

Communication with Advanced Cancer Patients: Hospital Social Workers' Experiences and
Observations

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By

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ABSTRACT

The purpose of this study was to understand hospital social workers' stories of supporting patients with advanced cancer. I used a narrative approach and interviewed three hospital social workers employed with Hamilton Health Sciences about their experiences of speaking with patients about their needs, concerns, hopes, and fears. The interviews also explored social workers' involvement in, and observations of, other professionals' conversations with patients about diagnosis, prognosis, treatment, and palliative care. Each interview raised a unique aspect of communication with patients with advanced cancer. In my analysis, I explore the 'mode' of communication each social worker highlighted: sitting (which included being present and spending time), being direct and diplomatic, and preparing patients. In the discussion section, I look across all three interviews and consider how the need for psychosocial support and the institutional context played a role in their communication. For future research, it would be beneficial to have multiple points of contact with the participants, extend this work beyond the hospital, and explore the identities of the participants to achieve a deeper understanding of the range and essence of communicating with advanced cancer patients.

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CHAPTER 1: INTRODUCTION

According to the Canadian Cancer Society, an estimated 641 Canadians were diagnosed with cancer every day, and 233 died (Canadian Cancer Statistics Advisory Committee, 2021). Cancer has become the leading cause of death in Canada and is responsible for 28.2% of all deaths (Canadian Cancer Statistics Advisory Committee, 2021). Where the medical condition is advanced cancer, death is almost certain (Gawande, 2022). It is evident that conversations about cancer occur daily and conversations around it are never easy to have. These conversations can involve more than just the doctor and patient, but also family members, other physicians, specialists, allied healthcare team members, and social workers.

The purpose of my study was to understand hospital social workers' stories of supporting patients with advanced cancer. This study explored social workers' experiences of speaking with patients about their needs, concerns, hopes, and fears. It also explored social workers' involvement in, and observations of, other professionals' conversations with patients about diagnosis, prognosis, treatment, and palliative care. Through these interviews, I explored the 'mode' of communication each social worker highlighted: sitting (which included being present and spending time), being direct and diplomatic, and preparing patients. With a narrative lens, I analyzed each aspect individually and the intersection of them.

This study will contribute to the existing bodies of research that surround hospital social workers, communication, and advanced cancer (where cancer is not curable) (Canadian Cancer Statistics Advisory Committee, 2021). In general, research shows that healthcare providers have difficulty delivering bad news and having end of life conversations (Marcus and Mott, 2014; Periyakoli et al., 2015). Studies also emphasize the importance of these conversations for

patients and caregivers; McQuellon and Cowan, for example, suggest that authenticity from the care provider can illuminate the meaning of life for patients and caregivers as they enter this, what could be terrifying, new stage together (2000). Another study found that there is a consensus among social workers that they play an important role in promoting and implementing advanced care planning, making it part of their duty and responsibility as they support patients at the end of life (Wang et al., 2018).

As most of the literature is focused on physicians and nurses, or is generalized towards all terminally ill patients, I hope for my research to fill some gaps within the social work specific realm and create space for their experiences and observations to be heard within their work with advanced cancer patients. I am especially interested in contributing with the use of a narrative methodology as social workers hear the narratives of their patients often, I use that framework to hear the stories of social workers and how they approach communication with advanced cancer patients.

This topic interests me due to my own lived experiences. When I was 11, my dad was diagnosed with a rare type of sarcoma cancer. Although I was not present during the diagnosis, he had written about his cancer journey in a journal which I was able to read through after his passing. In his journal was the following excerpt: “Thursday June 2nd, 2011. 4:00 pm - Dr.X called home and broke the news to Ancy [wife] that I had cancer - soft tissue sarcoma. 6:30 pm - Ancy told me the news crying. 7:00 pm - Dr.X called me and discussed the results and recommended to see an oncologist right away. I held up okay thinking a surgery, radiation, and chemo should take care of this. I didn’t break down, I guess it really didn't sink in”. “Friday June 3rd - Went to work. Went to Tim Hortons, got lunch. Pulled into a parking lot. Cried for the 1st time - “Why me?” Couldn’t find any answers”. “Saturday June 4th - ... Cried for a second time

in the night thinking of Ancy and Joshua - I know the rest of the family would be able to take care of themselves without me. But not Ancy and Joshua. I wanted to live longer for them. The thought of Ancy becoming a widow and Josh without a father is really killing me. Several thoughts crossed my mind but finally I put aside all those thoughts to calm my mind”.

In my dad’s case, I wonder: Why was my mom informed of my dad’s cancer diagnosis before my dad was? Was the social worker informed of his case? If not, why was there no social worker involved? If so, in what ways was the social worker involved in the conversation around diagnosis, prognosis, and treatment? How could the involvement of a social worker better support my dad through his thoughts of the diagnosis?

In the third year of my Bachelor of Social Work, my placement was at Juravinski Hospital on the oncology ward (C3), the same floor that my dad was in and out of during his cancer journey. This felt like a surreal moment to have once been a visitor on this floor to see my dad, and now being in the position of supporting both patients and visitors. During my placement, I was part of a few conversations that covered diagnosis, prognosis, treatment options, and palliative care in which my role was to shadow the social worker and document the conversation. It was from these experiences that I realized how important the role of the social worker is and the weight they hold in supporting these conversations. I also noticed the various factors that impact these conversations such as the pressure to discharge or the high caseloads which both lead to rushed or incomplete conversations. More specifically, my experiences in this placement ranged from supporting patients through their decision of Medical Assistance in Dying, supporting in conversations of moving to St. Peters Palliative Care Hospital, and having challenging conversations around treatment options with family members involved. This research is relevant to social work as it provides the space for hospital social worker stories to be

shared and possibly create some change and shifts in their role. I am hopeful that my research could help other social workers who are in similar positions feel acknowledged, validated, and seen as they support in the difficulties of these conversations.

CHAPTER 2: LITERATURE REVIEW

In discussions about important aspects of communication with patients diagnosed with advanced cancer, issues of prognosis and treatment decision making often come to the fore. However, there is a larger part of this conversation which is supporting patients in the overwhelming anxiety around death, suffering, loved ones, and finances - all of which are real terrors and worries (Gawande, 2022). As death is a one-time experience and patients often do not know what to expect, they expect healthcare professionals to say what they have seen, to work through the worries patients have, and to help prepare patients for what is to come (Gawande, 2022). Yet advanced cancer patients are oftentimes left in precariousness as they have to make important decisions about their treatment, care, and family life, which can be quite difficult (Lewis et al., 2021). In 2008, the National Coping with Cancer project published a study which found that two-thirds of terminal-cancer patient participants had reported no discussion with their doctor around goals for end-of-life care despite being only four months, on average, away from death (Gawande, 2022). It was found that those who did have substantive conversations with their doctors about their goals for end-of-life were more likely to die at peace, feeling more in control of their situation (Gawande, 2022). Evidently, these conversations with advanced cancer patients are important to have as helpful communication from healthcare professionals is powerfully important during this emotionally traumatic time (Thorne et al., 2010). Hospital

social workers have been identified as a profession commonly involved in supporting patients to feel some measure of personal control in situations where they might feel powerless (Miller et al., 2007).

As a result, I have focused this literature review on three components, (1) advanced cancer, (2) communication, and (3) hospital social workers, and how the three of them intersected to create my research purpose, which was to understand hospital social workers' stories of supporting patients with advanced cancer. This study explored social workers' experiences of speaking with patients about their needs, concerns, hopes, and fears. It also explored social workers' involvement in, and observations of, other professionals' conversations with patients about diagnosis, prognosis, treatment, and palliative care.

Advanced Cancer

Advanced cancer is defined as “cancer that is unlikely to be cured or controlled with treatment” and “is also called end-stage cancer or terminal cancer” (National Cancer Institute, n.d.). There is a real paradox to being diagnosed with advanced cancer where patients are given some hope in the form of treatments and told to be positive while also being told to be realistic (Broom and Kenny, 2021). Many utilize behavioral and cognitive ways to deal with the distress even though there is little to nothing that can be done to change the reality, that is, their life-threatening illness (Salander et al., 1996). An advanced cancer diagnosis creates a disruption in everyday life, and some try to avoid the information, avoid vital questions about the future, to protect their hope (Salander et al., 1996). Others attempt to stay positive by talking to a friend for example who had advanced cancer and is doing well after many years, providing the hope that the doctor could not provide (Salander et al., 1996). This push for positivity creates this

protection and hope and ultimately supports in the creation of their own illusion of reality (Salander et al., 1996).

When facing advanced cancer, patients oftentimes turn to their family and to spirituality (Salander et al, 1996). They relate and find protection through a system of faith that can bring meaning to their diagnosis (Salander et al., 1996). Oftentimes, social workers and other medical professionals avoid the conversation of spirituality as they might worry it is too personal or feel inadequate to talk about it (Carr and Morris, 1996). However, social workers can integrate spiritual assessments into their regular practice as an aspect of the patient's coping especially since some patients depend on their spirituality or return to it to seek new meanings to life (Carr and Morris, 1996). Further, patients' search for why they have been diagnosed with cancer can often lead to the conversation of God's will for them or their punishment for doing something bad (Carr and Morris, 1996). Also, they sometimes see their diagnosis as something that was meant to be, an opportunity per se to demonstrate their deservingness of a cure and to be the statistical outlier (Broom and Kenny, 2021).

