Finding meaning in hospice palliative care: An interpretive phenomenological study

by

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Abstract

This interpretive phenomenological study examines five caregivers’ hospice palliative care experiences. The goal of this study was to find out how hospice palliative care became meaningful to these caregivers and what that meaning was. I conducted my research using one-on-one open-ended interviews, followed by thematic analysis of the interview content. Turning to the voice of caregivers provides an opportunity for hospice palliative care providers to gain an increased understanding of how their work resonates with others. The findings in my study suggest that hospice palliative care’s tangible services were an entry point to caregivers’ connection with hospice palliative care. Despite having now used hospice palliative care services, the co-participants in my study had limited confidence in their understanding of hospice palliative care. Interestingly, at the same time, every co-participant in my study reported that hospice palliative became profoundly meaningful as emotional support for the caregiver. My thesis discusses the role of communication in how they developed that meaning and makes corresponding recommendations.

Keywords: hospice palliative care, interpretative phenomenological analysis, health communication, meaning
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Introduction

The number of Canadians dying each year is projected to increase 40% by 2026 and 65% by 2036 (Caring for Canadians at End of Life, 2015). Each death affects the well-being of, on average, five other people, such as family and loved ones (Caring for Canadians at End of Life, 2015). As a result of these projections, the Canadian Hospice Palliative Care Association [CHPCA] estimates that over the next 40 years demand for hospice palliative care services will continue to increase (CHPCA Fact Sheet: Hospice palliative care in Canada, 2014). Concurrently, there is a decrease in government funding for hospice palliative care (CHPCA Fact Sheet; Hospice palliative care in Canada, 2014) and, thus, an increase in the financial demands placed on hospice palliative associations, which are at minimum 50% funded by charitable donations (CHPCA Fact Sheet; Hospice palliative care in Canada, 2014). As the demands on hospice palliative care increase, numerous quantitative studies have identified that there is a lack of understanding about hospice palliative care services within Canada and abroad (McIlfatrick, et al., 2013; Zimmerman et al., 2016; Claxton-Oldfield J., Claxton-Oldfield S.& Rishynski, 2004; El-Jawahri et al., 2017).

Research demonstrates that there is a need for greater understanding about how to help non-professionals and medical professionals better comprehend hospice palliative care (Zimmerman et al. 2016; Cagle et al., 2016). This is a broad topic, and my study aims to add to the conversation about increasing hospice palliative care understanding by looking at the experiences caregivers have with hospice palliative care. My research asks the question “how was meaning made of hospice palliative care by caregivers and what was that meaning?” Looking at how meaning was made has important conceptual significance when it comes to hospice palliative care organizations’ understanding of why their work resonates with others. The results of this study can be used to help hospice palliative care professionals decide how and what
information to disseminate in order to increase understanding of their services. Research shows that in many countries, including Canada, there is a lack of comprehension about hospice palliative care (McIlfatrick, et al., 2013). A 2016 Canadian qualitative study of cancer patients and their caregivers by Zimmerman et al. (2016) demonstrated that the understanding of palliative care by patients and caregivers was limited primarily to care of the dying in the last few weeks of life. Another Canadian study, conducted by Claxton-Oldfield J., Claxton-Oldfield S., and Rishynski (2004), found that in a random grouping of 81 adults, 75.3% of the individuals surveyed had heard of palliative care. In a second survey in this same study, results indicated that 48.4% of participants defined hospice palliative care as care of the terminally ill, 18.8% defined it as care of the sick, and 15.6% defined it as care in the home. Complete understanding was limited, and it is worth noting that no respondents identified the role of the family in their understanding of hospice palliative care despite the definition of palliative care’s goal as “supporting the physical needs of the dying person and the psychological, social, cultural, emotional and spiritual needs of the terminally ill and their family” (Claxton-Oldfield et al., 2004). To further illustrate the lack of understanding of hospice palliative care it is worth noting that the problem extends beyond the layperson to the medical professional as well. A literature review by Ahmet et al. (2004) presented the problems and issues of accessing specialist palliative care by patients and professionals involved in their care. The study found that health and social care professionals lacked correct understanding of palliative services and this impacted patients’ and caregivers’ access to the services (Ahmet et al., 2004).

