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WHAT IS THE IMPORTANCE OF SOCIAL WORK INVOLVEMENT IN HOSPICE CARE TRANSITIONS FOR ILL CHILDREN AND THEIR FAMILIES

Natalie Rodas
California State University - San Bernardino

Guillermina Morales
California State University - San Bernardino

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WHAT IS THE IMPORTANCE OF SOCIAL WORK INVOLVEMENT IN HOSPICE CARE TRANSITIONS FOR ILL CHILDREN AND THEIR FAMILIES

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

Guillermina Morales

Natalie Rodas

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Guillermina Morales
Natalie Rodas
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Approved by:

Carolyn McAllister, Faculty Supervisor, Social Work

Yawen Li, MSW Research Coordinator

ABSTRACT

Thousands of children who face terminal illnesses die annually in the United States, 10% of those children and their families have hospice care services available. Through this study, the importance of social work involvement in hospice care transitions for ill children and their families were examined. Due to the scarcity of social work in hospice care settings, this study helped amplify research on the importance of social workers in hospice care for ill children and their families. The study consisted of individual interviews held via Zoom with medical social workers that have experience working in pediatric hospice care. The individual interviews were 30 to 60 minutes in duration. The data that was collected from participants through audio recordings, was also transcribed to identify common patterns through thematic analysis. The study supported the goal of expanding further research on social work importance for pediatric hospice care and assisted in educating on the importance of social work in a medical care team.

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CHAPTER ONE

INTRODUCTION

Problem Formulation

The practice of social work, within a hospice and palliative care team, is to provide psychosocial care for patients and their families during the ending stages of the patient’s life or during bereavement for the family (Bosma et al., 2010). It is significant to integrate social workers into hospice palliative care teams to allow them to bring in their expertise onboard (Bosma et al., 2010). Medical social workers have the ability to assist patients and their families with communication, death and recovery from loss, ethics, individual and family dynamics, multiculturalism, pushing in favor for the patient and their family, multidisciplinary practice and social systems. (Bosma et al., 2010).

In addition, hospice care social workers provide in depth support for patients and their families such as evaluating the needs of the patient and the family, preparing a care plan and delivering the care, and referring patients to necessary social agencies and resources such as mentoring programs (Bosma et al., 2010). As it is mentioned in the literature by Bosma, the skills mentioned above were rated as 100% essential, except for advocacy (94%), care delivery (94%), community capacity building (87%) and education and research (93%) (Bosma et al., 2010). Therefore, social work involvement in hospice care is beneficial for ill patients and their families. In fact, Paul (2013) argues in his study, that not only is it crucial for medical social workers to be aware of what hospice care entails of, but it should be an area that all social workers are familiar with.

Children and their families can have a more satisfying life if they choose to have hospice care at the final stages of illness (Vesel et al., 2018). Unfortunately, families do not always have the resources to access these medical services, and although over 70% of families say they would want their child to pass away in the comfort of their home, the percentage of children that do die at home is 15% to 30% (Vesel et al., 2018). Social workers are referred to as liaisons for ill patients (Beerbower et al., 2018). As a liaison, social workers advocate for patients and their families and facilitate communication between patients/families and medical providers (Beerbower et al., 2018). Additionally, social workers use a holistic approach by providing bio-psycho-social needs assessments for the patients (Beerbower et al., 2018).

Not all populations have access to resources or the option to receive hospice care. For example, at macro level, minorities may desire to have a medical social worker present to alleviate discomfort at the end-of-life stages of their ill child, but it is not always an available resource to this specific population (Vesel et al., 2018). Among the 50,000 children that die in the United States every year due to a terminal illness, hospice services are only available to 10% to 20% of the ill children (Varela et al., 2011). It is unfortunate to have such a large number of ill children go through their end-of-life stages without the proper support from a medical social worker to meet their psychosocial needs (Varela et al, 2011).

Purpose of the Study

The purpose of the research study was to assess the importance of social work involvement in hospice care transitions for ill children and their families. When assessing the emotional constraints that ill children and their families endure during hospice care transition, the competence of medical social workers is highly needed to provide support (Bosma et al., 2010). The transition from coping with an illness to end of life care can be tough on the children and their families, and according to Vessel et al., it is difficult to access professional support even when families request to have it. Through this study the importance of social work involvement in hospice care for ill children and their families was measured using a qualitative method of study.

The study addressed the significance of social work in hospice care for ill children and their families and helped strengthen further research through interviews between medical social workers who are directly working in a hospice setting or have had experience working with ill children who have transitioned to end of life care, and the researchers. The study consisted of an individual interview with medical social workers who currently work or have previously worked directly with children in an end-of-life care and hospice care setting. The research design that was utilized for the study is qualitative individual interviewing. This method was used in order to focus on collecting detailed data from professionals who understand the urgency of social work support for ill children and their families as they endure end of life. Additionally, this type of research design was selected due to the need for broad responses to grasp a better understanding of the respondent's experience within pediatric hospice care.

Significance of the Project for Social Work. The urgency to conduct this study resulted from the lack of social work practice within hospice palliative care teams, to bring awareness of how important it is to incorporate social work into hospice care teams, and to increase employment opportunities for medical social workers. It is critical to bring light to the need of social workers in hospice palliative care teams. The integration of hospice social workers would allow the medical team to collaborate and utilize social worker's expertise in advanced care planning. The findings of this study helped deliver a better understanding why social workers are essential in the field of medicine, especially in hospice care transition. Beaune et al., shares that families that experience illness and medical treatment for their child, often have to face very high expenses, this is a great demonstration of why a medical social worker would be necessary, with the support of a social worker, the family will be able to receive resources that they did not know were available if it was not for the advocacy of a medical social worker (Beaune et al., 2014).

Furthermore, enlightening the importance of trained social worker's expertise and skills in hospice care provides a better understanding of the need for healthcare management and administration. Spetz et al., (2016) suggested that palliative care programs do not meet the national staffing recommendations, which includes staffing of knowledgeable social workers. Palliative care programs often utilize volunteers rather than educated medical social workers to service ill patients and their families (Spetz et al., 2016). By educating healthcare management and administration teams of how the inclusion of skilled social workers will uplift ill patients who are facing end of life stages, it will prompt them to take action and increase employment opportunities in hospice care facilities, both inpatient and outpatient. In addition, this research brought awareness of how it will be beneficial to patients and their families during the end-of-life stages. The medical and social work fields are both helping professions and focus on client and patient care/needs. It is evident that patients who are coping with terminal illnesses and their families will benefit from having a medical social worker in their hospice care team. Many other burdens such as financial crisis and mental health crisis can arise from the absence of a social worker during the end-of-life stages.