On the contrary, the diagnosis of advanced cancer also calls for the choice as to what steps the patient wants to take. This poses the debate that many patients have with themselves in regard to pursuing, what is oftentimes difficult and indefinite treatment or attempting to live with the cancer; a constant juggle between wanting longevity, survival, and maintaining their quality of life (Lewis et al., 2021). It can be one of the most difficult tasks as a physician even to support in the conversation of what constitutes as a good quality of life and what is the limit to when treatment should discontinue (Marcus and Mott, 2014). Studies have shown that patients may lean towards certain choices because of what is valued or expected in Western society such as choosing treatment options that pursue longevity rather than other options such as Medical

Assistance in Dying (Lewis et al., 2021). Often, these conversations are seen as taboo which left patients making these decisions alone and privately, creating much distress in the unforeseeable effects of their decision (Lewis et al., 2021). For many, the decision they make is often in the interest of their family members and friends even if it increases their own suffering, specifically women, who frame their decisions around the need to protect partners, children, and parents which links to their identity as mothers, partners, and/or caregivers (Lewis et al., 2021).

Communication

As said previously, an advanced cancer diagnosis is typically a time of emotional turmoil for patients (Thorne et al., 2010). The way that healthcare professionals communicate these heavy pieces of information is powerfully important as it truly sets the stage for how the illness will be experienced (Thorne et al., 2010). Furthermore, a study by Marcus and Mott (2014) reviewed the literature around communication in multidisciplinary medical care and the findings showed how the psychosocial problems which are created or exacerbated by cancer, such as depression, can be effectively addressed if healthcare professionals used communication skills influenced by psychosocial interventions. Patients found that the communication used around diagnosis, treatment, and prognosis impacts their framing for what is to come (Marcus and Mott, 2014). There are a few basic components for healthcare professionals to keep in mind when conversing with cancer patients: “(1) be prepared by knowing the disease, its natural course, and treatments that have been given; (2) find out what the patient and family know; (3) secure an invitation to discuss these matters and fire a warning shot to prepare the patient for the discussion that is to follow; (4) provide the important facts the patient and family need to know with an appropriate manner and language; (5) deal with the emotions that this information occasions; and (6) have a plan” (Marcus and Mott, 2014, p. 714).

However, there are also many challenges and barriers to good communication. Although there are various strategies and techniques that could be used, it is found that there is little to no formal training for those communication skills (Marcus and Mott, 2014). As a matter of fact, miscommunication is quite common among staff, family, and patients which negatively impacts the patients' care and quality of life (Marcus and Mott, 2014). In addition, there are various communication challenges such as "demands from patients' relatives, intense emotions, troublesome doctor-patient relationships, insufficient clarification of patients' problems, promises that cannot be kept, feelings of helplessness, too close involvement, and insufficient anticipation of various scenarios" (Marcus and Mott, 2014, p. 713).

With that in mind, it is important to consider how social workers can engage with patients with a level of communication that follows a professional demeanor, involves receptivity, includes terminological sensitivity, has attention to time and space, and considers emotional well-being (Thorne et al., 2010). Patients have stated that they attend to the demeanor of the healthcare professional for signs of attentiveness and compassion and find comfort in interacting with those who are able to model an interactional environment which fits the tone of the conversation (Thorne et al., 2010). Patients also valued that although the healthcare professional may have experience with delivering bad news, they valued an individualistic approach that took into consideration their own needs and preferences as the patient (Thorne et al., 2010). In addition, patients reported that the terminological choices used by the healthcare professional made a significant impact in their capacity to understand what was being told and offered them the opportunity to seek clarity (Thorne et al., 2010). Lastly, patients valued that healthcare professionals were able to make judgment as to how much information they were able to handle and made sure that the patient was not being rushed to absorb all the news but was mindful of

their wellbeing during these highly sensitive interactions (Thorne et al., 2010). Although there is no one right way to have perfect communication with patients, these are a few basics that patients valued in conversations around their cancer illness with healthcare professionals.

Hospital Social Workers

Many think the role of a hospital social worker is to request referrals, fill home placement applications for example, and complete tasks that are usually straightforward, but the role is very far from that (Wilder Craig, 2007). Hospital social workers are key professionals that support patients and families with their skills in communication, negotiation, and advocacy (Wang et al., 2018). Oftentimes, nurses are the ones who request social work involvement based on their first few interactions with the patient (Wang et al., 2018). Many social workers are educated and skilled in areas of psycho-socio-spiritual interventions which aid in their capacity to provide support (Wang et al., 2018). Further, narratives play a big part of their role as they hear stories from patients, recite those stories within assessments for example, and ultimately build their own story as a social worker through their support of patients (Wilder Craig, 2007).

Cancer patients are often overwhelmed in the beginning stages of their illness with information such as their diagnosis, prognosis, treatment options, etc. and are usually left with several questions (Miller et al., 2007). Although many medical staff are prepared to address those questions and concerns, they are typically not trained in providing guidance in areas of community resources, emotional support, financial or legal support, support for their family members, etc. which is where hospital social workers step in (Miller et al., 2007). In the Miller et al. study, it was shown that integrating hospital social workers as a member of the healthcare team provides many benefits (2007). Hospital social workers are present to provide that

professional guidance which supports the patient in feeling some measure of personal control in situations where they might feel powerless (Miller et al., 2007). Generally, there are three areas that hospital social workers play a role, specifically with patients who are dying: (1) providing psychosocial support to the patients and their families, (2) supporting the patient in their advanced care planning or in their formulation of advanced directives, and (3) providing both anticipatory and grief counseling for the family members of the patient (Wang et al., 2018). As many patients are unable to identify what their unmet needs are, social workers are able to support in reviewing specific topics with the patient such as advanced directives and community resources, and contribute to the overall improvement of the quality of life for patients with advanced cancer (Miller et al., 2007).

One of those benefits is that when hospital social workers initiate conversation with patients around advance directives for example and provide some education on such topics, patients may feel enabled to create dialogue with their physicians in more meaningful ways (Miller et al., 2007). Since hospital social workers are often more familiar with their patient's wishes and needs, they play a major role in advanced care planning and are committed to respecting, valuing, and empowering patients through, what are oftentimes challenging conversations (Wang et al., 2018). A 2018 study by Wang and colleagues, one that is especially relevant to my thesis, reviewed research papers that revolved around advanced care planning and its relation to social workers. They found that hospital social workers feel a level of responsibility in implementing advanced care planning through their everyday duties of advocating for their patients, facilitating communication, engaging in conflict resolution, initiating those discussions, and documenting those discussions (Wang et al., 2018).

Furthermore, the end of life can bring about many emotions, feelings, opinions, and thoughts for the family members and the patients, which could result in conflict. Three quarters of hospital social workers who participated in Wang et al.'s study have had to engage in conflict resolution with families (Wang et al., 2018). In addition, almost all hospital social workers indicated that they had experienced at least one situation in which the family requested something different from what the patient had wanted and/or written in their advanced directives (Wang, et al., 2018). Social workers working in the hospital are "more likely to report encountering patient and family conflict regarding treatment decisions, difficulty in communicating with the patient and family, and lack of adequate guidance from medical professionals" (Wang et al., 2018, p. 16). Therefore, hospital social workers play a major role in conflict management, specifically within families during the end of life.

The intersection

Studies have shown that the inclusion and representation of hospital social workers in the healthcare team makes a significantly positive impact on patients (Miller et al., 2007). As patients have to make big decisions such as the next steps they want to take in their advanced cancer, they often turn to hospital social workers who can provide that professional guidance, without providing an answer for them, but support them in making decisions (Miller et al., 2007). It is with the communication skills of hospital social workers that they are able to build connections and support advanced cancer patients through difficult conversations (Wang et al., 2018). Through their multidisciplinary intervention approaches, social workers make meaningful improvements in the quality of life of their patients (Miller et al., 2007). Their conversations with patients even encourage the patients to create more dialogue with their doctors and find ways to engage meaningfully (Miller et al., 2007). The way that hospital social workers, and all

healthcare professionals, communicate on difficult topics such as diagnosis, treatment, and prognosis creates a framework that impacts the patient in how they move forward, and how they live with their illness (Marcus and Mott, 2014).

My research

In this thesis, I explored hospital social workers' experiences in supporting advanced cancer patients, specifically their conversations around their needs, concerns, hopes, and fears. I explored social workers' involvement in, and observations of, other professionals' conversations with patients about diagnosis, prognosis, treatment, and palliative care. This current literature reviewed has spoken to the importance and role of hospital social workers, some of the emotions and events that advanced cancer patients go through, as well as the impact of communication within medical settings. However, in my research study, I have used a narrative inquiry approach to hear, understand, and analyze the stories that were shared, and specifically delved into the intersection of hospital social workers, communication, and advanced cancer more deeply.

CHAPTER 3: METHODS AND METHODOLOGY

For my thesis, I used a narrative inquiry approach to hear the stories and experiences of hospital social workers in their communication with advanced cancer patients. In this section of my thesis, I will analyze the assumptions of narrative inquiry, specifically the form advocated by Jean Clandinin, a Canadian scholar known for her contributions to developing and defining narrative research. I discuss how narrative inquiry has framed my questions, the implications for data collection and analysis, and any limitations.

Approach to the Study: Theory, Methodology and Methods

Narrative inquiry as described by Clandinin (2016) not only hears the stories, but understands and studies the stories as experiences, creating a distinction between narrative inquiry and forms of narration framed by other philosophical stances. Narrative inquiry was inspired and developed by the human experience and how stories are lived through individual and societal perspectives (Clandinin, 2016). For many researchers, narratives are seen as a form of representational data: narratives are a way to make data “more compelling” (Clandinin, 2016). However, this assumption of narrative inquiry being a way of only representing data is limited. Clandinin argues that narrative inquiry is continually working from a relational ontology which is a fundamental aspect of the methodology (Clandinin, 2016).