This research on hospice palliative care is timely, not just because of the immediate need for hospice palliative care organizations to be more successful in increasing understanding of their services but also because the culture and public conversations around death are changing. There is an emergence of death cafes and death doulas, and stories about Bill C41 (Canada's new
assisted dying law) are common in the media. One could say there is a cultural shift brewing in the way we look at, or do not look at, death in today’s society. Research on the topic of increasing understanding of hospice palliative care is emergent (Paul & Sallnow, 2014) and necessary in order to increase earlier access to hospice palliative care by patients and their caregivers (Cagle et al., 2016) and to build the necessary community engagement to ensure that hospice palliative care services are sustainable. My hope is that the results of my research will increase the knowledge of where meaning is made in terms of hospice palliative care and that the information in this thesis can be used to create more effective communication to convey hospice palliative care’s purpose in a way that could debunk myths and increase understanding of these services.

**Definitions**

**Hospice palliative care:** Throughout this paper, I use the term *hospice palliative care*, which is in line with the current naming of these services by the BC Hospice Palliative Care. According to the Canadian Hospice Palliative Care Association [CHPCA], hospice palliative care aims to enhance the quality of life for those with life-limiting illnesses and their families through comfort rather than curative approaches (www.chpca.net). Hospice palliative care can support the dying and their family through physical, psychological, social, spiritual, and practical issues (www.chpca.net). Hospice palliative care typically also offers services for grief and bereavement (www.chpca.net). To be sustainable, hospice palliative care organizations in Canada typically rely partially on donors and fundraising. When I use the words *hospice* or *palliative* independently of each other, it is to match how it was named in the literature being discussed or in the words of my co-participants.

**Caregiver:** For the purpose of this research, the term *caregiver* refers to the primary person who provides ongoing care and assistance to the patient. The individual identifies as a family
member or friend of the patient who is not providing care in a formal capacity and is not professionally trained or financially compensated to provide care. All caregivers in my study are bereaved caregivers, meaning the individual who they were caring for, and who is discussed in this study, is now deceased.

**Co-participant:** Co-participant refers to those that I interviewed for this study. The use of the word co-participant is further explained in the methods section of this thesis.

**Doctor:** For the purpose of this research, *doctor* refers to the primary care physician or the emergency doctor who first introduced the caregiver to the concept of hospice palliative care.

**Patient:** For the purpose of this paper, *patient* refers to the individual who was dying and being supported by the caregivers who were my co-participants.

**Literature Review**

This literature review begins with a review of studies dealing with barriers to understanding hospice palliative care. These barriers include the inconsistent naming and descriptions of hospice palliative care, the exclusive language used in hospice palliative care, and the stigma surrounding hospice palliative care. This literature review will also discuss the role of conversation in constructing the meaning of hospice palliative care. Next, I will present information on the place of the caregiver within hospice palliative care. Finally, since death and bereavement are culturally relevant, the review of the literature will also look at the changing approaches to death in North America.

**Understanding Hospice Palliative Care**

There are barriers to developing an understanding of hospice palliative care. These include the dual naming (*hospice* and *palliative*) of the service, the inconsistent descriptions of hospice palliative care, the impact of exclusive language, and the stigma associated with hospice
palliative care services (because they fall within the scope of death and bereavement, which can be an uncomfortable topic of discussion in North American society).

**Inconsistent naming and language.** A barrier to the understanding of hospice palliative care lies in the inconsistent use of language to describe these services, including the name itself. The inconsistent use of the words *palliative* and *hospice* causes contradictory understandings of the services by the layperson and healthcare experts (O’Connor, Davis & Abernethy, 2010; Pastrana, Jünger, Ostgathe, Elsner & Radbruch, 2008; Weil et al., 2015). In a quantitative study by Weil et al. (2015), which included focus groups with healthcare experts who work with palliative patients and telephone interviews with emergency health professionals, it was found that the inconsistent use of the term *palliative* led to contradictory understandings of palliative services. Weil et al. (2015) suggested that this deep-seated misunderstanding was a significant barrier to understanding of and engagement with hospice palliative care. Similarly, a discourse analysis performed by Pastrana et al. (2008) focusing on the terms *palliative care* and *palliative medicine* found that there was a notable lack of agreement on the meaning of these terms. While the Pastrana et al. (2008) study did not research the possible variations in the definitions of hospice, the authors noted that this would be a valuable line of future research insofar as the term *palliative* originally came from the hospice movement, and the terms *hospice* and *palliative* also often overlap.