The findings of our research study contributed to providing an understanding of the importance of social work involvement within hospice care for ill children and their families. The outcomes of our research are of interest to hospice care facilities, as well as to healthcare management and administration teams in order to modify their organization’s culture to match their goals and mission to provide the utmost service and support to patients who are facing a terminal illness and their families. In addition, our research findings will encourage hospice care facilities, healthcare management and administration teams to expand their employment opportunities to trained medical social workers to integrate social workers’ expertise into hospice care teams. The generalist intervention model was utilized as the study was carried out. The research study focused on the exploring phase of the generalist model by engaging with medical social workers to assess the significance of their role in hospice care teams. As the research was addressed during the interview, open-ended questions, active listening skills, and proper documentation skills were utilized to address the following question: What is the importance of social work involvement in hospice care transitions for ill children and their families?

CHAPTER TWO

LITERATURE REVIEW

Introduction

The purpose of this chapter was to analyze the current literature that supports the need for social work involvement in hospice care. The topics include lack of social work support for ill children and their families, the type of support provided by social workers in hospice care, and the effect of policy change on patient care. The final subsection of the literature review examined symbolic interaction theory and general systems theory, which are both pertinent to researching the importance of social work involvement in hospice care transitions for ill children and their families.

Need of Social Work Involvement

In the last few years there has been a significant increase in the number of children who unfortunately are dependent on ventilation machines (Amin et al., 2012; Price et al., 2018; Tearl et al., 2006; Wallis et al., 2011). As a result, children and their families face a variety of unsteady feelings and may even experience an impact on their health from stress (Cockett, 2012; Price et al., 2018). When a child is ill, let alone dependent on medical devices in order to survive, it can be a heavy reality for the family and requires support both emotionally and with resources (Price et al., 2017; Wallis et al., 2011). The pressure the family has to endure from having their child sick is exhausting and requires professional assistance (Carnevale et al., 2006; Kirk et al., 2005;

Murphy et al., 2006; Price et al., 2018; Whiting, 2014; Woodgate et al., 2015). The need for a social worker during these types of situations is much needed. As Carter et al. (2016) and Price et al. (2018) explained in the literature that even when a child may be medically stable, it is often too difficult to send the child home because there is not enough staff to support care at home. Based on the literature, it is evident that there are barriers which prevent a child from returning to the comfort of their home as they reach end of life but having professionals such as a social workers can help with staff limitations in order to be able to have an equipped team to care for children in a hospice setting (Price et al., 2018; Smith & Hilliard, 2011).

Support Provided by Social Workers. Social workers are essential in a hospice care setting in order to provide the utmost care in a timely manner for hospice patients and their families (Price et al., 2018; Smith & Hilliard, 2011). Social workers provide support using the holistic perspective to ensure all the patient's and the family's needs are met and understood (Price et al, 2018). The holistic approach social workers utilize is critical for their essential role of assisting with the process of transitioning into palliative care (Gerbino, 2014). Gerbino (2014) argues that social worker involvement is significant because of the vital support and resources that they provide. Social workers utilize their exceptional skills to assist patients and families to better understand medical terms, provide counseling and emotional support, and refer patients and families to resources (Gerbino, 2014). Gerbino also highlights social worker's role in communicating the possibility of palliative care and educating the patient and family about the process and the illness (Gerbino, 2014). It is evident that social workers play an important role in medical settings, and with great emphasis in palliative care where patients with critical illnesses, such as cancer are treated (Fobair et al., 2009; Gerbino, 2014). Social workers in a medical setting have the skills equipped to contribute to care such as palliative care, and based on professional knowledge, and values, social workers are highly qualified in a distinctive way to be part of palliative care (Gerbino, 2014).

Policy Change as a Barrier. It is evident that policy changes and shifts in payment models decrease interdisciplinary support for social support workers (Cain, 2019; Light, 2010, & Timmermans and Hyeyoung, 2010). The pressure of Medicare policy changes affected hospice facilities in a direct and indirect manner (Cain, 2019). As a result of the policy change, hospice agencies geared their focus more towards management, rather than maintaining their focus on patient care and needs (Cain, 2019; Mahar, 2006). Due to the policy changes, workers feared for what hospice care would become in the future (Cain, 2019). As Cain (2019) describes in the results, the fear of workers affecting their work performance, which led to destabilizing the structure of interdisciplinary support for social support workers. In addition to policy changes, change in payment models has increased the gap in support of social support workers (Cain, 2019; Ritzer & Walczak, 1988). The changes support the profit interests rather than the patients' needs and necessary support that is essential for patients to have the proper care during their end-of-life stage (Cain, 2019; Ritzer & Walczak, 1988). It is significant for this study to be conducted throughout the country in order to analyze the effects of Medicare policy change and the possible responses to the change that have risen in order to maintain the interdisciplinary support for social workers (Cain, 2019). As Cain (2019), Patterson (1998) and Rosenberg (2007) argue the holistic care approach is utilized to locate the gaps among medical hierarchy and patients' needs. Social workers are a crucial source of support for patients and their families in the process of the patients end of life (EOD) stage, which is why it is significant to integrate and close the gap between the medicine approach and social services support (Currie et al., 2012; Cain, 2019).

The purpose of this study was to strengthen the understanding of the necessary social work involvement in hospice care in order to provide a smooth transition for ill patients and their families. Similar to other studies, this study helped strengthen research. The focus of the study was to conduct interviews directly from social workers themselves. Receiving feedback directly from social work professionals grants an understanding of the great need of social work involvement when caring for children and their families experiencing a terminal illness. Although there has been continuous research that addresses similar studies, this research developed the importance of why social work involvement is crucial when it comes to medical illness circumstances.

As Feudtner et al. (2019) clarifies, the study of pediatric palliative care (PPC) is still very new in the United States, and it is in dire need of further growth. Suggested by Feudtner et al. (2019), the research on pediatric palliative care desperately needs further research to be able to improve the standard of care. Through our study we helped contribute to the development of knowledge on pediatric palliative care and the urgent need for better care and support as a child and their family face the final stage of care for a terminal illness. Weaver et al. (2015) conducted a study that specifically targeted the need for psychosocial care for ill children and their families. Our goal for this study was to help further progress Weavers and colleagues' (2015) argument with our own collected data to expand on the understanding of why professionals such as social workers are greatly needed when dealing with such a sensitive stage of illness for a child and their family. According to current research, palliative care among children and families has the potential to offer comfort to the patient and reduce the discomfort that may present from illness at the end of life (EOD) stage (Bousso et al., 2012; Mack et al., 2005; Mitchell et al., 2005; Theunissen et at., 2007; Tomlinson et al., 2011; Weaver et al., 2015). It is recommended that further research addresses direct perspective from the patient (Weaver et al., 2015). With our own research we interviewed social workers that directly work with pediatric patients as an alternative in order to avoid any possible discomfort to the children and families. It would have been inconsiderably inappropriate to directly ask the family for their perspective during a very vulnerable stage but interviewing a social worker helped strengthen research on the topic of social work involvement and why it is important.