In addition, narrative inquiry understands continuity as an ontological matter (Clandinin, 2016). It is understood that experiences are continuous, and the view of continuity has implications for how we think about the inquiry itself (Clandinin, 2016). Clandinin explains that inquiry is itself within a stream of experience which generates new relations and becomes part of the future experience in a continuum (Clandinin, 2016). On a similar wave, narrative inquiry adapts a view of experience as composed, something that is lived over time, making it understood as a narrative phenomenon (Clandinin, 2016).

Lastly, narrative inquiry has an ontological emphasis on the social dimension of our inquiries. The stories that we share, the narratives, are all influenced in some capacity by the social aspects of our inner life which could include our environment and/or personal history (Clandinin, 2016).

For Clandinin, the ideal for narrative inquiry is to create a new relationship between the human being and their environment, one that is less overwhelming and oppressive in their relation to their life, community, and the world (Clandinin, 2016).

With that, I can align my own ontological perspectives with narrative inquiry as I honour multiple truths, holding the belief that multiple realities exist, which is evident through the stories of individuals. This also connects to my epistemological perspective of how knowledge and data are generated and the importance of recognizing people's stories as legitimate forms of knowledge that must be acknowledged which narrative inquiry does.

For my thesis, the title that I chose is *Communication with Advanced Cancer Patients: Hospital Social Workers' Experiences and Observations*. The purpose of my study was to understand hospital social workers' stories of supporting patients with advanced cancer. This study explored social workers' experiences of speaking with patients about their needs, concerns, hopes, and fears. It also explored social workers' involvement in, and observations of, other professionals' conversations with patients about diagnosis, prognosis, treatment, and palliative care.

Narrative inquiry connects to my research questions and objectives that I have articulated in a number of ways. To illustrate, narrative researchers question the relationship between narratives, truth, and reality, and see that relationship as a way to create a reflexive text (Denzin, 1997). In the context of my research question and objectives, my goals were to hear the narratives of hospital social workers, bring to light their truths of what their role is like and how they go about difficult conversations, while also bringing it down to the reality of the institution they work under and the role of the whole healthcare team in these conversations. I see this

narrative approach, in conjunction with my research objective, to create a piece of reflective text that can offer new pathways and insights about social workers' practice approaches in the advanced cancer context.

Furthermore, narrative inquiry acknowledges the value of people's stories, recognizes their strengths, and engages in meaning-making dialogue (Fraser, 2004). By doing so, it helps social workers go beyond the specific problem at hand to explore the broader, more general, social phenomena (Fraser, 2004), in this case, the complexities of social workers' engagement with people with advanced cancer.

I find narrative inquiry compelling and applicable to my research interest because as niche as my research interest is, it is broad enough to provide the space for various narratives to be shared for the purpose of hearing stories and making meaning from them rather than having a specific goal in mind. Since I am not using a goal-oriented approach or creating a thematic analysis, narrative inquiry helps keep my research question interpretive, and helps the participant engage in a dialogue that recognizes their strengths and abilities as a practitioner. Overall, I find narrative inquiry compelling because it is a methodology that recognizes how fragile truth is (Clandinin, 2016) and, with my research question in mind, narrative inquiry creates the ability to connect the participant to other social workers, healthcare professionals, patients, caregivers, grievers, and others within the advanced cancer realm.

Based on these perspectives of narrative inquiry, I conducted my research in a way that aligns with the methodology and my own research purpose. The main consideration I had to make is the nature of the questions I asked and ensuring that they were grounded within the methodology. In a narrative inquiry approach, the objective is to generate a detailed account of

the participant's story rather than brief or general statements (Riessman, 2008). The researcher should not have a firm, complete, and sequenced set of scripted questions to concretely adhere to (Mason, 2002). A qualitative interview, such as one based on narrative inquiry, is designed to have a flexible structure that allows for fluidity in the conversation with the possibility of unexpected themes and discussions to arise (Mason, 2002). In addition, narrative inquiry interviews acknowledge that it is a collaboration between the researcher and the participant over time, meaning that it should not be rushed, or goal driven, but rather intentional and paced with the understanding that it could take a few interviews (Clandinin, 2016). This also means that they work together to generate the discussion by following the rules of everyday conversation: "turn-taking, relevance, and entrance and exit talk (where a speaker transitions into, and returns from, the past time story world)" (Riessman, 2008, p.41).

Recruitment and Ethics

For this study, participants were recruited through Hamilton Health Sciences (HHS) which is a healthcare organization that services southwestern Ontario. With approval from the Hamilton Integrated Research Ethics Board (HiREB), the HHS social work professional practice lead was able to support in the recruitment process. They distributed a recruitment email which included the letter of information and consent form. Those who were interested in partaking in my study were asked to contact me by email or by phone. Once they contacted me, I answered any questions, reviewed the study with them, and found an agreed upon date and time to conduct the one-on-one Zoom interview.

In the letter of information, I outlined the steps I have taken to ensure safety and confidentiality. As these interview questions were about their experiences and stories as a

hospital social worker and supporting advanced cancer patients, it was expected that there might be some emotional difficulty in discussing those matters. They were reminded of their choice to decline in answering any of the questions asked, their option to pause the interview at any point, or their option of no longer participating in this study. However, all the participants answered all the questions and discussed the importance of this research to be done and available to the community.

In addition, there was the ethical concern of their employment status and patient information as they were sharing stories of the patients they have supported as well as the environment of their workplace and their co-workers. To mitigate this ethical concern, participants were assigned a number to be used in association with the quotes used in this research study. Also, participants were informed both in the letter of information and at the start of the interview that stories can be identifiable, however all patient and professional names along with any identifiable information will and have been removed or changed.

Participants and Interviews

I recruited three participants, all employed with HHS at the time of the interview. They were diverse in their areas of speciality, but all indicated that they have worked with advanced cancer patients.

As my participants were full-time HHS employees, I wanted to be as flexible as I could when organizing and scheduling their interviews. For that reason, I conducted all my interviews over Zoom and any other communication was done through email. I provided them with open availability so they could choose a date and time according to their availability. With consent, I recorded all Zoom interviews and transcribed them for the purposes of data analysis. My

interview questions were semi-structured to align with my theory and research purpose. I took a conversational approach to make my questions open enough for exploration and interpretation while providing a flexible structure to allow them to share as much or as little as they wanted knowing that we could reconvene. At the outset of the interview, I confirmed their employment status, the floor/ ward they worked on, and their age bracket. My interview questions are listed below:

1. Can you recall a specific story of an advanced cancer patient you have worked with?
2. Please tell me a bit about your experiences with this patient, possibly talking about their needs, concerns, hopes, and fears.
3. Can you tell me a bit about your observations of other professionals' communication with patients about diagnosis, prognosis, treatment, and/or palliative care?
4. What was your role in these conversations?
5. How did you feel mentally and emotionally while engaging in and observing these conversations?
6. If you are comfortable, could you talk about what influenced your approach, to these conversations? [your own experiences, your education, aspects of your identity, your values, and so on].

Data Analysis

Once the transcripts were completed, I began analyzing each transcript individually using the narrative guidelines of Fraser (2004). Fraser (2004) identifies that a narrative analysis “is not meant to be governed by formulas or recipes” but their guide is meant to provide support for the researcher as they explore the stories of their participants (p. 8). Although all 7 phases of

narrative analysis that Fraser discusses are important and used in some capacity in this study, phase 3, “interpreting individual transcripts”, was used heavily in the analysis stage. Phase 3 focuses on identifying the types and directions of the stories being analyzed and any contradictions (Fraser, 2004). This could look like participants either sharing stories that circle a specific theme, or stories that might sound perfectly rehearsed, or it may be a story that has never been vocalized until that moment (Fraser, 2004). Phase 3’s challenge is to disaggregate large chunks of text into smaller segments of narratives while scanning for characterization and/or chronology to segment the material (Fraser, 2004). Questions that Fraser asks us to consider in phase 3 are:

1. What are the common themes in each transcript?
2. Are there ‘main points’ that you can decipher from particular stories?
3. Where are the vocal inflections? What might they signify?
4. What words are chosen and how are they emphasized?
5. What kinds of meanings might be applied to these words?
6. What other vocalizations and non-verbal gestures are present?
7. What contradictions emerge?
8. Are there notable silences, pauses or gaps? If so, how might they be distinguished and what might they suggest (for instance, disagreement, boredom, distress)?
9. Are there any other useful ways to disaggregate the stories and lines? If so, which form of disaggregation will be used?
10. If stories are to be named as well as numbered, how are the names derived? Is the logic of this system made clear to readers?

In my own analysis, I focused less on the questions related to the ‘how’ of the storytelling, such as analyzing vocal inflections, pauses, etc. Rather, focused more on the common themes, keywords and their meanings, and the idea of naming the central story each participant told.

In addition, narratives play a big part in the role of hospital social workers as they themselves hear many stories from their patients, recite those stories for assessment or advocacy purposes for example, and ultimately build their own story as a social worker through their support of patients (Wilder Craig, 2007). Therefore, while analyzing the data, it was important to recognize that the story they have built was not only shared with me as a researcher, but also as a learner, and a future social worker and, as a result, is framed to me in that context. Consequently, it felt important to title each story in a way that captured the core message that each participant was attempting to share beneath every story. With that in mind, I began analyzing the transcripts to develop my results section.

Limitations of Methodology

Although narrative inquiry is a methodology that fits my research question, data collection, and data analysis, there are also limitations to it. The first limitation is that as much as I have in mind the actual interview with the social worker, I am more so analyzing the transcript from the interview. As Riessman argues, each transcript is only a partial representation of the speech as it excludes some and includes other features of speech and sometimes rearranges the flow of the interview (2008). Riessman continues by using the analogy of a photographer, someone who guides the viewer to use their lens and see what they see, to understand that the ways in which we display text and make decisions about the boundaries of particular narrative

segments, we are creating grounds for our argument (2008). Therefore, in my research and use of narrative inquiry, it is important to reflect on how the particular texts and quotes chosen might be shaped to my research goals and the implications of it.