In addition to its naming problem, hospice palliative care has the challenge of lacking consistent industry-wide language for explaining its services. In other words, hospice palliative care does not have what French philosopher Michel Foucault refers to as a *discursive formation*, which is described as “groups of statements which deal with the same topic and which seem to produce a similar effect” (Mills, 2003, p.64). Typically, discursive formations are associated with a certain institution and have functional significance (Mills, 2003). In an editorial paper by
researchers O’Conner, Davis and Abernethy (2010), the authors studied 40 different palliative care organizations and established that there was little consistency in the language used throughout the organizations’ mission statements. This lack of discursive formation throughout the industry could be due to organizations having different mandates, or simply a result of hospice palliative care being a relatively new phenomenon. Regardless of the reason it exists, the fact is that the inconsistent language within hospice palliative care acts as another barrier to gaining understanding of its services.

To understand the root of the inconsistent naming and definition dilemma, it is important to briefly review the history of hospice palliative care. The label *palliative* came into use in the 1970s when Canadian doctor Balfour Mount created a unit for terminally ill patients at the Royal Victoria Hospital (Weil et al., 2015). Despite being highly influenced by Dame Cicely Saunders, who spearheaded the hospice movement in the United Kingdom in the 1960s, Mount chose to name his initiative palliative care. Mount thought the term hospice could be confused with France’s meaning of the word, where it is used to describe nursing home care (Duffy, 2005; Weil et al., 2015). In its initial North American inception, not only was the name different than its UK counterpart, but so was the structural model. The funders of Mount’s project decided that the UK hospice model, which was community funded, was financially prohibitive and therefore instead opened a ward in the hospital called palliative care where they also provided a consultation team to work with other hospitals, a home support system, and bereavement services (Duffy, 2005). While Mount’s palliative services were slowly gaining traction in the medical system, community based hospice associations were forming to fill gaps that were not available in mainstream health care (Syme & Bruce, 2009). As palliative care became more rooted in and recognized as a mainstream medical specialty, it became more distinct from hospice organizations, which were a more community-minded grassroots volunteer-driven service (Syme
& Bruce, 2009). In the early 2000s there was friction over the convergence and divergence of these services, and the overlapping naming that had developed, and a movement began in the United States that influenced the continued separation of hospice and palliative care in parts of North America (Syme & Bruce, 2009). However, meanwhile in 2002, in Canada, the Canadian Palliative Care Association accepted a motion to change their name to Canadian Hospice Palliative Care Association [CHPCA] (Syme & Bruce, 2009) because it reflected both palliative and hospice’s shared principles (“A model to guide,” 2014). According to the CHPCA website, both palliative care and hospice have the same meaning, but hospice care is sometimes used to describe care that is offered in the community rather than in a hospital (www.chpca.net). However, some hospitals have hospice units. This varied labeling of end-of-life services adds to the misunderstanding of their function (Weil et al., 2015) and could impact community understanding of their services. Despite an attempt to decrease confusion in Canada by assimilating the word hospice and palliative, there still is not consistent use and understanding of the name hospice palliative care within the Canadian healthcare industry.

Since the emergence of hospice palliative care, the terms hospice care and palliative care have been interwoven. This inconsistent structural model that existed in hospice palliative care’s formative years, and the variance in the naming and describing of its services, laid a confusing foundation that still has implications and is a barrier to the understanding of hospice palliative care’s function. This reality makes it all the more important for hospice palliative organizations and medical doctors to use language that people can easily understand.

**Exclusive language.** Within the topic of language there is another barrier that exists. The language used in discussing palliative hospice care can create an environment of exclusivity, which can position hospice palliative care as a topic not open for conversation. Palliative care, according to death sociologist Walter (1991), who has written extensively about death’s place in
society, is typically medicalized and placed within the context of practical, psychiatric, and medical services, and then similar discourse follows suit. This typically involves what is considered to be expert language or “medical jargon” (Parrot & Kreuter, 2003). O’Connor et al. (2010) noted in their editorial paper about language, discourse and meaning in palliative medicine that this use of expert language in palliative discourse creates an environment of power and authority, making it difficult for the layperson to join the conversation. This can be explained via Foucault’s theories on discourse and its relationship to power. Foucault claimed that language perpetuates levels of power in society, and that discourse could impact the role of the person in relation to the world (Littlejohn & Foss, 2009, p.39). Discourse does not just reflect the world in which we live, it also serves to shape how people perceive themselves and their reality (Brown, Crawford & Carter, 2006), which subsequently impacts the way they behave (Mills, 2003). Therefore, discourse can impact the way a community views a phenomenon. In a discourse analysis study of palliative care mission statements, O’Connor (2005) concluded that the statements employ exclusive language that leaves ordinary users of the system in the dark. Examples include the use of the words holistic, integrated, and life-limiting. While the meaning of these words, out of context, might be clear, when they are put in the context of hospice palliative care, the layperson is likely unable to interpret their meaning and significance (O’Connor, 2005). Clearly, language could be creating a barrier to the layperson’s understanding of, and subsequent access to, hospice palliative care and the framing of hospice palliative care as a community health issue.

