have been overlooked by other health care professionals.

Five of the eight respondents identified concerns with either lack of time, lack of finances or lack of interest in palliative care. These issues were considered barriers to bridging their educational gap in this specialized field. One LSW prepared social worker stated, “I don’t make enough money to really want to invest my own money in social work training”. While another said, “I could use more training in palliative care but funding is limited. I also would tend to put my educational funds towards training on topics I am more interested in or that I

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would use more day in and day out. Palliative care isn't one of those areas". Not a single social worker interviewed acknowledged having a strong interest in palliative care despite verbalizing a perceived importance of understanding the programs benefits and services. However, two of the respondents did identify feeling comfortable facilitating these consults as they have regular exposure to end of life or critical care situations.

Seven out of the eight social workers interviewed, identified that additional palliative care training would be helpful to advancing their practice. The individual who did not identify needing further training identified completing on average one to two palliative care consults a month in a hospital-setting. This was the second lowest referral base of the candidates interviewed. The lowest referrals took place in an Emergency Room setting where the social worker estimated to complete between six to seven palliative care referrals within a calendar year. This was also an individual who was one of the two social workers selected to attend palliative care training from her social work department a couple years ago. This respondent noted that she requests the attendance of either Pain Management or the Palliative Care Nurse to accompany her during these consultations as she is less familiar with the program. Interestingly, this same respondent was able to identify an established Perinatal Palliative Care program but admitted that her knowledge of palliative care in the adult population was limited. In fact, the respondent was not clear on what the social work role was in the delivery of palliative care referrals in their hospital. The two individuals that produced the lowest referral base to palliative care identified that competence in palliative care is critically important, rating it at ten which was the highest level of importance.

Implications for Social Work Practice

Findings from this research project highlighted that there continues to be discrepancies in the delivery and understanding of palliative care services amongst medical social workers. Several of the respondents identified that patient's, families and even primary care physician's view palliative care as end of life care and have a difficult time differentiating between palliative care and hospice. The majority of the social workers interviewed in this research study acknowledged struggling themselves with explaining how palliative care is different than hospice at times. Interchanging palliative care and hospice leads to further confusion amongst medical professionals, patients and their families. This supports the misconception that palliative care is only appropriate for end of life situations. It also leads to the oversight of other patient populations that might otherwise benefit from palliative care services.

To complicate matters further, seven of the eight social workers interviewed recognized lacking a vision of how palliative care services are carried out in the community setting. Without having a clear understanding of this delivery service, there is a risk of fragmentation in support, lack of coordination of care, potential for fewer referrals and concerns of community sustainability. To improve coordination and build growth in community palliative care, collaborative partnerships between the primary health providers and these specialized teams is crucial.

Several social workers noted that palliative care was most widely referred to when end-of-life conversations arose, there were barriers to patients or families accepting a prognosis or repeated re-hospitalizations for symptom management were occurring. A few respondents

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identified having clients who viewed enrollment in palliative care as the last stages of treatment like hospice, when curative treatments were no longer available to them. Two social workers interviewed even referenced the term hospice in their definition of palliative care. A term several respondents described as fear provoking and often used to describe someone who is in the final stages of their life.

In contrast to the fears associated with the words palliative care or hospice, several social workers interviewed recognized an increased level of acceptance by patients and their families with receiving Pain Management services for the same chronic or acute illnesses. It remains unclear at this time what access patients and families have to medical social workers while receiving pain management services. Given that a significant number of patients experience concerns with symptom management and pain, it would be beneficial to have medical social workers assigned to Pain Management Teams in the community. This is largely in part to the fact that this type of care is more widely accepted and frequently overlaps with palliative care. Communication between Pain Management Teams and primary care tend to be strong. This is likely a result of treatments such as narcotics being highly controlled. Patients are prohibited from having multiple prescriptions filled in an effort to reduce dependency and misuse.