Theories Guiding Conceptualization. Current research utilizes the symbolic interaction theoretical framework to analyze the significance of including social workers in the interdisciplinary care teams for patients who are facing the end of life (EOL) stage (Wallace, 2016). Symbolic interactionism defined as the meanings and symbols are created through social interactions and how individuals interact with one another based on the meanings that were created (Wallace, 2016). Symbolic interaction is critical between hospice social workers and patients as it is “the ideal base for social work” (Forte & Herman-Kinney, 2003; Wallace, 2016). The involvement, closeness and social interactions among social workers, patients and their families is what alleviates the process of death and makes it a normal aspect of life (Wallace, 2016). Even though hospice care is not geared towards prolonging the ill individual’s lifetime, the human communication through symbolic interaction helps address any possible barriers for the patient and the family (Mead, 1967; Wallace, 2016). Communication and social interactions also make the process of the patient dying as normal as possible, although a loved one dying is not an everyday occurrence, as it is in the rural areas (Kiernan, 2006; Wallace, 2016). Wallace (2016) argues that we currently live in a death-denying society, meaning that today’s society is in denial of a loved one's last day coming when they are under the care of hospice, as many families portray hospice care as the interdisciplinary team giving up on their loved one. In order to eliminate the negative perception of end-of-life (EOD) it is crucial to utilize the symbolic interaction framework.

In addition, Wallace (2016) and Bertalanffy (1968), also explain how utilizing a general systems theory is a “general science of ‘wholeness.” A general systems theory and symbolic interactionism can both be utilized to guide research in demonstrating the significance of social work practice being a part of the wholeness in interdisciplinary hospice care teams (Wallace, 2016). General systems theory focuses on the interactions between and within systems (Wallace, 2016). In other words, general systems theory focuses on the relationship between the individual, which would be the patient, and their social environment, which would be with the healthcare professionals and their family (Wallace, 2016). Wallace (2016) and Bertalanffy (1968) clarifies the significance of having an open system among the patients, families, and the healthcare providers (social workers, physicians, nurses) and accepts feedback from one another in order to progress and reach the goal of allowing the ill patient to pass at ease. Social workers are known for being accepting of feedback and utilizing their comprehensive lens to coordinate the proper psychosocial and resources for the patient and their family (Wallace, 2016).

Summary

This study explored barriers and facilitators to the importance of social work involvement in hospice care transitions for ill children and their families. Social workers play a significant role in a medical setting, with even greater sense in hospice care (Bosma et al., 2010). Social workers provide support, evaluate needs, organize, and prepare plans for care, and offer resources to ill children and their families as they navigate the hard reality of end-of-life care (Bosma et al., 2010). This study sought to add the social workers perception of social worker involvement in hospice care for ill children and their families to the literature and expands on research which currently is limited.

CHAPTER THREE

METHODS

Introduction

This study focused on analyzing the current data that supports the significance of social work involvement in a hospice care setting. In addition, the study aimed to identify the significance of social work involvement in hospice care transitions for ill children and their families. This chapter includes details regarding the study's following subsections: study design, sampling, data collection and instruments that will be used, procedures, protection of human subjects, data analysis and a summary.

Study Design

The purpose of this study was to address the importance of social work involvement in hospice care transitions for ill children and their families. During the initial stages of the study, we utilized a qualitative method study design using cross sectional interviewing. Our study was exploratory due to it being a relatively new topic and there is a limited amount of research that addresses the importance of social work involvement in hospice care setting. As our study was an exploratory research study, it allowed for us to become aware of fundamental information involved in the research, involving both the population involved as well as any apprehensions (Grinnell & Unrau, 2018). Using an exploratory approach assisted in developing a clear understanding of what is occurring as the study progresses (Grinnell & Unrau, 2018). Our study was a cross sectional survey study, as the co-principal investigators made an observation at one point which was done during the individual interviews. In order to obtain the high-quality data our source was social workers who work directly with pediatric patients in a hospice care setting. We refrained from directly using patients and their families as our source of data to ensure that our study did not add to the difficulty of processing the end of life (EOD) stage of their loved one.

As previously mentioned, we utilized a qualitative method for our study which consisted of open-ended questions which were developed by the co-principal investigators that will solely focus on factual answers, rather than opinionated answers. The strength of utilizing concrete open-ended and follow up questions is that it allowed participants to elaborate and provide as much detail as possible with fact-based answers. The feedback obtained from medical social workers through individual interviews using an exploratory, qualitative approach strengthened our study by collecting their viewpoints that may have not been included in previous research.

The practical methodological design has strengths, but it also has limitations. One of the limitations of utilizing a qualitative approach is that it can be time consuming due to the interviewing process. Another limitation that may have arisen during our study is that there is no certainty of the information being provided by the participants as the data collected through a qualitative approach cannot be verified. Lastly, there may have been biased answers according to the perspective of each participant.

Sampling. The sampling approach that was utilized in our research study is snowball sampling. The snowball sampling method was used to recruit medical social workers that currently or have previously worked with children and their family in a hospice or palliative care setting. As the snowball sampling method was utilized to obtain participants who are acquaintances, professional colleagues, family, and friends that are or have been medical social workers in a hospice or palliative setting, there was no need to obtain approval from an agency. Our study consisted of a total of 11 participants that were interviewed individually.

Data Collection and Instruments. The study’s qualitative data was collected via audio recorded individual interviews between medical social workers and the co-principal investigators in January-May 2022. Each interview began with an introduction to the study and its purpose, along with confidentiality disclosure. The focus of the individual interviews was based on medical social work experience and expertise that helped expand research on the topic of social work involvement in hospice care transition for ill children and their families. Each participant's demographics was obtained prior to the scheduled interview but was verified during the interview. The following demographic questions developed by co-principal investigators were obtained during individual interviews: What gender do you identify as? What is your ethnicity? What is your age? What university did you graduate with your MSW? Are you currently employed as a medical social worker, if so, where? How many years have you been in the field of medical social work, in a hospice care setting?

Both co-principal investigators conducted each interview that consisted of questions that highlight the need for social work in hospice care for ill children and their families. In order to ensure the questions, have face validity and content validity the questions that were created by the co-principal investigators were inspired by this study's literature review. The questions were refined with the instructor/researcher supervisor. The general questions that were addressed are the following: What is your role as a medical social worker who works with ill children under the care of hospice? Based on your observation, do you notice positive changes when a child and their family receive palliative/hospice care? Please explain. Do patients and families get resources offered to them when in the care of hospice or palliative care, if so, how often? What type of resources are available? Is there a difference in health progression when a child receives palliative care? Please elaborate. How have the children's families responded to hospice/palliative care, based on your experience? Tell me about a time when you provided hospice care services to an ill child and their family and saw progress. What type of progress did you see? Describe a time where your unique skills/knowledge benefited the patient going through end-of-life care. As a medical social worker how have you made an impact, whether it is positive or negative, on this specific population? Describe how you and the interdisciplinary team collaborate to serve the ill patient and the family's needs. From reports of families, what are the benefits of having a medical social worker as part of the patient's care team?