**Discomfort with discussion of death.** The discomfort people feel in talking about death and bereavement could impede understanding of hospice palliative service. Although death is a human commonality, death conversation can make people uncomfortable and be considered taboo (Connor & Bermedo, 2014). The societal misunderstanding of hospice palliative care as a
service for the final stages before death places it within the context of a taboo subject, that people therefore may avoid discussing.

In a phenomenological study of bereaved caregivers’ experiences and preferences in palliative care services, Sekelja, Butow, and Tattersall (2010) reported that some participants did not access palliative care services, or acquire them for their loved ones, because they felt the services symbolized an oncoming decrease in quality of life for the patient. However, one of the mandates of hospice palliative care is contrary to that myth—rather, hospice palliative care aims to increase the quality of life for caregivers and those with life-threatening illnesses (www.chpca.net), and there is no evidence that hospice palliative care has been shown to decrease the quality of life for the dying and the bereaved. Caregivers in Sekelja et al.’s (2010) study indicated that they would only use hospice palliative care as a last resort. Similarly, Ahmed et al. (2004), in a systematic review of the problems and issues of accessing palliative care by patients, caregivers, and health and social care professionals, found that hospice palliative care was not accessed because it was seen as giving up on the patient and was something to be used as a last resort. This false association of hospice palliative care as a last resort connects it to the “society as death-denying thesis” because it implies that if we are engaging with hospice palliative care, we are accepting death, and the standard way of thinking about death is that it is not something to be accepted.

According to the Worldwide Hospice Palliative Care Alliance (Worldwide Palliative Care Alliance, 2014), people avoid using hospice palliative care services because doing so acknowledges that an individual is moving towards death, and psychologically most people want to avoid facing this reality (Worldwide Palliative Care Alliance, 2014). However, there is an ongoing debate about the validity of the theory that death denial is a barrier to understanding and accessing hospice palliative care services. For example, McIlpatrick et al. (2013) conducted a
community-based cross-sectional survey that researched knowledge of hospice palliative care which identified fear of death as a barrier to increased understanding of palliative care. However, other opinions challenge the weight of McIlfatrick’s study results. Community health professor and author Allan Kellehear, who is at the forefront of challenging the death denial hypothesis, suggests that denial is the most “overworked word in health care” (Kellehear, 2005, p. 86) and that death denial doesn’t reflect the state of mind of the dying but rather it is society that has created this culture of death denial (Kellehear, 1984). Furthermore, Kellehear (1984) claimed that the reason we do not talk about death is not because of inherently psychological reasons but because death conversation is not proper social conduct and therefore death denial is a social construct.

Perhaps both the psychological death denial and the death denial as a social construct hypotheses hold some truth. It must also be considered that death is constructed differently depending on culture. Zimmerman and Rodin (2004), in their paper discussing the societal implications of the death denial thesis on palliative care, suggested that hospice palliative care holds some responsibility for the social construct of the concept and of the term death denial because interestingly, death denial began being taught and used in the United States in the 1950s and 1960s together with the development of hospice movements (Zimmerman & Rodin, 2004). My own experience, when a family member was dying, was that death denial by the patient is a barrier to caregivers developing understanding of hospice palliative care, because hospice palliative care was considered a last resort and was seen as giving up on the patient. My family members were not willing to contact hospice palliative care until my dying step-dad clearly stated that he was ready to die. Perhaps this is because once he was ready, they could no longer stand in denial of his impending death and therefore the barrier to learning about and understanding hospice palliative care came down.
Summary. Hospice palliative care is a relatively new phenomenon which doesn’t have consistent naming and language. This had laid a foundation that contributes to the societal lack of understanding of their services. Hospice palliative care is often discussed in the context of medical services where expert language is used and this can add an additional barrier to the understanding of its services. Additionally, one of the societal understandings of hospice palliative care is that it is a last-resort service for patients before dying. According to some experts, this results in hospice palliative care being difficult to discuss because society is death denying and death is a taboo topic.