A second limitation of using narrative inquiry as my methodology is the understanding that the outcome of the research is purely based on the stories of my participants which are not static. Riessman identifies that over time, the memories and meanings we put to our stories and experiences change over time, therefore we cannot make firm conclusions based only on one or a few interviews (2008). Furthermore, the participants may not even agree with the ways in which we display their talk or messaging and how we use it analytically which is why it is very important to distinguish between the researcher's views of the subject and the participants (Riessman, 2008).

In conclusion, the use of narrative inquiry as my methodology paired well with my research question and interests in several ways. Although it came with its own set of ontological and epistemological origins and assumptions, it connected with my own views and with the goals of the research. Narrative inquiry has shaped the ways in which I collect and analyze my data while recognizing that the methodology came with a few implications within the research. For me, the beauty of narrative inquiry is how it shifts away from the colonial and institutional forms of what is considered "valid research" and recognizes the value of stories and their impact in micro, meso, and macro settings. It honours the original form of research, which was through the stories and knowledge of community members, and illustrates how we can continue this method of research in our society.

CHAPTER 4: RESULTS

In this section, I attempt to convey the experiences of the hospital social workers I interviewed. From each interview, I identified a key aspect or message related to my study focus of communication with advanced cancer patients. I have arranged this analysis using the titles I gave to each participants' central story: sitting; being direct; and preparing patients.

Sitting

Participant 2 is a hospital social worker who has a wide range of experience but has predominantly supported advanced cancer patients. When interviewing participant 2, a word that was repeated multiple times was 'sitting'. Traditionally, the word 'sitting' means to physically be in a seated position for a period of time. However, as we moved through the interview, the participant's stories brought forward multiple dimensions and metaphors for sitting including the physicality of sitting, the mentality of sitting, and the relationship between sitting and knowing.

Participant 2 provided a few examples of when they would physically sit with their patients and the impact of their presence. In the first quote below, the social worker reflected on requests they have had to sit in on appointments. The second quote was part of a story about a patient who was struggling with communicating to her family her decision to request Medical Assistance in Dying (MAiD).

Patients have asked me to come to clinic with them, to just be there. They don't want me to do anything, they just want me to physically be there as a support person. I'm like "you want me to take notes?". "No, it's fine. Just sit there with me".

And so she actually had asked me to just, me and the physician, to tell her family [about her decision to request Medical Assistance in Dying (MAiD)], and so I was like, "I will help you, and you know I will sit with you, but I'm not gonna like, take them into a room and tell them". And she was okay with that. I really, like, encouraged her to [tell her

family herself]. I mean, if a patient was absolutely adamant that they didn't want to say it, we would work it out, right. But this patient she was like, "Okay, I will tell them, or I would like you to tell them in front of me" is how she initially ordered it. But then we got in the room, and she just told them.

Due to participant 2's specific ward, they usually have the ability to sit with patients throughout the day, for multiple days in a row. It is possible that since the social worker is most likely with the patient from the first day at the hospital to the last, they have a connection to them and have a desire to stay connected with them throughout their illness journey. As doctors, nurses, or other healthcare staff switch in and out throughout their time at the hospital, the social worker is normally the only staff member that stays with the patient consistently, creating a deeper bond and connection. It might be that when the social worker is physically sitting with them, the patient feels supported in the difficult decisions they have to make. It also seems like the presence of the social worker helps the patient feel grounded and safe, which shows how powerful their presence is in these conversations.

In other instances, physically sitting with a patient had a more specific purpose or goal. Participant 2 shared a story of another patient, who was difficult to engage with, and whose medical situation was quickly becoming more serious. They stated that they would attempt to have multiple conversations, but the patient would always shut down the conversation and dismiss the social worker.

He didn't really engage, didn't really have a whole lot on his mind. Didn't really like identify concerns. But he just, you know, we were cutting close to discharge, and he never was able to leave hospital. Things just kept happening. And so I remember just sitting down on his bed and just sitting with him, and I remember telling myself like, "don't let him push you out this time, just sit with him and like just push him a little bit more," and he was very clear that he felt like he couldn't do it anymore. He was feeling exhausted.

When the social worker decided to physically sit with the patient and make an effort to stay with them despite the patient's previous rebuffs, the patient was able to open up and share how they were feeling about their illness. It can be assumed that when the social worker is with the patient physically for a longer period of time, they feel more comfortable, safe, and trust them enough to be vulnerable.

Evidently, there is some importance to the physicality of sitting with patients, and it seems to be connected to their mental state as well. This social work conveyed that, when they are physically sitting with patients, patients feel comfortable and safe. To further that, participant 2 used 'sitting' in terms of being in a mental state of understanding, processing, and accepting certain pieces of information or parts of their illness.

The next quote shows the reality of what sitting in these thoughts look like and the helplessness the team sometimes feels.

And so, like a big part of what we do, is like sitting in this with people: We can't make it better, I can't make this symptom go away. It's their new reality. But I think again, like the validation, and just acknowledging like ... how many medical professionals are sitting with their patients and saying "this fucking sucks" ... So what do we do? We sit in it with people, right? We remind them they're not alone, and that no matter what they feel and what they're experiencing, we're gonna support them and help them figure it out as best as we can.

In this anecdote, participant 2 shares another approach to sitting which is the act of attending to another person's emotional wellbeing. This new reality of knowing that there is very little or nothing more than can be done medically – no more treatment options, no hope for cure or recovery, no chance of change. It means validating the difficulties of this new reality and the loss that they are feeling, along with the loss that the healthcare team is feeling. As cancer progresses,

the options of what can be done become narrower. Sitting in this space with the patient as the social worker can be difficult.

Participant 2 talks about how to balance this idea of sitting in that difficulty in the moment, knowing that tomorrow could bring other feelings, thoughts, or emotions:

Maybe what I'm saying is like really capitalizing on that duality right like, "let's sit in this together, and then maybe tomorrow we'll reach a different place".

It could be that when in practice, this means that there is no goal per se when sitting with patients, or no mental place you want to reach with them, but rather just being present with them and exploring these spaces of sitting one day at a time. For some patients, the situation might be too difficult for them and therefore it will be intolerable for them to sit in.

We had a patient recently, when the palliative team came in, completely shut down, triggered. Their trigger word is like "palliative" ...Couldn't handle it. Severe pain. Needed the palliative team involved...but absolutely not willing to sit in that at all.

The story shared here shows how the patient themselves were not able to sit in the fact that the palliative team had to be involved and certain treatments were recommended to them for their pain. Participant 2 used 'sit' here in a way to not describe their role as a social worker necessarily, but how patients themselves are not willing or able to sit in certain feelings and thoughts and how certain words can trigger them into those spaces they refuse to sit in.

Although participant 2 provided the approach of sitting being a way to attend to another person's mental wellbeing, they also use the word sitting as a way to draw a connection between the power of sitting and knowing.

Because I got to know so much more about her than just her cancer, which, again, is so unique to social work. Right? We have the opportunity to sit and get to know people.

In this statement, we can see how the participant links their engagement of sitting with the patient as a way of getting to know the patient. Used in this context, 'sitting' involves being physically close in proximity to the patient and spending time with them. They discuss how they get this opportunity, which is so unique to the profession of social work, and how by sitting with the patient, both physically and mentally, it gives them the bigger picture of who this person is.

Expanding on that point, participant 2 notes that social workers also get the opportunity to see patients throughout the day, which allow them to see patients move through their daily routines and gain insights that other healthcare professionals may not get to see.

And I think a lot of times because we are so heavily involved we're spending so much time with people and like more casual way, almost like they are not that they're more honest with us, but we just see them in a different way. The doctors in and out, right, like maybe 10 min. But we get to sit with them. We see them throughout the day. We see how they mobilize. Like we just get to know them in a more holistic way. I think we can sometimes pick up on those changes that are happening that maybe the labs aren't showing, or you kind of have to really know the person to witness it. So we're like, we're able to sort of instigate and initiate those conversations or ask the doctors to look into something more, because we're seeing it in a different way.

Here, this participant compares how scans or labs may show very specific aspects of the patient's illness, and the doctor usually does not get the opportunity to spend more than 10 minutes with patient, and both examples are to show the unique and more comprehensive understanding that social workers may have about a patient. Social workers get to see the patient throughout the day, sit with them for a long period of time, and get to know them holistically. Due to their engagement of sitting with the patient, they get this deeper understanding of the patient and see physical and medical changes in them. Similar to family members, social workers observe the patient by the bedside and get those critical pieces of the patient's physical wellbeing and bring those observations to the medical team and advocate for possible additional or different care.

Lastly, participant 2 discusses sitting in the context of being present in those difficult spaces with patients, specifically for medical professions and the importance for them to engage in this form of sitting.

A challenge is that there's not always somebody there to open the door for patients and their loved ones to have those conversations, right. Like, if you're in front of a patient and you're having a discussion about their cancer, I really feel like I want people, regardless of if you're the dietitian or the oncologist or the social worker or the physio or like the nurse or the healthcare aid, you should feel like you can sit in that space with your patient.

My analysis of this is that medical professions often only focus on their direct speciality, and when those difficult conversations arise with patients, they try to avoid or dismiss it because they may feel like it is out of their capability to have those conversations. However, being able to sit in those difficult spaces can sometimes support in gaining more knowledge about the patient and having a deeper understanding of their story which could then influence their approach in supporting them.