Procedures. Due to the use of snowball sampling, the investigators gathered participants based on connections through family and friends, professional colleagues, acquaintances, social media recruitment and other online platforms such as Linked In and Reddit. The co-principal investigators accommodated with participant's schedules to arrange individual interviews. Both co-principal investigators communicated with participants before scheduling an interview for clarification, purpose of study, to provide the demographic questionnaire via Qualtrics, to address any questions and concerns the participants may have had, and to confirm if the participant agreed to move forward with the interview.

Since interviews were conducted during unforeseen times due to COVID-19, interviews were held via Zoom in order to follow the social distance protocol, this prevented any safety concerns that may have arisen for the participants. Although the cameras were on during the interview, co-principal investigators did not keep video footage of the participants. The co-principal investigators only kept an audio recording of the interview which was transcribed utilizing the feature on Zoom. Before the interview began, co-principal investigators introduced themselves, discussed confidentiality and collected consent from participants. Investigators thanked participants for taking the time to be part of the study and proceeded to begin the interview. Before the interview progressed to questions, the co-principal investigators turned on the audio recorder feature on Zoom. At the end of each interview, participants were once again thanked and a closing statement regarding the study's findings and its future results were explained.

Protection of Human Subjects. The identity of the participants was protected and kept confidential from other participants and anyone who is not the principal investigator or co-principal investigator. The interviews were conducted individually to keep the session private to ensure that participants were in a safe and COVID-19 free environment. The interviews were recorded but in order to refrain from sharing the participant's identity the videorecording was discarded. If there was any personal identifiable information for participants or patients, the identifiable information was removed immediately. In order to refrain from using participants' names, each participant was assigned an identifying number. The data was made confidential and was encrypted onto our CSUSB account. The electronic data required a password that was only accessible to the principal investigator and both co-principal investigators. There was a secondary storage for the confidential information which was on a USB drive that required a password as well and was stored away in a locked desk that was only accessible by the principal investigator and co-principal investigators. The audio-recordings and data collection will be destroyed after three years.

Data Analysis. The data that was collected during the individual interviews was analyzed using thematic analysis. The interviews were audio recorded using

Zoom, and then were transcribed into a written format. Each participant was given a number to be able to identify the data collected for each participant. The co-investigators listened to the data collected multiple times to be able to depict common responses and patterns as well as input from the participants. For our descriptive analysis, co-investigators used the following demographic identifiers, gender, ethnicity, age, university where degree was obtained, employment status, and number of years in pediatric hospice care setting.

Summary

This study examined the importance of social work involvement in hospice care transition for ill children and their families. The individual interviews assisted in collecting the viewpoints of professional medical social workers and their expertise to expand research on the importance of social workers involvement in hospice care for children who are terminally ill and their families. The process of this study was guided by using qualitative methods.

CHAPTER FOUR

RESULTS

Introduction

This chapter presents the results of the analyzed data from the conducted individual interviews, and demographics which were gathered from participants through a brief questionnaire before each individual interview took place. Co-facilitators came together to analyze the data that was collected during the individual interviews with medical social workers based on an open-ended questionnaire guide. Each co-facilitator concluded their own themes based on individual data analyzes that were found, then came together to compare themes for the purpose of finding validity. The final congruent themes that were found are as follows; resources, unique skills of social worker, mental health services, concurrent care, need of social work services, benefits for the family, families' responses, collaboration, positive impact, and graduating. Co-facilitators carefully gathered the themes by confirming repetitiveness through all interviews according to the responses from all participants.

Data Analysis

The sample consisted of eleven participants, who are social workers (N = 11). The eleven participants completed an online Qualtrics Survey in order to provide demographic information for the study. The online survey consisted of six questions regarding the participant's race, gender identity, age, university attended, whether the participant is currently employed as a medical social worker, if so where they are currently employed and how long has the participant been in the field of medical social work, specifically in a hospice care setting. Out of the 11 participants, 1 participant is African American (9.09%), 2 participants are Hispanic/Latino (18.18%), 7 participants are White/Caucasian (63.64%) and 1 participant is Asian/Pacific Islander. All of the participants were female (100%), therefore, there were no male (0%) participants in the study. The participant's ages ranged from 29 to 52, with the breakdown being 7 participants (63.63%) being of ages 29 to 40 and 4 participants (36.36%) being of ages 41 to 52.

Being that the participants were all from different states and/or countries, they did not all attend the same university. One participant attended Andrews University in Berrien, Michigan, one participant attended University of Toronto located in Ontario, Canada, one participant attended Concord University in Montreal, Quebec, Canada, one participant attended Salisbury University located in Salisbury, Maryland, two participants attended West Virginia University located in Morgantown, West Virginia. Another participant attended University of Louisville located in Louisville, Kentucky, one participant attended University of Connecticut located in Storrs, Connecticut, one participant attended University of Michigan in Ann Arbor, Michigan, one participant attended Michigan State University in Lansing, Michigan, and one participant attended Loma Linda University in Loma Linda, California.

When analyzing the eleven participants' current employment, two participants (18%) currently are not employed as a medical social worker and nine participants (82%) are currently employed as a medical social worker. Of the nine participants, five participants (56%) are currently employed at Hospice of Panhandle, one participant (11%) is currently employed at Hospice of the Valley, one participant (11%) is currently employed at McMaster Children's Hospital and two participants (22%) did not provide details of where they are currently employed as a medical social worker. There were no participants (0%) who have worked less than 6 months in the field of medical social work, specifically in a hospice care setting. one participant (9%) worked from 6 to 12 months in the field of medical social work, specifically in a hospice care setting, three participants (27%) worked in the field of medical social work, specifically in a hospice care setting, two participants (18%) worked in the field of medical social work, specifically in a hospice care setting and five participants (45%) worked in the field of medical social work, specifically in a hospice care setting.

The interviews consisted of ten open ended questions. The duration of the Zoom interviews ranged from 18 to 48 minutes. The questions aimed to obtain a clear understanding of the participants' role, their experience as a medical social worker, how their role has been beneficial to ill children and their families, the resources provided to families and the ill child, and the logistics of the interdisciplinary team. The data analysis approach that was utilized to conclude with the following themes was the constant comparative analysis and the thematic analysis. The eleven interviews that were conducted were transcribed and were dissected into different themes by both co-facilitators. Upon completing the transcription of the interviews and analysis of the themes that were dissected from the eleven interviews, the co-facilitators proceeded to compare the themes that each co-facilitator concluded with. The co-facilitators concluded with a total of ten themes, which will be discussed in the following section.