Constructing the Meaning of Hospice Palliative Care

The theory of social constructivism suggests that the way we experience and respond to communication contributes to how we understand and make meaning of a topic (Jones & Brader-Araje, 2002). Additionally, the theory of social constructivism states that the process of coming to know something is an active process that involves interaction with others (Jones & Brader-Araje, 2002). Moreover, health communication literature points to the role conversation can play in the understanding of a phenomenon such as hospice palliative care. As explained by the coordinated management of meaning [CMM] theory, when an individual encounters a conversational situation, they assign meaning to it and then decide to act on that meaning (Cline, 2011). If individuals remain adaptable in communication, conversations become jointly created, and mutual exchange of information occurs, which can lead to meaning making (Jordan et al., 2009). Meaning making is also happening as people engage in their own ongoing heuristic relationships between managing their own meanings and actions and interpreting those of others (Littlejohn & Foss, 2009, p. 200). In other words, communicators interpret and act based on their own experiences, and make meaning based on a loop between their self and conversational episodes (Littlejohn & Foss, 2009, p.200).
In order to facilitate this meaning making, scholars are suggesting that health communication shift to include a more interpersonal communication style (Duggan, 2006). It is important to recognize that moving towards a more conversational communication approach within the medical system has some barriers. The conversational process involves time, which is often a challenge in delivering health-related information in the healthcare system as doctors are often rushed (Jordan et al., 2009). However, in doctor-patient and doctor-caregiver communication, doctors can be mindful of the importance of not being completely scripted (Jordan et al., 2009) and remain cognitive that understanding and meaning typically occur in a non-linear fashion and involve relational conversational experiences, not just instruction-giving (Jordan et al., 2009). The other challenge for engaging in conversational communication in the health care system is that there are issues of power inherent in the medical system between doctors and patients (Bylund, Peterson, & Cameron, 2012). For doctors, the conversation can be one that is familiar, however, for patients and caregivers the conversational topic of death and caregiving, especially as it pertains to self, is typically unfamiliar, not to mention emotional and transformative, territory (Omilion-Hodges & Swords, 2017).

Within this conversational process of facilitating meaning making, there are other barriers that exist. For example, there are process barriers, which refer to the receiver’s inability to intake information because of a breakdown in a give-and-take process of communication between sender and receiver. These process barriers include psychosocial barriers, such as noise (Lunenbrug, 2010). Noise refers to external factors, such as stress, outside of the sender-receiver dialogue that can impact the ability of someone to receive information (Lunenbrug, 2010). Communication is a complex process of transmitting information between sender and receiver, and being mindful of the barriers that exist in this process will allow for improved communication and the development of greater understanding of a phenomenon.
Despite hospice palliative care’s definition and function as a not-for-profit service that aims to increase the quality of life for the dying and their family, the dominant institutional conversation in hospice palliative care has primarily been in the realm of the clinical or practical (Kellehear, 2005). The more robust and accurate definition of hospice palliative care as a service which also aims to support the psychological, spiritual and social needs of a patient with a life-threatening illness and their family members (chcpa.com) is clearly not reaching the general public. Kellehear (2005), who is the founder of the Compassionate Community movement, which aims to position palliative care as a community health issue as opposed to a site for service on an object (the patient), explained that, in order to build increased understanding of the meaning of hospice palliative care, attention needs to be turned towards the non-medical community to see where and how meaning is being made beyond the clinical context. While the community is often seen just as a resource base for palliative care, the community can also be a place to find a broader context for palliative care (Pastarana, 2008), which can be used to develop new education and impact how hospice palliative care is discussed.