This interview with participant 2 demonstrates a form of communication named 'sitting' which had various interpretations that interplayed between both physical and metaphorical spaces. Participant 2's use of 'sitting' was a powerful way to exhibit how communication with advanced cancer patients starts by being present with the patient. They stated a few times the importance of sitting with difficulties that patients have in accepting their illness and being okay with the fact that this illness is bringing about various emotions. Participant 2 states how part of sitting is validating those experiences and not always coming in with a problem-solving method, but rather just being someone that can be present with them in those difficult conversations. Due to participant 2's specific ward, they usually have the ability to sit with patients throughout the day, for multiple days in a row, gaining a more holistic understanding of the patient. To conclude,

participant 2 makes it a point to address that we live in a death-avoidant society, and that it is not only the oncologist or the healthcare staff that need to work towards being comfortable in sitting in these uncomfortable conversations, but it is something that we need to address on a broader social level (20:14:04).

Being Direct and Diplomatic

Participant 1 has been a hospital social worker for over 25 years and has worked in various areas such as general medicine, rehab, orthopedics, and oncology. Participant 1 prefaced their interview by stating that many of their stories have been jumbled together due to their years of working, but they had a few stories that really stood out to them. While participant 1 was sharing their stories, a common theme that I noticed was the importance they placed on being direct and diplomatic with patients. They shared stories that covered how to be direct and diplomatic in conversations with patients, being diplomatic with healthcare staff, and the relationship between spirituality and diplomacy.

Participant 1 shared how they have been direct and diplomatic in conversations they had, or doctors had, with patients. Participant 1 also discussed how being direct and diplomatic results in patients coming to terms with their illness, how some patients want staff to be direct with them about their illness, and how we serve patients better by being direct and diplomatic with them through their illness journey.

He wasn't able to care for himself anymore...He was past living independently. But the issue was that he was having a hard time accepting the terminal nature of his illness. And I recall having conversations with him, you know, because...I have a way of being direct with people, but I mean I could be a bit abrupt sometimes, but I've learned to temper that over the years. I have a way of being diplomatic with people, and direct about the issues that we need to talk about. And I recall talking with him [about] the reality of the

situation and his inability to returning home to independent living and just to...help him come to grips with...the nature of his terminal illness...

In this story, the social worker felt the need to be direct because there needed to be a different living situation for the patient and changes had to be made. Eventually, when the social worker was able to be direct and help the patient understand the need for this change, they filled out the palliative care application and relocated the patient to a better suited environment. After the move, the patient's family was very thankful and wrote a letter to the social worker in gratitude for their work in supporting the patient through this decision. Being direct with people seems to be a skill that participant 1 has developed over time and really values in their practice. They believe that some issues require social workers to be direct because it is something that needs to be talked about. With this story in mind, being direct is important as it can support patients in coming to terms with decisions that can be quite difficult.

On the other hand, it is evident that some patients want news to be directly given to them, like in the second story (a story that also makes evident the complexity of interprofessional relationships):

One time this doctor...he's so passive in his approach...The doctor had to tell her that, you know, you got like, there's some terminal thing that she was, you know, she's gonna be terminal. That was the message. And this guy, like the doctor, it was painful. It must have taken 10, maybe...15 min for him to kinda get to the point. And the patient actually, cause he kind of was beating around the bush and wouldn't, you know, come out and tell...actually says "Oh, doctor, why don't you just tell me I'm gonna die, right?" ...Then that's when he kind of acknowledged that it's true, like, you know, you're terminal. It was just brutal watching that play out, and that wasn't something I could really jump into the middle of to you know, kind of move it along...You know she was fully ready to accept the fact that she was gonna die. She just didn't want the doctor to beat around the bushes. "Tell me I'm gonna die" right like, please.

Beating around the bush, which could look like avoiding certain pieces of information for a variety of reasons or saying information in a way that is not clear, might provide false hope or

minimize the seriousness of the news. Assumingly, during a patient's illness journey, it might be common that people are always indirect with news as they might not have guaranteed answers or may need more tests and results to provide more definitive news, which could ultimately lead to some miscommunication. Therefore, the social worker places importance on being direct with advanced cancer patients as they want to have clear and direct messaging when there is important news such as a diagnosis, prognosis, or treatment.

However, many are uncomfortable in being direct with patients.

I've noted that...some doctors have a really hard time...it's a very personal thing ... Maybe it's how they, you know, come to terms with their own mortality. Who knows what comes into play with all this stuff? Because doctors are people too, but some doctors are way less comfortable in discussing those end-of-life matters than others. But you know for me, my experience, I think that people do well with it directly. I don't think we serve people well at all if we're not direct, there's a way to be diplomatic and direct instead of like sharp and unkind. But, you know, there's a way to be direct in a kind, sensitive manner.

Participant 1 theorizes that professionals' discomfort could be because of their own views of mortality. In addition to that, I assume that it could also be because it is human nature to have difficulties in breaking bad news. No one wants to be the bearer of bad news, but we must find ways to do it because, as participant 1 stated, we do not serve patients well if we are not direct with them. There needs to be a balance of being diplomatic and direct while being kind and sensitive, according to participant 1.

Although being direct with patients is important, participant 1 also discusses the importance of being diplomatic with staff and family members. In family meetings, for example, where there can be heightened emotions or overly medical jargon is used, social workers ensure that everyone understands the situation and are all on the same page.

So if we're in the middle of the conversation, some doctors are very good at taking complicated medical issues and communicating that to family. Others are so stuck in the books that, you know, like I have to jump in...I'll do it in a very diplomatic way. Right? Because respect to the doctors, right? But sometimes I'll jump in with like "excuse me doctor, you know just a can I"...You know, "maybe just clarify..." cause I'll note that, you know, if I see inquisitive looks and the families, you know, I'm watching to see whether they're getting everything that just being a right. And if I see it there, if I hear him speaking something, and I kinda catch the family sort of maybe not getting that point, I may kinda jump in and say, "excuse me, doctor could but could you clarify that I point about"... I'll kind of anticipate what their needs are and I'll kind of give an opportunity to the doctor to clarify that for them.

Participant 1 emphasized how sometimes, depending on the doctor, they have to jump in on family meetings more often, specifically in a diplomatic way. For this participant, I assume that their role of being diplomatic means being delicate and sensitive in those moments to respect the doctor and their work, while making sure the family members are understanding exactly what the doctor is saying. In addition, the social worker mentions a few times how they are continuously seeking clarity from the doctor to ensure the patient and family understand what is being said. In a way, the social worker is juggling diplomacy with healthcare staff, with family members, and with the patient, to ensure clear and kind communication, which could ultimately define what their meaning of being direct and diplomatic is.

Tracing back their steps, participant 1 recalled how their spirituality has impacted their role and positioning as a social worker, and I analyze how their spirituality has influenced their approach in being direct and diplomatic.

When I was in my twenties and I became a born again Christian, and that faith foundation, it's really, for me, the beginning of the end of the past... it was just a significant event that happened in my life and became foundational for living and, you know, because I'm secure in my own [understanding], you know, with regards to life and death issues... and I'll die one day, and I'm at peace with that, and I'm ready for it whenever it comes. I'm okay with it, right? And so I think that helps me deal with other folks who are dealing with life and death issues like, you get the one doctor who's really comfortable, or one of the other doctors that are really uncomfortable to deal, where they

can't, you know, be the savior in that situation, like, you know, it may speak to their own issues of. But I'm well grounded, I think, for dealing with life and death issues, and I've always regarded my approach with families, whether they're hostile or ungrateful, or whether they're friendly and thankful, or whatever their circumstances are, I'm serving patients' needs by, you know, kindly and diplomatically facilitating a meeting.

Participant 1 shares their perception that the doctors' own level of understanding and their acceptance of death impacts the way they approach conversations with patients, and how participant 1's faith has really shaped their practice. Participant 1 uses 'grounded' as a way to explain how their beliefs of life and death, influenced by their faith, anchors them in being able to facilitate family meetings, for example, in a way that is diplomatic. Although the relationship between spirituality and diplomacy seems to be correlated, both do not need to be present to coexist in my opinion. However, for participant 1 and for many others, spirituality does play a big role in issues around life and death and does impact the ways in which these conversations are being held, the language being used, and the approach to the conversation. As participant 1 stated, regardless of how the family and patient are, participant 1 will ensure to always be diplomatic because that is what is at the core of these conversations, and possibly, what is at the core of their spirituality.

This interview with participant 1 raised a very nuanced perspective of the need to be direct and diplomatic in conversations with advanced cancer patients. They shared many stories which discussed how to be direct and diplomatic in conversations with patients, being diplomatic with healthcare staff, and the relationship between spirituality and diplomacy. It is important to consider the experiences of participant 1; their work experience in the hospital setting for over 25 years, and their life experiences which have led them to their approach to practice. Although social workers must adjust their approach on a case-by-case basis, participant 1 emphasizes that to serve the patient well, we must ultimately be direct and diplomatic with them.

Preparing Patients

Participant 3 is a hospital social worker who specifically works as a palliative care social worker seeing patients from oncology, medicine, rehab, and even emergency. They also identified supporting patients with advanced cancer who are declining and needing a palliative approach to care. Since participant 3 supports palliative patients mostly, it was evident through their interview that they spend a lot of time supporting and preparing patients for their end of life. This included preparing them emotionally, logistically, and some of the challenges that come with it.

Here, participant 3 provided an example of what preparing a patient could look like.

So I'm usually there as emotional support for the patient and the family. Support around, answering some of the questions about what are the next steps, where we go from here, what are the options? Not just in terms of like disposition or discharge, although sometimes that's the first thing people think of. It's just like "I wanna get out of here, how do I get out of here?" It's also things like, "well, I haven't put any of my affairs in order", or "I don't want so and so making decisions about my healthcare". And then it's like arranging, helping them figure out what those things look like.