Themes

As a result of the data analysis process, the co-facilitators concluded that the themes that follow would be presented as supporting evidence for the importance of social work involvement in pediatric hospice care: 1) social worker's role as a case manager, 2) social workers as an interdisciplinary team member and 3) the social worker role within the family system.

Social Worker's Role as a Case Manager

The purpose of case management is to provide a well-rounded service that can ensure that the patient and family has an advocate, support system, and is being provided education on medical and treatment care. As case managers, social workers provide a wide range of services not only to the ill patient, but to the family as well. Through case management, social workers provide recourses to ensure that all needs are being met. In addition, social workers also provide counseling, and other mental health support as they take the role as case manager.

Resources. One of the many roles that a medical social worker fulfills for ill children and their family during the end of life, is to provide resources and connect them to outside resources when necessary. Having access and being connected to resources during the final stages of life is vital to help decrease the families' stress and increase the ill child's level of comfort. Participant 6 disclosed that resources are offered all the time, as there is not a time in which resources are not offered. In addition, Participant 6 stated:

> There is volunteer support available to help give the family a break. Not all hospice facilities do, but we have an inpatient facility where, if a family needs to, we could bring their loved one to our facility for us to care for them for up to 5 nights and 6 days, at no charge. We transport them here, so that the family can get a break or go out of town (Participant 6, 2022).

In addition, Participant 6 shared that families also receive support in being connected to resources that help provide equipment that helps with the care of the ill child. Participant 6 stated the following:

> For example, this young lady needed support in getting a comfortable bed that was safe for her and we were able to do that. I am also working on helping get her a chair that is called an aquatic chair because she loved the pool. There is a pool here that has a beach entrance, but her mother is not able to get her in and out safely enough because she is no longer able to walk without her mother's support. I am working on finding an aquatic chair but the cost of it is $1,500 so we don't just say I cannot do it, as we have to find a way to get the funds or reach out to local companies for support (Participant 6, 2022).

Participant 2 discussed resource programs such as the Wish Program and Rainbow Connection that are programs that allow for ill children to make their final wish. Participant 2 shared the following:

> Usually these organizations, Wish Program and Rainbow Connection, you have to be 2 years old to get a wish, but they have started to do what is called mini wishes. This goes for ill children under the age of 2 and so it might be something on a smaller scale, such as a photoshoot, shopping spree or an overnight trip with the family (Participant 2, 2022).

Participant 11 discussed how families are connected to financial assistance as there are monetary challenges that arise. Participant 11 stated the following:

> Some parents are unable to work as they have to leave their jobs because they have to take care of their child full time. There is only one working parent or sometimes both parents need to stop working when their child is at the end of life. There are a lot of financial resources available as there are different agencies that provide funeral assistance. There are also other agencies that provide utility assistance, and cancer organizations that provide stipends on a quarterly basis for cancer patients (Participant 11, 2022).

<u>Unique Skills of Social Workers.</u> The perspective and skills of a social worker is quite different compared to a medical professional in an interdisciplinary team. Social workers have the unique skills that allow for them to provide psychoeducation, resources, support with planning, having the ability to utilize

their skills to support the family as a whole by being an advocate for the family and being a Licensed Clinical Social Worker (LCSW).

> Well, my understanding, out there in most hospices you don't have to have an LCSW. I do have the LCSW, so I have a pretty good clinical background. I did private practice for a while and brief counseling for a while. I think, utilizing those counseling skills, that is not always required in this position, is so very helpful (Participant 5, 2022).

Another participant stated,

> I happen to speak Spanish and so living in an area where not lots of professionals do, that helps to mesh those two in a clinical setting. And of course, not just the language, but like a bit of a cultural understanding, explaining to the other team members, you know what different nuances of the care (Participant 5, 2022).

In addition, Participant 3 shared how their unique skills of advocacy are utilized to help support the ill child and their families:

> We bring a lot to the table because we use the strength-based perspective, we look at systemic approach. We don't just look at an individual. I think we look at the individual in their environment, and really try to identify the strengths and resources that the clients and their families have. You also discover the things that they have yet to tap into. At the same time, we work to minimize, if not eliminate, barriers that they may have in the micro, mezzo, macro levels. Whether we advocate for policy

> change or working with insurance companies to make sure that they are able to receive services that they need to connect clients to services that they may not qualify for, but we can advocate (Participant 3, 2022).

<u>Mental Health Services.</u> It is crucial that the ill children and their family have access to mental health services to help cope with stress, upcoming grief and so that the families know they are not alone in the process. Participant 3 shared details of the support groups and/or camps that families have access to.

> For example, the hospice agency that I worked for had a support group for caregivers like grown-ups. But also, we also did a camp for children, so that the siblings of the clients who were receiving hospice could later receive support. They can go for a week, and they are able to connect with other children going through losses that they've lost their loved ones, and they have an opportunity to share without worrying about traumatizing other kids. (Participant 3, 2022).

Participant 5 also shared additional mental health services such as anticipatory grief counseling and pet therapy counseling, that families have access to in hospice care. The following was stated by Participant 5:

> We have anticipatory grief counseling, and that is for anybody in the family, including the patient. We call it preparatory. Pet therapy, we literally just visited a kiddo. That's the one I was late at, where we were discussing with them the idea that he might be able to get some pet therapy. Mom

> had tried to have a dog and she just couldn't manage a full-time dog and the child's needs pet therapy (Participant 5, 2022).

Needs of Social Work Services. It is evident that social work services play a large role in a hospice interdisciplinary team. Social work services meet the needs of the ill child and their family such by helping them navigate through the end-of-life care, whether it may be by being their voice during the interdisciplinary team meetings, providing emotional support or connecting them to resources. The following statement made by Participant 3 supports the needs of social services.

> I think we also are a very client- centered system and when ethical issues come up, we can give that perspective and advocate because a lot of times clients and their family members can't attend meetings. At my agency we have a weekly interdisciplinary meeting that the clients are invited to but because of their condition, they were never able to attend. So I think that I and other social workers would really try to voice their perspective because that's what's important. So I think, although I'm biased, I think we bring a lot to the table (Participant 3, 2022).

Social Workers as an Interdisciplinary Team Member

Social workers play a crucial role in ensuring that the needs of the patient are being met both emotionally and physiologically. As part of the interdisciplinary medical team, they bring an empathic approach in collaboration and teamwork. Being part of the medical interdisciplinary team is an important aspect of the role of a medical social worker because learning through other professionals, and their different viewpoints on the patient can assist in understanding the need of the patient. Additionally, the social worker role can bring advocacy for the patient when collaborating with other professionals working with the patient.

Concurrent Care. It is beneficial for ill children to receive treatment while still receiving hospice services. Participants 7 and 9 discuss how concurrent care is helpful. Participant 7 stated the following:

> There are all kinds of benefits to increase support in the home. The ability to do concurrent care to get that help in the home for comfort, but also for them to still continue to get aggressive treatment if they want to. There aren't any billing issues, that's fantastic (Participant 7, 2022).