**The Caregiver’s Place in Hospice Palliative Care**

An opportunity exists to expand the understanding of hospice palliative care by turning towards caregivers and researching where meaning was made for them in their experience with hospice palliative care (Sekelja et al., 2010). This will increase understanding of what hospice palliative care means to this important stakeholder group, one that hospice palliative care aims to serve. This knowledge, can impact the way hospice palliative care is talked about in conversation. Perhaps the experience of the caregiver is more easily accessed and identifiable than the stories of the dying patient, as there is potentially less cognitive dissonance in understanding the role of a caregiver as compared to that of the dying.
While research on the impact of hospice palliative care on the caregiver is still sparse, it has been found that earlier access to hospice palliative services reduces the emotional needs that the caregiver might develop once the illness is further advanced (Sekelja et al., 2010). Family members who accessed hospice palliative care for support for their patient felt more competent in caring for the dying person and were better prepared for their death (Poulton, Wiseman, Waterhouse, & Faul, 2012). Inviting family caregivers into conversations about care can help them feel supported in caring for the dying and in managing their own emotions around the process (Goldsmith, Wittenberg-Lyles, Ragan, & Nussbaum, 2011). The invitation to participate in conversations about death also leads to an increasing understanding of end-of-life services and plays a role in facilitating shared conversations about difficult health, which subsequently reduces stress and grief (Goldsmith et al., 2011). Goldsmith et al. (2011), in an essay about end-of-life health communication, discuss the implications of inter-communications between patients and their family members. The essay suggested that the way in which death is typically managed is by not talking about it, a process that is jointly enacted between both groups of people because they are in denial (Goldsmith et al., 2011). Subsequently, this lack of conversation about, and acceptance of, death becomes a barrier to receiving care, which can cause additional stress for the patient and family members (Goldsmith et al., 2011). By researching this section of the community, new education can be developed that can best serve this community (Kellehear & O’Connor, 2008). This information can be used to help hospice palliative care providers make decisions about how they and other medical professionals communicate about hospice palliative care.

**Summary**

Recent academic literature, along with the objectives of organizations such as the BC Centre for Palliative Care (http://www.bc-cpc.ca/), conclude that increasing the correct
understanding of hospice palliative care is a priority. Hospice palliative care is a community service that is misunderstood, and there are numerous communication barriers to changing this reality. However, against the backdrop of a society that is increasingly talking about death and bereavement, researching the experience of caregivers and looking at how hospice palliative care meaning developed and what that meaning was for them can further uncover how hospice palliative care resonates with people. This information can be used to help increase both caregiver and societal comprehension of hospice palliative care service.

**Methods**

The study looks at the lived experience of five caregivers taking care of a dying loved one. The goal of this study was to find out how hospice palliative care became meaningful to these caregivers and what that meaning was. Using interpretive phenomenological analysis (IPA), I conducted semi-structured open-ended interviews with caregivers, who are also referred to as my co-participants. After the interviews, I engaged with my data to organize my findings into themes.

**Research Design**

In my research, I operated under the interpretive paradigm and its constructivist assumptions about the nature of knowledge and meaning. The interpretive paradigm, according to Merrigan, Huston, and Johnson (2012), generates “descriptive claims that represent participants’ meanings” (p. 58) and is used by researchers wanting to understand how and where meaning is made. Constructivists acknowledge that individuals “develop subjective meanings of their experiences” (Cresswell, 2013, p. 24). These meanings of their experiences are impacted by their social, cultural and historical perspectives (Cresswell, 2013, p. 25) and therefore are varied and complex, without one homogenous definition. Since I am interested in uncovering how meaning is made of hospice palliative care and what that meaning is, which lies in individual experience
and perspective, the interpretive constructivist approach aligns with my methodology and goals. My methodology entailed a qualitative phenomenological approach. Phenomenological researchers use one-on-one open-ended interviews to generate data and then analyze the data for meaning and themes to gain a greater understanding of the phenomena (Mapp, 2010). The goal of phenomenology is to study the lived experience of an individual within one specific phenomenon (Mapp, 2010).

There are many types of phenomenological research, and I employed interpretive phenomenological analysis [IPA] as my methodology. While there is no single way to undertake IPA (Smith & Osborn, 2007), the goal of the methodology is always to understand a person's experience and where meaning is made (Clarke, 2009), which is relevant to my research purpose of understanding how meaning is made by the bereaved caregiver, and what that meaning is, in regards to hospice palliative care. According to Smith (2010), IPA “considers that experience is only accessible through a process of interpretation on the part of both participant and researcher” (p. 1). IPA is influenced by hermeneutics, which, according to IPA researchers Smith, Flower and Larkin (2012), is concerned with “examining how a phenomena appears, and the analyst is implicated in facilitating and making sense of this appearance” (p. 28). In IPA, there is a dynamic relationship between the researcher and participant (Clarke, 2009) as the researcher, through active listening and open-ended questions, aims to understand what it was like to be that participant (Pietkiewicz & Smith, 2012). Brocki and Wearden (2006) conducted a critical review of 52 IPA studies and concluded that IPA is a suitable emergent method of research for illuminating the meanings of a phenomenon. In fact, interpretive phenomenological analysis is particularly effective when the area of research involves looking at a complex phenomenon (Smith & Osborne, 2003, as cited by Skinta & Benjamin, 2017) and involves topics that could have stigma associated with them (Skinta & Benjamin, 2017), which is the case for hospice
palliative care. For example, Skinta and Benjamin (2017), who used IPA methodology to research stigma and HIV among gay males, found IPA’s “robustly person-centric approach” (p. 5) well suited for exploring sensitive subjects. As researcher Clarke (2009) explained, IPA employs empathy and curiosity, because the researcher positions themselves as interested in understanding what the phenomena was like for the participant.