Evidently, participant 3 prepares patients emotionally for conversations with physicians about what can or cannot be done medically. They also support patients in getting their affairs in order which includes will writing, deciding on who will be their power of attorney, substitute decision maker, etc. These can be very difficult topics for patients to tackle, especially when these decisions can involve the opinions of family members, but they are aspects of end-of-life which are important to discuss and have organized which is part of the preparing process.

However, not every patient engages in this form of preparation immediately.

Sometimes it's just like sitting with them, being like "that [diagnosis/prognosis] was really hard to hear". So, after the doctors all file out of the room and everything, I just

stay behind for a moment. That's what they want. And just sitting with that with them. And sometimes we talk about it. Sometimes we just sit.

Part of preparing patients may not always look like having those difficult and logistical conversations around their cancer journey or end-of-life right away. Part of it could be sitting with patients (which is similar to participant 2's narrative, and that I reflect on more in the discussion). For some, it could be spending a lot of time in this space of sitting before moving into conversations about next steps, while others may just skip ahead and only talk logistics. The key here is understanding that there is no one way to prepare patients as every patient has different needs.

Participant 3 shared a story about how preparing patients can also look like supporting patients in their ability to self-reflect.

I'll talk about [patient name], who was a young guy and had a one-year-old kid...He was quite close to the end of his life...And some of the conversations we had was around what his life was like...how proud he was of his own kid, and how he was glad that he was able to meet them. And that, to him, was part of his life well lived. He couldn't go on any longer, and he had not much of his life left...him meeting his wife, meeting his kid, that was like, to him, the top of the hill, that was the best thing for him. I think given the right person in the right certain sense, the right, like ability to self-reflect...everybody can sort of find something in their life that was that made their life worth it, or that was a good life well lived.

Preparing patients, as we can see in this story, includes having conversations around the patient's life and what they value and hold with them. For this patient, their life well lived was defined as having their life spent with their wife and kid. They go as far as saying even just meeting their wife and kid is what brought them meaning. In a way, it is possible that participant 3 values patient self-reflection as they want to ensure every patient has found worth and meaning in the life they have lived. This ability and level of self-reflection is something that participant 3 works towards with patients as part of the preparing process.

For some patients, this self-reflection can be a scary process as it could lead to thoughts they had not thought about before, and/or thoughts that are quite difficult to navigate during their cancer journey.

I think most patients have fears about what dying is gonna be like, or a lot of times, it's about the suffering like the physical symptoms. But what sort of stands out is a patient who didn't have fears around physical suffering so much as being afraid of what was waiting after death. Just being afraid of like, was there gonna be nothing? Was there gonna be something? Was that something going to be good or bad?

Although it is common for patients to fear what their illness or death will be like as it is unknown, this patient feared what comes after death. They had fears on the existential level which can be quite complex. This participant shared another story of a patient who had fears of their illness but rather than wanting to discuss them in the process of preparation, they did not want to engage.

I had one gentleman recently...a few months after his cancer was diagnosed...he could not wrap his mind around it understandably. And so he was not only in physical distress, because his symptoms were so unmanageable that it was like a moving target every day to try and get them under control, but also existentially, he was distressed at the thought of dying. At the thought of leaving his family. At the thought of even like talking about what he would want for his end of life right up until the date he died... anytime it was brought up, he just shut down...it was distressing for everybody. It was distressing for his family to watch him suffer like that physically and emotionally. It was hard on the staff, who were just like, again, same thing, like to watch him suffer, especially emotionally, was very difficult for everybody, and to not be able to have frank conversations with him, to not be able to like, do any legacy with work with him for his kids, because he just couldn't face it, was hard.

This story exhibits some of the difficulties in preparing patients for the trajectory of their cancer journey. This patient was physically and existentially distressed but had this wall built up that every time the social worker would try to talk through it, the wall would stand firm. Evidently, it can be difficult to support patients through this time in preparing them when it can sometimes be

so overwhelming or new to the patient that they do not engage in it. Participant 3 describes this disengagement as a protective measure for patients.

...not that they're purposely trying to be difficult or anything, or they are purposely like, "I'm not going to believe this". But more as a protective measure. I think a lot of people find it might not even be fully conscious for them that they're like, "no, I'm not gonna engage with this...I'm gonna pretend it's not real". I think it's more of their way of coping with the situation. So when I say, "not able to talk about it" ...that's part of the way that they're coping with their situation. I think that it probably occupies their mind most of the time.

This participant is sharing an important message of how they as a social worker must understand and relate to, what we view, as the patients' resistance to these conversations. As stated, their end of life is something they are most likely always thinking about. Although it can be difficult to engage with patients, they build up a guard as a protective factor for what could be the new reality as they might not want to accept it, might want to hold onto hope, or do not feel ready just yet to have those conversations which is okay. Since this can oftentimes be the reality, patients not wanting to talk about their end of life, social workers have to consider how they can support patients in other ways.

Furthermore, participant 3 shares a story regarding the pressure they sometimes feel to prepare patients and have these difficult conversations faster due to the environment of the hospital and the pressure to discharge.

That was my first time experiencing anybody who is so unable to have, like a realistic conversations about their health...and I was also being pressured from my manager to get them out. I wish I had the experience now that'd be able to either push back or maybe change my tactic cause I felt terrible going in every other day to be like, "okay, we need to have a conversation about like your goals with care, like your code status, your disposition like where, if you can't go home...where are we going?". And the patient was like, "I'm staying right here" ...it just broke up the whole family, too. It was so hard to see like their family that was once very close, from everything that I could tell from, just like completely crumbled with all of this division about how to manage these conversations and treat her cancer.

From this story, it is evident that social workers experience pressure in their position between patients and management. They are feeling responsible to support the patient and advocate for their wants and needs to stay in place. However, from the management, social workers are faced with the pressure to discharge patients as soon as possible to make room for another patient. As this social worker reflects on their first few experiences of facing this pressure, they wish they had the ability that they have now to push back because they felt wrong in pressuring the patient to make decisions. Conversations around goals of care, code status, disposition, etc. are big decisions that the patient has to make and, although they do have to make those decisions in a timely manner, the pressure coming from above does not support the decision-making process and strains both the social worker and patient relationship, and even the relationship with the family.

Participant 3's interview was filled with many stories that covered the need for preparing patients for the final stages of their cancer journey, and from their palliative perspective, preparing for the end-of-life. Their stories illustrated how social workers support patients emotionally through difficult conversations of what their end of life will look like medically and what needs to be done logistically, and there is an expectation of social workers to make such arrangements and sort out their next steps. In addition, this participant provided insight on what it is like to have patients who are ready to engage in these conversations and others who shield themselves or shut down when these topics are brought up. Lastly, this participant shared stories of how wider systems pressures can affect the preparing that social workers, patients and families are doing.

CHAPTER 5: DISCUSSION

This study set out to explore HHS social workers' experiences in communicating with advanced cancer patients. With the narrative approach I used, I had the privilege of hearing their many stories which contributed to the main findings of this study. Each interview raised unique aspects of communication which included sitting, being direct and diplomatic, and preparing patients. Participant 2 shared stories that involved many forms of sitting such as physically sitting with patients, emotionally sitting with them, and goal-oriented sitting. Their stories also highlighted the relationship between knowledge and sitting, as well as the benefit for all healthcare staff to engage in any form of sitting. Participant 1's experiences seem to be grounded in the importance of being direct and diplomatic in conversations with patients, being diplomatic with healthcare staff, and the relationship between spirituality and diplomacy. Lastly, participant 3 placed a focus on the need to prepare patients emotionally and logistically and the challenges that arise. Key aspects of communication can be seen across all 3 interviews such as the need for psychosocial support and the impact that the institution has on communication. These results are discussed in further detail below.

It is also important to recognize how I have chosen to arrange my findings in the order of sitting (participant 2), being direct (participant 1), then preparing patients (participant 3), rather than in the chronological order of my interviews. The intent behind this was that after I had read through the results, it seemed like sitting – in the sense of being physically present, emotionally present, and with a goal-oriented approach – was a fundamental aspect to communication. In retrospect, sitting, in its many meanings, was at the core of being both direct and in preparing patients. Therefore, it made sense to arrange my research in that order to create better flow and

understanding of the aspects of communication between hospital social workers and advanced cancer patients.

Sitting

In the insights that came forward in my study on the theme of sitting, I can see it relate to the findings from Thorne et al. (2010). Thorne et al. (2010) discussed the value patients placed on receptivity during the diagnosis conversation and throughout their cancer journey, knowing that their needs and preferences were taken into consideration from healthcare professionals. This also includes how healthcare professionals consider terminological sensitivity, have an attention to time and space, and consider emotional well-being.

In reflection, many of the stories that participant 2 shared used sitting in the context of being physically sitting in close proximity to the patient and spending time with them. Something that stood out to me was how this action of sitting is much deeper than that physical action. When doctors enter a room, they stand. Standing gives the nature of overpowering or being in control. However, sitting down, getting to the same level as the patient, provides a sense of comfort and understanding. Being at their eye level ties into the basic communication elements between healthcare professionals and patients which are being polite, respectful, and ultimately being receptive (Thorne et al. 2010). Participant 2 emphasized how their physical presence of sitting can provide that sense of receptivity – the feeling of being supported and heard even if they are just physically sitting with them.

Furthermore, participant 2 describes sitting as a way of attending to another person's emotional wellbeing. As Thorne et al (2010) stated how patients find comfort in interacting with healthcare professionals that are compassionate and attentive, participant 2 describes sitting with

someone as a way of acknowledging their new reality of their illness, validating how they are feeling about it, and ultimately providing that sense of comfort during a state that might feel out of control.