Participant 9 stated the following:

> I do think the fact that we're able to have some wiggle room as far as medications and things that we can do when they are receiving concurrent care does help in my opinion. It prolongs life and quality of life, and potentially, whatever it is that they have going on, because you have multiple team players. Both at the hospital and in the home, to continue to monitor a progression of a disease or what is currently going on with the patient (Participant 9, 2022).

Collaboration. Medical social workers play a pivotal role in interdisciplinary med teams, and through teamwork with other medical staff participate in ongoing collaboration. Medical staff such as doctors, nurses, Chaplin, volunteers, and social workers have ongoing biweekly meetings to discuss treatment progress, and important conversations on the patient. Through these ongoing meetings, social workers as well as other medical staff keep each other up to date on any changes, progress, and challenges.

Participant 2 stated:

> We have every other week (IDT) interdisciplinary team meeting, and it is with the physician, social worker, nurse, Chaplin, and volunteers. And a lot of the time, my partner in crime is the nurse. We might make joint visits again. Just before I was on here with you, I was chatting with one of my nurses about a patient I have. So we’re always you know, just collaborating you know, conversing about our patients.

Additionally, Participant 6, disclosed how important it is to have the support of all medical staff as a whole.

> Well, the one thing that I value more than anything is knowing I don’t have to do it all on my own. I might not have the best idea; I might be clear and be like I don’t even know where to start when I can bring this to the team and know that they can help problem solve. Right? Like 5 brains are better than one. That is how we work together to make sure that we are covering all bases. (Participant 6, May 2022).

A commonality that was observed across all 11 participants was the frequency of their interdisciplinary meetings, which is biweekly.

Social Worker Role Within the Family System

Benefits for the Family. Having a professional individual that provides a variety of services to ill children and their families at the final stages of treatments can come with several benefits. When participants were being interviewed, co-facilitators asked regarding the benefits that specifically come from having a medical social worker on board. Participant 6 expressed emotional support as one of the benefits and stated:

> My role is to help them, and their family navigate this very difficult time. Unimaginably difficult time, and to give them the best quality of life that they can possibly have given the limitations of their illness. And all the challenges they face. I'm somebody that can help them do problem solving and get things in order. Provide lots of education and emotional support (Participant 6, May 2022).

Additionally, Participant 1 shared the benefits to the family of having a medical social worker as part of the medical team. Participant 1 stated:

> Social workers have more time to explain things because they're not the nurse, they're not the doctor, they're not there to give medicine. So just more time, I guess, given to the kids, and their families (Participant 1, February 2022).

In support, Participant 2 shared the feedback that is given to them as a medical social worker from the patient/ and or families.

> I think most of the time I’ve had families say just having somebody there to talk to because I mean a lot of the time or sometimes families come to us and it’s totally like a new experience for them. Like they don’t know what to do or how to navigate. So just having somebody to be able to talk to about like, you know, how hard this is, or just understanding what they’re going through. (Participant 2, March 2022).

During this end-of-life stage in the child’s medical care, the family may display little to no desire to worry about certain documents, processes, and figuring out hospice as a whole, with the support of medical social workers, not only do the patient and the families benefit from moral and emotional support but also assistance in figuring out documentation and applying to different programs. Participant 5 stated:

> I spend a decent amount of time helping them with paperwork, whether it be for waivers, Medicaid, social security, sometimes FMLA. (Participant 5, May 2022).

Families’ Responses. Although social workers play a crucial role in the medical setting, some of the responses from the families based on the participant’s sharing during the individual interviews can be a mixture of feelings. Some families respond positively, while others may be ambivalent when introduced to their hospice social worker. Based on the responses of participants, families may be conflicted with having a social worker involved because it may mean end of life planning, or grief support, which leads to denial or disbelief that their child is dying.

Participant 7 stated:

> It's very variable. I’ve had some families who are very welcoming. We’ve had some families who are not very welcoming who kind of want the help and want the service, but they’re just generally angry at the world, which why wouldn’t you be it’s completely understandable so they’re kind of torn between these 2, between knowing that their child has a terminal illness and wanting assistance, but also wanting them to live, and not wanting to need you there. (Participant 7, May 2022).

Additionally, Participant 2 shared that some of the families mix responses to having a social worker when introduced to hospice can be due to cultural factors.

> I think a lot of times, families based on their culture, they might want to do everything. To them, you don’t start treatment like, only you know, God is able to make that decision, and so they don’t sign the DNR. They want it to be full code and we respect that. And again, we just provide education. So a lot of times cultural reasons might be a reason why somebody's like ambivalent about it, or just seeing hospice in a negative way. (Participant 2, March 2022).

Furthermore, although on occasion, families may have a difficult time accepting hospice and bringing a medical social worker on board, according to responses from participants, some families have a positive welcome.

Participant 5 stated:

> They are very thankful for it. They're very aware, this mother yesterday was like it's so very difficult because there aren't a lot of people you can identify with, not a lot of other people well-meaning friends and families don't know what you're going through.

In support, Participant 10 shared:

> They love us. Yeah, I have parents at new referral who like we've seen them once. We haven't even really done anything but they're like where have you been? Why haven't I heard of you before like that's very common.

Positive Impact. Medical social work involvement in pediatric hospice care can contribute a variety of services for the patient and the family as a whole. Hospice medical social workers provide the necessary time to help a family understand the meaning of having their child start hospice, provide necessary resources to alleviate additional stress, be an emotional support professional, contribute to assisting the family with final meaningful memories, and making sure the patient has a longer quality of life.

Participant 11 shared on the importance of assisting the family in navigating hope with acceptance:

> So we usually see a lot of progress just like the acceptance. They’re still holding on to hope. Hope is always going to be there, but just the acceptance of where they’re at, and how to integrate this moment into creating memories and to learn new coping skills and being able to find peace still at the end of life. (Participant 11, June 2022).

Additionally, Participant 8 shared their own patient story and the contribution that they had to the patient’s quality of life that was reflected as a positive impact by empowering the patient and allowing the patient to find their voice, stating:

> I think of one of my teenagers, she was 16 years old. And I think being a typical 16-year-old she wanted her voice heard. And mom and dad were divorced so she was going back and forth between two households, which that was hard to navigate and when I would speak to her she's like I just feel like I’m kind of getting lost in the shuffle and you know my mom is technically my medical power of attorney because I am a minor but then mom and dad disagree on something and they don't even ask me what I might want. So, in terms of that case, in particular, I would say, progress was I worked with that family and identifying that hey she's very much a part of this care that we're providing. You know, her voice needs to be heard and I’m going to speak directly towards her because she deserves to have her voice she's already losing so much, that she deserves this little piece of control. And the progression that I saw within that family after kind of putting that truth out there was pretty amazing. So not necessarily

> your typical progress with health but with quality of life. (Participant 8, May 2022).