Implications for Policy

Policy implications begin with the recognition that many patients and their families lack knowledge and understanding of palliative care programming and the benefits afforded to them while receiving this type of care. Patients suffering an acute or chronic illness often rely

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heavily on family or close friends to provide caregiving assistance. This commitment can take a considerable toll on both the mental and physical health of these caregivers, as well as pose a socioeconomic burden. Fears that caregivers may limit their efforts or availability and abandon their ill loved one raise concerns with how these potential caregiver expenditures would be absorbed and who would be responsible for paying for this type of care. "Policy makers have perceived the problem as one of trying to avoid paying for something that they have been accustomed to getting for free" (Levine & O'Shaughnessy, 2014). With policy makers already anxious to control and reduce healthcare costs, the threat of adding benefits that have the potential of raising costs to overextended programs raises fear. Caregivers are a valued thread linking patients care between hospitals, clinics and the community settings. They were reported by several of the respondents in this study to be a barrier for patients receiving palliative care as they identified it as a service primarily for the dying. By including caregivers in the early stages of diagnosis and providing education on the progression of disease, potential barriers to care may be avoided down the line. This ultimately could impact the frequency of visits and dependency on healthcare providers. Further research on how this educational component might impact health care costs would be beneficial to highlighting the cost-benefit relationship. It is imperative to have caregivers be a voice in the discussions on palliative care policy as they are the individuals managing complex cares at home, often without any support or supervision of trained health care providers. As a result, caregivers have the most insight and direct knowledge of the challenges and needs of patients living with an acute or chronic illness.

If larger programs like Medicare adopted a palliative care benefit, the potential for other insurance providers to follow suit or to create payer-provider partnerships would likely

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increase. Currently Medicare covers some treatments and medications but not all. A palliative care benefit needs to be clearly defined as medically necessary and should cover related services and treatments for any acute or chronic illness that would fall under the programs eligibility. If broader insurance coverage existed, the need to expand palliative care in the community would also increase. This could lead to reductions in the disparities of access to palliative care in both socioeconomic and geographical domains.

Another implication for policy would be requiring palliative care be part of one's professional education. By doing so, professionals would have a common understanding of the program, learn how to assess for eligibility and would have more familiarity and comfort with the language used to explain the program. By not having any common professional education on the topic, health care providers are left to fall back on their on-the-job exposure, their comfort level with the topic and support from fellow colleagues. The ability to present palliative care in a way that doesn't create fear or promote confusion with other programs like hospice or pain management requires a degree of competence. "When presented as an option that relieves pain and suffering and that supports the patient and family in achieving the best quality of life possible, palliative care is more likely to be accepted, requested, or even demanded. Palliative care has much to offer people with serious illnesses and their families; it should be readily acceptable, available, and affordable" (Levine & O'Shanessey, 2014). Over half of the respondents in this research expressed experiencing some degree of stress facilitating these difficult conversations. They referenced palliative care providers having the fluency to conduct these discussions more naturally, leading the social worker to depend on these providers to

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guide the consultations. Given that not all settings currently have Palliative Care Teams, the concern for underuse rises.

Implications for Research

Additional research is needed to fully capture the needs of Medical Social Worker competence in palliative care. While this research study showed 87% of the interviewed social workers would be interested in additional palliative care training, the research lacks tools to accurately define individual competence as perception is subjective and not easily quantified. For instance, a social worker may perceive having a high level of competence in palliative care training, yet they may underscore their comfort level having these difficult conversations or may lack the efficiency in assessing appropriate candidates for this program. Time constraints and heavy caseloads may also factor into lower referrals in particular settings. This research study did not account for any of these factors.

Competence in palliative care consists of more than just understanding the programs ins and outs. It requires broader understanding of ancillary services like pain management and hospice services and treatment plans that negate eligibility to palliative care. It requires an understanding of the qualifying indicators with different types of chronic and acute illnesses, recognizing others perspective of where they are at with accepting the needs of their disease and facilitating difficult conversations with patients and families that may not want to hear that their condition is not curative. Much of this training is learned on the job while being immersed in different clinical situations. These case situations are unique to the individual experiencing the medical crisis and cannot be easily replicated for training purposes. Therefore, each case a

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social worker participates in will look different. As a result, it is challenging to offer training for clinical situations that you may not anticipate encountering. In addition, newer staff may not fully recognize the scope of clinical situations they will be called in for so they may view their competence higher than it really is. Structured mentoring, the integration of more palliative care teams both in hospital and community settings, the offering of extensive continuing education opportunities and yearly mandatory education may offer opportunities to strengthen competence in the field of palliative care.