However, Thorne et al.'s (2010) emphasis on terminological sensitivity is not that prominent in participant 2's interview. Thorne et al. (2010) argued that the terminological choices made had a significant impact on the patient's understanding of their illness. However, participant 2 placed more significance on how to be present with the patient, to sit with them in various aspects, but did not focus much on how to pick and choose the right words to use. Although the terminology used in this context is very important, I can argue that participant 2 strives more towards achieving a physical and mental space that is comforting for the patient.

Through the stories of participant 2, we can see how when the social worker is with the patient physically for a longer period of time, the patient can feel more comfortable, safe, and trust them enough to be vulnerable. One thing to be mindful of is how the ward that participant 2 works on impacts their perspective and orientation to sitting. Since it is not common for patients to be in the hospital for a long enough time period to have multiple moments of sitting with the social worker to achieve a certain level of vulnerability, sitting can look different and have different goals based on the ward.

Being Direct and Diplomatic

In participants 1's interview, the key theme of being direct and diplomatic connects to the findings from Marcus and Mott's 2014 study. Marcus and Mott (2014) outlined the SPIKES model which are 6 basic components for healthcare professions to keep in mind when communicating with cancer patients and/or delivering bad news: "(1) be prepared by knowing

the disease, its natural course, and treatments that have been given; (2) find out what the patient and family know; (3) secure an invitation to discuss these matters and fire a warning shot to prepare the patient for the discussion that is to follow; (4) provide the important facts the patient and family need to know with an appropriate manner and language; (5) deal with the emotions that this information occasions; and (6) have a plan” (Marcus and Mott, 2014, p. 714). When analyzing the stories of participant 1, I argue that they naturally follow these 6 communication components. For example, participant 1 shared a story of how their patient was declining and it was therefore necessary to fill out the palliative care application and relocate them in order to provide better care. This example shows how this social worker knew their patient’s disease and its natural course which allowed them to support accordingly. In addition, they work with the patient and family members to find out what they know and organize family meetings to discuss and prepare them for the next steps in their illness. They shared their strategy on how to organize family meetings, who is involved in them, how they prepare the family, and their role during them. Participant 1 also provides important facts with appropriate manner and language which is evident through their stories of providing direct and clear messaging, even if it is difficult at times, because they believe that they do not serve patients well if they are not direct and diplomatic with them. Participant 1 continued to share stories of supporting patients and family members with the emotions that come after having difficult conversations such as when family meetings are occurring and how they have to de-escalate situations, regulate emotions, and seek clarity from the doctor to ensure all information is made clear and understood during these times of heightened emotions. The sixth component of communication is to have a plan, and participant 1 shared that the majority of the work they do revolves around some measure of

discharge planning to create a course of action based on the needs of the patient and advocate for them.

In participant 1's story of supporting the patient through the palliative care application, they stated that being able to get through to the patient and to support them in making this decision, all while being direct and diplomatic, felt like a rite of passage as a social worker. They stated that they were able to serve this patient's needs in a way that a lot of people do not get the opportunity to. Through the SPIKES model as discussed by Marcus and Mott (2014), it is evident that being direct and diplomatic play a role to some degree throughout every component of communication, and for this participant, we can see how they place this high value and need to be direct and diplomatic for the sake of fulfilling the patient's needs.

Preparing Patients

A key aspect of communication with advanced cancer patients, according to participant 3, is the need to prepare patients which relates to Wang et al.'s 2018 study around advance care planning. Advance care planning could look like getting the patient's affairs in order which participant 3 shared as their will, power of attorney, substitute decision maker, etc. Beyond these specific forms of decision making and documentation, however, the study found that hospital social workers feel a level of responsibility in implementing advance care planning through their everyday duties of advocating for their patient, facilitating communication, engaging in conflict resolution, initiating those discussions, and documenting those discussions (Wang et al., 2018). Wang's study continued to discuss how social workers working in the hospital are "more likely to report encountering patient and family conflict regarding treatment decisions, difficulty in communicating with the patient and family, and lack of adequate guidance from medical

professionals” (Wang et al., 2018, p. 16). With that in mind, we can see how participant 3 was engaging in advance care planning through advocacy, for example, when they had to support the patient in their decision regarding a treatment option that differed from the family’s wants. This story also included elements of facilitating communication and conflict resolution between the patient and family members to come to terms with the patient’s decision. Conversations around advance care planning can be difficult as they are big medical, personal, and social decisions being made in what is usually a short, pressured, amount of time that involves many moving pieces.

However, what Wang et al’s study did not touch on was the inclusion of emotional needs as being part of advance care planning. Although advance care planning is defined as “a process of discussion that enables competent adults to express their wishes about end-of-life care through periods of decisional incapacity” (Wang et al., 2018, p. 1), participant 3 states that there are many difficulties in having these conversations with patients as they are very emotionally heavy. They shared stories about patients who did not want to engage in those conversations, or how advance care planning can impact the family members, healthcare staff, and those around the patient. Although conversations of advance care planning are important especially when preparing patients for the end of life, participant 3 recognized that these conversations become more difficult for all parties when we, social workers and all healthcare professionals, do not step back and recognize how the patient is feeling throughout this process. In a way, this discussion relates to participant 2’s key aspect of communication which was sitting in both physical and emotional contexts. Although advance care planning seems to contrast what sitting entails, I argue that they relate to each other and should work together. As participant 3 stated, not every patient is ready to have those difficult and logistical conversations around their cancer or end-of-

life immediately and might require some time to process before making any big decisions. Therefore, we can see how engaging in sitting, with the aspects of validating the patient's feelings and being present emotionally, can also be a way to prepare for advance care planning.

Looking Across the Three

In this narrative analysis that I have undertaken, I had the privilege of listening and analyzing each participant's story individually. Two aspects of communication with advanced cancer patients are common across all three interviews and merit further discussion as they relate to the literature: (1) psychosocial support, and (2) the impact of the institution on their support.

When reviewing the literature, Wang et al. (2018) state that one of the three areas that hospital social workers play a role in is providing psychosocial support to patients and their families. They continue to say how many social workers are skilled in psycho-socio-spiritual interventions which aid in their capacity to provide support. A study by Marcus and Mott (2014) found that when healthcare professionals used communication influenced by psychosocial interventions, psychosocial problems that are created or exacerbated by cancer in patients can be effectively addressed. For participant 1, they discussed how their spirituality has influenced their beliefs of life and death and has influenced their approach to supporting patients and family members. Participant 2 states that from a psychosocial perspective, it is beneficial to have social workers be part of difficult conversations, such as prognosis for example, because they get to see their patients every day which is oftentimes more than the doctor sees them. As a result, patients view the social worker as a safe person. Someone they can trust in having conversations about the existential, about what prognosis means beyond the medical terminology. Participant 3 discussed how their own discomfort as a social worker in asking patients about their spirituality

only lead them to realize that by asking the patient, they are able to either have a conversation that supports them through any existential distress, or provides a pathway to connect the patient to the spiritual care team for further support.

The second aspect of communication with advanced cancer patients was the impact of the hospital's institution which was not prevalent in the literature. Throughout the interviews, it was evident how the hospital institutional context shaped the nature of their communication. All three participants discussed discharge planning in some capacity and the difficulties behind it. For example, participant 1 stated how people do not want to be at the hospital and are afraid to go due to the power imbalance and the mistrust some patients have, which can make it difficult to build trust with the patient and have those difficult conversations around discharge. Participant 2 discussed how there is a small window of time where they can safely discharge an advanced cancer patient home, but when they are not able to get the supports and resources needed in place fast enough, that window closes due to their declining health, making the discharge plan not possible. Participant 3 discussed how the pressure to discharge from management resulted in them rushing important conversations with the patient, which ultimately hindered their relationship with the patient. Although discharge planning is important in ensuring the patient has all the right supports in place at home, this process should not be rushed especially when it negatively impacts the social worker and patient relationship, and even the relationship with the family. Conversations around goals of care, code status, disposition, etc. are big decisions and, although patients and families do have to make those decisions in a timely manner, the pressure coming from above does not support the decision-making process. It is evident through these interviews how the institution can negatively impact the communication hospital social workers have with advanced cancer patients.

Implications for Practice

When reflecting on this research study as a whole, I think about myself possibly being a hospital social worker in the future and how this study has impacted my role moving forward. Each participant I interviewed was a registered hospital social worker at Hamilton Health Sciences. They all support patients with various illnesses but have all supported advanced cancer patients at some point in their career. Each interview showed us a different mode of being: sitting, being direct and diplomatic, and preparing patients. These are three ways in which hospital social workers can approach their conversations with advanced cancer patients. One mode is not more “right” than the other, though my participants each emphasized one way of being over the others.

However, stepping back from the individual interviews and reflecting on them together, I can perceive more of each way of being in the other. For example, when being direct and diplomatic, social workers are simultaneously preparing patients in a way since their directness is for the purpose of preparing them for what is to come. Further, when preparing patients, they are also sitting with patients because the information and steps in preparing a patient do not happen overnight. They have to take their time and sit with them before engaging in those difficult conversations. As we can see, there are 3 modes of being, but the line that divides the 3 might be more blurred than presented in my thesis. Each may have a time and place and it is evident that these modes of communication can co-exist.

As a future social worker, and possibly a hospital social worker, I can see myself resonating with the mode of sitting in my approach to communicating with advanced cancer patients. I view sitting as being the foundation of the three modes, especially considering the

advanced cancer population where there are so many moving parts and things may always feel out of control for the patient. To me, sitting is a way to ground the patient, to validate, to hear, and to be receptive during a really difficult time. Through sitting, I can then see myself being direct and diplomatic in my approach while also preparing patients for their end-of-life.