Summary

In addition to the themes found an individual example of the response social workers receive from patients and families was presented by participant 9:

> He was a 17-year-old teenager, and he had a very, very rare form of cancer. I was very lucky that the family appreciated my support, and so my team, the chaplain, myself, and the nurse took a team approach, in meeting with the family, Quality of life was very important to this child. He was autistic, so it made it very difficult for us to be able to kind of know what he understood about his disease progress. And actually, we were able to understand that more through an aid respite, where an aid was present with the patient and he had mentioned he didn't want to die alone. So it was after that we had realized that he understands more of what's going on, and we were able to explore those things given that he did have those intellectual deficits, and then also he had been at children's hospital for years and years and years on and off he I didn't wanna go go back there. He wanted to stay at home, so we're able to bring the care to him. He was able to continue with zoom meetings with his fellow classmates and then I was able. He really wanted to go to the Wolf, the Great Wolf lodge, and I was able to get him to a local water park arcade. Golf course.

> it's a fun place called jds and outing with this family, and we got to participate in that as well with him, and about 2 weeks later he passed. (Participant 9, May 2022).

The study’s results of 11 participants’ individual interviews concluded themes that were gathered based on data analysis which include: social worker’s role as a case manager, social workers as an interdisciplinary team member, and the social worker role within the family system which were all discussed in this chapter. Co-facilitators used direct quotes that participants shared during the individual interviews in support of the presenting evidence. The approach that was utilized is qualitative, with the use of constant comparative and thematic analysis. Additionally, the demographic information that was collected through a short questionnaire survey utilizing Qualtrics Survey was presented.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter will discuss the results and a further analysis of the results that were concluded upon the completion of the research study. The analysis will discuss whether the results supported the research question. The discussion section will include a comparison of the current literature review, whether the results are in support of the results. The following section of this chapter will identify recommendations for social work practice, policy, and future research. This chapter will conclude with a conclusion that will explore the process and the results of the study.

Discussion

The purpose of this research study was to examine the importance of social work involvement in hospice care transitions for ill children and their families. The study analyzed the responses of medical social workers who have previously or currently work in a hospice care program/facility with ill children. The results of this research study highlighted the significance of social work involvement in hospice care transitions for ill children and their families. The findings emphasized how significant the social worker's role as a case manager, the social worker role as an interdisciplinary team member and the social worker role within the family system and how the roles positively impacted the ill child and their family. Hospice social workers fulfill many roles such as utilizing their unique skills by connecting ill children and their families to resources and providing mental health services. The services provided by the skilled social workers demonstrate the need of social work services to ensure that the families' have the support when going through the end-of-life process with their ill child. The results evidently support the research question, as the data provides responses from participants that have direct involvement in hospice care with ill children and their families'.

In addition, the results also support the findings of the studies that were previously discussed. As the results indicate, in agreement with Gerbino (2014) social work involvement is significant as it is vital support for the families, as well as networking the families and ill child to the resources needed to meet their needs (Gerbino, 2014). This study demonstrated that social workers are resourceful and connect ill children and their families' to respite care, transportation for the ill child when needed and other resources such as Make a Wish and Rainbow Connections. Furthermore, the study conducted by Bosma et al., (2010) also supports the study's findings as it concluded that hospice social workers provide for patients and their families being that hospice social workers bring the expertise onboard when they evaluate the needs of the patient and their families', prepare a care plan and refer the families' to the necessary resources and agencies (Bosma et al., 2010). The study's findings support Bosma et al., (2010) as the findings state that social workers utilize their unique skills to educate the families' about the program, support the family as a whole by advocating for them and being their voice. In addition, the findings of the Gabino (2014) study discussed that a social worker's role is imperative as they educate the patient and the family about the end-of-life process, while providing mental and emotional support, which is consistent with the findings of the study conducted (Gerbino, 2014). The study's conclusion is consistent with the study conducted by, as Forbair et al., (2009) and Gerbino (2014) discuss in their study and has been demonstrated in our findings, although hospice care interdisciplinary teams consist of numerous medical professionals compared to the number of social workers, social workers continue to fulfill a significant role in medical settings as the outcome of the study discussed that social workers collaborate with the interdisciplinary team to be the voice of the ill child and their family and also provide a psychosocial perspective (Fobair et al., 2009; Gerbino, 2014).

Recommendations for Social Work Practice, Policy, and Research

Social Work Practice

Social work professionals are required to honor the NASW code of ethics, which encourages social workers to follow 6 core values: service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence (NASW, 2021). Social workers carry a responsibility to clients to ensure that all 6 values are being utilized in their service.

All 6 of the core values social workers practice are highly required in pediatric hospice care in order to provide quality care not only to the patient but to the family as well. Medical social workers are advocates to medical patients and with the use of NASW code of ethics are able to confront limitations and barriers that some families may undergo. Utilizing and honoring the 6 core values ensures that all patients are served with integrity and justice. As advocates, social workers ensure that patients are treated with respect, receive quality service, and are not faced with discrimination. Social workers also have the role of case managers, and through this title are able to provide necessary resources to the patient and their families' and be able to connect the patient to better opportunities for a better quality of life and ensure that there is no unequal distribution of resources.

Social workers are culturally responsive and provide service that is appropriate. Through cultural humility, social workers are able to serve patients and families that struggle with language limitations and take into consideration cultural factors when serving the patient and their families when in the care of hospice. Families that struggle with language barriers are able to have a social work professional that can assist them with communication, documentation, and education that can alleviate the experience of having their child go through end-of-life treatment.

Macro Social Work Changes

A macro change that can be encouraged is outreach and education to the community in order to dismantle the stigma that exists within hospice care and the link of social work involvement. One of the findings that was identified during the study was the hesitation that may sometimes come up from the family of the patient when introduced to the hospice social worker. Implementing more advocacy within the community and a plan of action that can introduce medical social workers into hospice care at an earlier stage in the pediatric patient’s treatment can help with allowing the patient and their family to understand the role of the medical social worker. This can assist in clarifying any uncertainties and concerns for the patient and their families.

Research

The expansion on this topic of study is greatly necessary. Hospice care has limited research, and with a greater emphasis on pediatrics. It is important to continue researching on this topic to expand on insight from hospice professionals and patients in order to better serve the community. It would be beneficial for future studies to explore the perspective of pediatric patient’s families’ experience with working with hospice social workers. This will help social work hospice research have a better understanding of the needs, and experiences of these families, and expand the knowledge of the importance of social work involvement in hospice care.

Limitations

Despite the consistency among the study conducted and the studies utilized in the literature, there were some limitations as the co-facilitators concluded that there are not many social workers who have experience in working in pediatric hospice care. The scarcity of pediatric hospice social workers made it challenging to recruit participants and there was a limited number of social workers with pediatric hospice care experience. A suggestion for future research is to utilize a different method to recruit participants rather than the snowball method. The use of a direct method, possibly obtaining written permission from pediatric hospice organizations to interview their social workers would make participant recruitment more attainable.