Further research should be conducted to understand how palliative care actually differs in the hospital and clinic settings. While the majority of participants in this study worked in a hospital setting, many of them identified being unfamiliar with the delivery service of palliative care in the community. This illustrates an educational opportunity that could improve service lines between these organizations. The two clinic social workers interviewed during this research voiced concerns with feeling palliative care in the community setting is different than their experience of palliative care in a hospital setting. One respondent identified feeling that the relationship between community palliative care and clinic social workers was not as close or as collaborative. This respondent identified not being able to locate electronic documentation from community palliative care staff, which led to poorer communication between providers and feelings of frustration.

Several respondents identified that Palliative Care staff are more equipped and more comfortable navigating difficult conversations surrounding an illness than the rest of the interdisciplinary team. Having additional training around end of life conversations, disease-

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specific illnesses and having more time in their schedules to allocate to these conversations were reasons provided for these differences.

Strengths and Limitations

There are a number of strengths with using qualitative methods. Face to face interviews offer an opportunity to hear one's lived experience which is often more compelling than reading results from a questionnaire. Allowing the respondents to expand on their experiences provided the researcher an opportunity to identify new topics or barriers that were not initially considered. Case in point, is the acknowledgment that the delivery of palliative care looks different in the hospital setting than in a community setting. There was no consideration to exploring the different training needs in these settings when the questionnaire was developed or when the respondents were selected. Given the response during the independent interviews, the researcher was able to recognize common concerns surrounding these differences and was able to explore these experiences further. The researcher had the ability to direct the conversation in a matter that provided her with additional information on the influences of these lived experiences. In addition, the data that was collected was occurring in a more natural setting and distractions were avoided or minimized during the collection process.

Limitations included the recognition that the scientific community values numbers. Data collected from a smaller population cannot be generalized to a larger community. Findings from qualitative research can also be more challenging to characterize in a visual way. The quality of the interviews may be influenced by the researcher's personal biases and the respondents

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comfort sharing lived experiences with a stranger. Respondents' answers to questions could be influenced by the researchers' presence and demeanor during the data collection, for which there is no accountability. In addition, qualitative research may be more challenging for the researcher to secure enough participants to interview as staff may have difficulty setting aside an hour of their day to participate in a study they may have little interest in.

The sample used in this research consisted of two clinic-based medical social workers and six hospital-based medical social workers. There were three metropolitan hospitals, two separate clinic-settings and two separate health systems represented in this research. Within the Twin Cities metropolitan community there are over twenty hospital settings and an endless number of clinic settings. Therefore, the sample pool in this research project is very narrow and may not reflect the broader experiences of other medical social workers in the Twin Cities area.

Working with only two health systems offers an opportunity to explore if employees who have similar access to palliative care training have similar competence. While the results of these conclusions can vary based on the population of clients one works with, years of experience and level of interest in the topic. It can offer a glimpse into the health systems value on palliative care programming. Conclusions may be drawn if health providers offer regular trainings, have full time certified palliative care teams in place and provide annual updates as opposed to counterparts that don't have palliative care teams or support in place.

Another strength of this particular research included the ability to remain anonymous which offered respondents the ability to answer more honestly without fear of being identified or singled out, particularly if they felt underqualified in a particular service area. A limitation in

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this research included the fact that each hospital or clinic setting offered varying degrees of access to palliative care. They also offered different groupings of certified palliative care staff which comprised their retrospect Palliative Care Teams. A couple hospitals represented in this research offered a collaborative team which consisted of physicians, nurse practitioners, social workers and chaplains, while the third hospital exclusively offered a palliative care nurse for consultation. Neither of the clinic settings identified having a palliative care specialist on site. They referenced initiating referrals to an outside home care agency. One social worker also expressed frustration that there was no direct communication from home care on what type of palliative care support they were offering clients in the community. These social workers expressed a fragmented delivery system between palliative care services offered at home and the primary care team in the clinic setting.