Limitations and directions for future research

After completing this study, there are a few limitations that have come to mind. First, it would have been beneficial to have completed a second interview with all my participants. Having multiple points of engagement with my participants would have tied any loose ends, enhanced my understanding of their stories, and deepened my narrative approach to create space for further discussion on their identity, for example. In participant 1's interview for example, they mentioned being direct and diplomatic in their work but had never provided a clear definition of what that entails. A follow up interview with them would have allowed me to ask questions such as: Share a time when you were being direct with a patient? What did it look like? What steps were involved in being direct? Can you share a time when it was not appropriate to be direct?

Another limitation to my study was that I had only interviewed hospital social workers employed at Hamilton Health Sciences. However, social workers in another setting might have a whole other mode of communication. For example, I could add another dimension by interviewing hospice social workers. Although they are still in the realm of healthcare and often support advanced cancer patients, their mode of communication could be very different since they are working with individuals who are closer to the end of life. Therefore, I could develop

this study further by looking at social workers in an array of settings to understand more the essence of what communication looks like in those settings and for those workers.

Moreover, a limitation to this study which could be a direction for future research is furthering the exploration of the participant's identity. Although I collected some demographic information as a checklist and asked one general question about the impact of their identity on their communication, it would be beneficial to spend focused time and attention on this question of how they perceive their identity to play a role in their communication. I would ask: Tell a story of when a part of your identity bonded you closer to a patient. How did that impact your communication and relationship with them? Share a time when you found your identity conflicting with the needs of the institution. In what ways has your identity influenced your role as a social worker? By taking this route, this means that I would be intentional on who is being recruited for the study. Rather than accepting the first three participants, I would ensure to collect a group of participants that could speak from diverse standpoints.

Many of the limitations discussed are a result of the short time frame given to conduct this MSW thesis project. Conducting follow up interviews, recruiting outside of Hamilton Health Sciences, and deepening questions around the participant's identity would require more time to complete. These limitations are things to consider as directions for future research as these layers could ultimately result in a plan for action to improve the communication between hospital social workers and advanced cancer patients.

Conclusion

This research has taken a narrative approach to understand the stories of HHS hospital social workers supporting advanced cancer patients, specifically their communication with

patients around their needs, concerns, hopes, and fears. The interviews drew attention to the role that social workers play in conversations around diagnosis, prognosis, treatment, and palliative care. The participants shared their unique experiences and stories and highlighted three key aspects to communication: sitting (physically, emotionally, and in a goal-orientated way), being direct and diplomatic, and preparing patients. The analysis also prompted a reflection looking across all three which found how psychosocial support seemed to ground all 3 aspects to communication and the impact that the hospital institution has on the way they communicate. It was also made evident how these 3 aspects to communication can be seen as 3 modes of being as a hospital social worker, and how each mode can be practiced singularly or simultaneously.

After completing this thesis study, I think back to where my research began and reflect on the story of my dad and his cancer journey. Although I have not and will not get the answers I am looking for in regards to his cancer journey, such as the exact communication around his diagnosis, the level of social work involvement, or how exactly he was supported through those difficult thoughts, it is his story that guides me in my work as a future social worker. This research is for the social workers who are trying to find better ways to communicate with their advanced cancer patients. It is for healthcare workers to understand the role of social workers and the impact they have on patients. It is for the patients to know and understand that they can turn to social workers for support during these difficult conversations, because these thoughts are never easy to work through alone, especially in a Tim Hortons parking lot.

APPENDIX 1**LETTER OF INFORMATION / CONSENT****Communication with Advanced Cancer Patients: Hospital Social Workers' Experiences and Observations****Investigators:****Local Principal Investigator:**

Dr. Christina Sinding
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Purpose of the Study

The purpose of this study is to understand hospital social workers' stories of supporting patients with advanced cancer. This study will explore social workers' experiences of speaking with patients about their needs, concerns, hopes, and fears. It will also explore social workers' involvement in, and observations of, other professionals' conversations with patients about diagnosis, prognosis, treatment and palliative care.

I intend to use a narrative inquiry approach to bring voice to social workers' stories of these conversations.

You are invited to take part in this study, which I am conducting for my MSW thesis.

Procedures involved in the Research

This study involves a one-on-one interview with me for approximately 60-90 minutes. The interview will be conducted over Zoom. You will be asked to share stories and experiences of having and witnessing conversations with advanced cancer patients. Questions may include:

- Can you recall a specific story of an advanced cancer patient you have worked with?
- Please tell me a bit about your experiences with this patient, possibly talking about their needs, concerns, hopes, and fears.
- Can you tell me a bit about your observations of other professionals' communication with patients about diagnosis, prognosis, treatment, and/or palliative care?
- What was your role in these conversations?
- How did you feel mentally and emotionally while engaging in and observing these conversations?

- If you are comfortable, could you talk about what influenced your approach, to these conversations? [your own experiences, your education, aspects of your identity, your values and so on].

Once the interview ends, I will ask demographic information if it has not already been discussed such as:

- What age bracket do you fall in? (18-29, 30-39, 40-49, 50-59, 60+)
- What is your current employment status? (Full-time, part-time, casual, temporary, permanent)
- What floor/ward do you work on?

I may also approach you for a shorter follow-up interview to clarify or expand on parts of the first interview, and you can agree or decline at that time.

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are quite minimal. However, it is possible that questions and discussions regarding your experiences of working with advanced cancer patients may trigger distressing memories and/or feelings of discomfort. At any point throughout the interview, if you feel uncomfortable, you may pass on the question, take a break, and/or withdraw (stop taking part). Further below, I have outlined the steps that I am taking to protect your privacy.

Potential Benefits

The potential benefits of this research may include contribution to the existing body of knowledge on conversations with advanced care patients and contributing to a newer body of knowledge surrounding this topic from the social worker perspective. However, it is important to note that you will not be benefited directly. I hope that by gathering the stories of hospital social workers and the observations and feelings you have around these conversations, I can bring more voice and awareness to your experiences.

In addition, participants will receive a \$30 gift card as an appreciation for their time and participation in this study.

Confidentiality

In this study, you will have the choice to participate confidentially. If you choose to participate confidentially, I will not use any information that would allow you to be identified. 2-3 weeks after the transcripts are complete, all data will be de-identified through a pseudonym of your choice, and this includes changing the names of any colleagues or patients or names of care settings mentioned. I will report information about your work setting at a high level (e.g. social workers working at a tertiary care hospital in southwestern Ontario). Unless you choose to tell other people, only you and I will know of your participation. Please be aware though that we are often identifiable through the stories we tell. You will have the opportunity to review and edit the transcript of your interview if you wish to do so.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board, affiliated sites, or institutional regulatory body, may consult your identifiable research data. However, no records which identify you by name or initials will be allowed to leave the institution. By participating in this study, you authorize such access.

The study will use Zoom to collect data, which is an externally hosted cloud-based service. A link to their privacy policy is available [here](#). While the Hamilton Integrated Research Ethics Board has approved using the platform to collect data for this study, there is a small risk of a privacy breach for data collected on external servers. If you are concerned about this, let me know and we will make alternative arrangements (i.e. telephone interview).

All information and data that you provide me with will be kept in both an encrypted MacDrive folder as well as an encrypted hard drive. This computer, the hard drive, and all files are only accessible to me. Once my thesis has been defended and the study is complete, all data and the files will be deleted from my computer and hard drive, making it no longer accessible.

Participation and Withdrawal

In this study, you have the choice to participate, making it completely voluntary. You will also have the choice to decline any questions during the interview. You will also have the option to remove sections or edit the transcript once the interview is complete. By participating in this study you do not waive any rights to which you may be entitled under the law. If you choose to be part of this study, you also have the choice to withdraw (stop taking part) without any consequences. If you choose to withdraw after the interview/data collection, I will delete any data from your interview from my computer, and hard drive. You can withdraw until June of 2023, when I will begin analyzing the transcripts. If you choose to withdraw from the study, please contact me via email or by phone.

Information about the Study Results

I anticipate that I will have completed this research project by the end of August 2023. If you would like a summary and overview of the study results, or a copy of my final thesis, please let me know and I can share the results via email.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at:

Email: sebasj1@mcmaster.ca

Phone: 905-975-7812

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Joshua Sebastian, of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time until June 2023.

I understand that I may be approached for a follow up interview and I can agree or decline at that time.

I will be given a signed copy of this form. I agree to participate in the study.

Name of Participant (Printed)

Signature

Date

Consent form explained by:

Name & Role (Printed)

Signature

Date

APPENDIX 2

INTERVIEW QUESTIONS

Communication with Advanced Cancer Patients: Hospital Social Workers' Experiences and Observations

Using a narrative inquiry methodology, the interview questions may include:

1. Can you recall a specific story of an advanced cancer patient you have worked with?
2. Please tell me a bit about your experiences with this patient, possibly talking about their needs, concerns, hopes, and fears.
3. Can you tell me a bit about your observations of other professionals' communication with patients about diagnosis, prognosis, treatment, and/or palliative care?
4. What was your role in these conversations?
5. How did you feel mentally and emotionally while engaging in and observing these conversations?
6. If you are comfortable, could you talk about what influenced your approach, to these conversations? [your own experiences, your education, aspects of your identity, your values and so on].

Once the interview ends, I will ask demographic information if it has not already been discussed such as:

7. What age bracket do you fall in? (18-29, 30-39, 40-49, 50-59, 60+).
8. What is your current employment status? (Full-time, part-time, casual, temporary, permanent).
9. What floor/ward do you work on?

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