Conclusion

The purpose of this research was to determine the importance of social work involvement in hospice care transitions for ill children and their families. Through this study, co facilitators conducted individual interviews with medical social workers and gathered supporting evidence that determined the need for social workers in this setting. This study was able to expand on previous literature on the significant contribution of medical social workers' positive impact to pediatric patients and their families. This studies’ evidence concluded, medical social workers provide significant support, resources, and mental health services with their unique role as case manager. Additionally, medical social workers are an important component to the medical interdisciplinary team and contribute to collaboration with other medical professionals to provide quality treatment and service to the patient.

APPENDIX A

INTERVIEW QUESTION GUIDE

- WHAT IS YOUR ROLE AS A MEDICAL SOCIAL WORKER WHO WORKS WITH ILL CHILDREN UNDER THE CARE OF HOSPICE?
- BASED ON YOUR OBSERVATION, DO YOU NOTICE POSITIVE CHANGES WHEN A CHILD AND THEIR FAMILY RECEIVE PALLIATIVE/HOSPICE CARE? PLEASE EXPLAIN.
- DO PATIENTS AND FAMILIES GET RESOURCES OFFERED TO THEM WHEN IN THE CARE OF HOSPICE OR PALLIATIVE CARE, IF SO, HOW OFTEN? WHAT TYPE OF RESOURCES ARE AVAILABLE?
- IS THERE A DIFFERENCE IN HEALTH PROGRESSION WHEN A CHILD RECEIVES PALLIATIVE CARE? PLEASE ELABORATE.
- HOW HAVE THE CHILDREN’S FAMILIES RESPONDED TO HOSPICE/PALLIATIVE CARE, BASED ON YOUR EXPERIENCE?
- TELL ME ABOUT A TIME WHEN YOU PROVIDED HOSPICE CARE SERVICES TO AN ILL CHILD AND THEIR FAMILY AND SAW PROGRESS. WHAT TYPE OF PROGRESS DID YOU SEE?
- DESCRIBE A TIME WHERE YOUR UNIQUE SKILLS/KNOWLEDGE BENEFITED THE PATIENT GOING THROUGH END-OF-LIFE CARE.
- AS A MEDICAL SOCIAL WORKER HOW HAVE YOU MADE AN IMPACT, WHETHER IT IS POSITIVE OR NEGATIVE, ON THIS SPECIFIC POPULATION?

- DESCRIBE HOW YOU AND THE INTERDISCIPLINARY TEAM COLLABORATE TO SERVE THE ILL PATIENT AND THE FAMILY'S NEEDS.
- FROM REPORTS OF FAMILIES, WHAT ARE THE BENEFITS OF HAVING A MEDICAL SOCIAL WORKER AS PART OF THE PATIENT'S CARE TEAM?

Demographic Questions

- WHAT GENDER DO YOU IDENTIFY AS?
- WHAT IS YOUR AGE?
- PLEASE SPECIFY YOUR ETHNICITY.
- WHAT UNIVERSITY DID YOU GRADUATE WITH YOUR MSW?
- ARE YOU CURRENTLY EMPLOYED AS A MEDICAL SOCIAL WORKER, IF SO, WHERE? PLEASE SPECIFY COUNTY AND ORGANIZATION.
- HOW MANY YEARS HAVE YOU BEEN IN THE FIELD OF MEDICAL SOCIAL WORK, IN A HOSPICE CARE SETTING?

The interview question guide was developed by Natalie Rodas and Guillermina Morales.

APPENDIX B

IRB APPROVAL

IRB #: IRB-FY2022-45

Title: The Importance of Social Work Involvement in Hospice Care Transitions for Ill Children Creation Date: 9-8-2021

End Date:

Status: Approved

Principal Investigator: Carolyn McAllister

Review Board: Main IRB Designated Reviewers for School of Social Work

APPENDIX C

INFORMED CONSENT

INFORMED CONSENT

The study that you are being asked to participate in is being conducted by Guillermina Morales and Natalie Rodas, both graduate students who are under the supervision of Dr. Carolyn McAllister, Director and Professor in the School of Social Work at California State University, San Bernardino (CSUSB). The study intends to highlight the importance of social work involvement in hospice/palliative care transitions for ill children and their families and help strengthen the research on this specific topic. The study has been approved by California State University, San Bernardino Institutional Review Board.

PURPOSE: The purpose of the study is to assess the importance of social work involvement in hospice/palliative care transitions for ill children and their families and to strengthen the understanding of the need for social work involvement in interdisciplinary teams.

DESCRIPTION: Participants will be interviewed via Zoom. During the interview, participants will be asked questions that touch basis on their roles as a Medical Social Worker, observations in patient's health progression, positive/negative changes observed in patients, availability of resources, how Medical Social Workers impact this specific population, and demographic questions.

PARTICIPATION: Your participation in our research study is completely voluntary. You may refuse to participate in the study at any time without any consequences.

CONFIDENTIALITY: All your responses will remain confidential, as all identifiable information will be removed.

DURATION: The duration of the interview will be about 30 to 40 minutes and it will be scheduled with you to accommodate your schedule.

RISKS: There is minimal to no risk that is anticipated, as some questions may require participants to think back to sensitive patient cases. You will have the ability to skip any questions that may be triggering.

BENEFITS: There will not be any direct benefits to the participants. However, findings from the study will contribute to our knowledge in this area of research.

CONTACT: If you have any questions about this study, please feel free to contact Dr. McAllister at cmcallis@csusb.edu.

RESULTS: Results of the study can be obtained from the Pfau Library ScholarWorks database (http://scholarworks.lib.csusb.edu/) at California State University, San Bernardino after July 2023.

APPENDIX D

DEBRIEFING STATEMENT

The study you have just completed was intended to examine the importance of social work involvement in hospice care transitions for ill children and their families. Co-Investigators are interested in expanding research on the involvement of social work in a pediatric medical team and bring awareness to the need of social workers in pediatrics hospice care.

Thank you for your participation in this study. If you have any questions regarding the study, please contact Natalie Rodas, Guillermina Morales, Co-Investigators, or Dr. Carolyn McAllister at cmcallis@csusb.edu. If you would like to review the study’s results, please contact Dr. McAllister after May 2023.

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ASSIGNED RESPONSIBILITIES

This was a two-person project where authors collaborated throughout and completed each responsibility as a joint effort. Therefore, the responsibilities listed below were all completed jointly.

1. Data Collection: Joint Effort
2. Data Entry and Analysis: Joint Effort
3. Writing Report and Presentation of Findings:
    a. Introduction and Literature: Joint Effort
    b. Methods: Joint Effort
    c. Results: Joint Effort
    d. Discussion: Joint Effort