Another potential limitation to this study was the acknowledgment that social work staff had limited funds allocated by their employers for furthering their education. Nearly all the respondents recognized that they use these funds on trainings that either they are passionate about or on issues they frequently encounter in their current positions. Not one of the social workers specifically recognized palliative care being an area they were invested in.

The research findings in this study emphasize that competence in palliative care is critical to enhancing a patient's and family's experience coping with an acute or chronic illness. Competence also strongly influences the identification of potential recipients, coordination of services and the comfort with facilitating difficult conversations surrounding patient's goals of care and end of life issues. As healthcare providers continue to receive pressure to reduce

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length of stay during inpatient hospitalizations and overall dependency within their systems, it is crucial that social workers become trained to support the growing needs of palliative care in both inpatient and community settings. Further research on this topic may aid in the identification of core competencies, the establishment of an evidence base and best care practice models that would support the growing needs of palliative care programming.

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Appendix A

Medical Social Worker's Perception of Their Competence in Palliative Care Consultations INFORMATION AND CONSENT FORM

Introduction:

You are invited to participate in a research study investigating the perceptions of Medical Social Worker's competence in providing Palliative Care consultations. This study is being conducted by Katie Rubischko, a graduate student at St. Catherine University under the supervision of Rajean Moone, PHD, LNHA a faculty member in the Department of Social Work. You were selected as a possible participant in this research because of your experience being exposed to patients that have experienced either chronic or acute illnesses or patients that have faced a life limiting illness. Please read this form and ask questions before you agree to be in the study.

Background Information:

The purpose of this study is to identify if any training gaps in Palliative Care exist and if so how that affects a Social Worker's comfort level providing Palliative Care services. Approximately 10 people are expected to participate in this research.

Procedures:

If you decide to participate, you will be asked to partake in one-in-person interview with one researcher. The interview will be audiotaped. This interview will take approximately one hour to complete.

Risks and Benefits of being in the study:

This study does not have any direct risks to the participant. In addition, there are no direct benefits to you participating in this research.

Confidentiality:

Any information obtained in connection with this research study that can be identified with you will be disclosed only with your permission; your results will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented. No one from your agency will know your comments and thoughts on this matter (all identifying information will be removed from your comments) and no direct information will be released to your place of business.

I will keep the research results in a locked file cabinet in my home office and only I and my advisor will have access to the records while I work on this project. I will finish analyzing the data by June 1st, 2016. I will then destroy all original reports and identifying information that can be linked back to you. Only I will have access to the audio tape and when it is not being used for transcription, it will be locked and stored in the filing cabinet in my office. The audio tape will be destroyed by June 1st, 2016.

Voluntary nature of the study:

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Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University in any way. If you decide to participate, you are free to stop at any time without affecting these relationships.

New Information:

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

Contacts and questions:

If you have any questions, please feel free to contact me, Katie Rubischko at 952-210-4936. You may ask questions now, or if you have any additional questions later, the faculty advisor, Dr. Rajean Moone will be happy to answer them. He can be reached at 651-235-0346. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

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

Statement of Consent:

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study.

I consent to participate in the study and agree to be audio-taped.

Signature of Participant

Date

Signature of Researcher

Date

Appendix B

1. Can you describe the population that you currently work with?
2. What is your experience working in health care? When was the first time you did a palliative care consult?
3. How do you define palliative care?
4. Describe a situation where either you or a colleague experienced obstacles providing support to a patient/family receiving palliative care. What factors would you attribute to these challenges?
5. Did you receive any training in palliative care prior to working in your current position? If so, what did your training consist of?
6. Have you received any palliative care training by your current employer? What did this include? Would you find additional palliative care training helpful?
7. How many palliative care consults would you say you participate in during a given month?
8. Identify situations where you feel palliative care consultation is helpful?
9. What gaps exist in palliative care training for Medical Social Workers? What would you identify as the educational priorities in bridging this gap?
10. What specific training would you find valuable to advancing your practice in palliative care?

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11. What would you identify as the core competencies in providing palliative care? Are there any core competencies that you could use more support in?
12. Would you feel comfortable asking for additional training in palliative care? Who would you likely first ask for this support?
13. On a scale of 1-10, how important is it to be competent in palliative care when it comes to direct practice? (1-little or no importance/ 10-critically important)