In phenomenology, the meanings of a phenomenon are explored and not assumed (Moustakas, 1994), so it is important to recognize my own subjectivity in order to understand the perspective of my co-participants. My own subjective view, from my lived experience and active observations, on the topic of hospice palliative care, is that there is reluctance to talk about the issues surrounding dying and the care of palliative patients and their family members, and that this negatively impacts hospice palliative care organizations. My experience is that this barrier leads to a lack of understanding about what hospice palliative care is, which adds a challenge to building community support for hospice palliative fundraising initiatives and to family members accessing hospice care as early as they could. According to Moustakas (1994), in phenomenology research questions should develop from the researcher having an awareness of particular problem and becoming curious and passionate about it. My initial interest on this topic developed while I was doing volunteer work in health communications and became aware of this problem and saw how it impacted community buy-in for fundraising efforts. My relationship with the topic became more intense and personal when I witnessed family members struggle to understand hospice palliative care and as result of that lack of understanding they didn’t access their services. This was frustrating because I knew hospice palliative care could provide valuable support during this challenging time.

Data and Data Gathering
My study used a small sample size; co-participants were chosen through purposeful and criterion sampling. Once the co-participants were chosen, I conducted face-to-face interviews with them. I asked them open-ended questions that encouraged them to talk freely. Throughout the data gathering process, in order to remain committed to being clear about the essence of my co-participants’ experiences, I made field notes about my own reflections and reaction to the data.

**Sample size.** Phenomenological research typically works with a small sample size due to the depth of the data collection and analysis (Moser & Korstjens, 2017; Skinta & Brandrett, 2017; Mapp, 2010; Milevsky, Niman, Raab & Gross, 2011). Mapp (2008) explained that in phenomenological research the “goal is not to generalize the findings, therefore large numbers of participants are not required” (p. 309). Similar to the study on stigma and HIV among gay men by Skinta and Brandrett (2017), and in line with other recommendations by qualitative researchers such as Cresswell, (2013), my sample-size goal was between three and five people. I began with three people, however, as per Cresswell (2013), Moser and Korstjens (2017) and Mapp’s (2010) recommendations to add more data if the researcher felt it was needed, and I later added two additional co-participants to broaden my data set.

**Co-participants.** Upon approval from the Royal Roads University Research Ethics Board, I found participants for my research through purposive and criterion sampling via word of mouth within my extensive community network. Instead of the term *subjects*, in line with IPA methodology of keeping the research person-centric and to emphasize the importance of their voice in the study, I referred to those that I interviewed as *co-participants* (Donalek, 2004; Moustakas, 1994). Purposive sampling refers to me being able to make a judgment call about whether or not participants would be effective at sharing their lived experience (Moser & Korstjens, 2017), which was necessary because I had a small sample size and required rich data.
It was my experience that all those who contacted me would be valuable co-participants. Criteria for inclusion in the research included, being an adult who has experience with hospice palliative care in the role of caregiver, on Vancouver Island north (Nanaimo and north), British Columbia. I chose a limited geographic area, in line with IPA methodology of maintaining a homogenous sample (Smith, Flowers & Larkin, 2012), but kept it broad enough to ensure I could find participants. While hospice palliative services in different towns operate independently of each other, they all fall under the umbrella of the BC Hospice Palliative Care Association and the variables between them, in regard to the population they serve, their mandate, and services, are minimal. Other criteria for inclusion included co-participants being willing to participate in an interview and follow-up phone conversation or email, and allowing the interview to be tape-recorded and used in a thesis. The final criterion was that co-participants were all a minimum of one year out of being in the active role of being a caregiver and the dying person they were caring for must have been deceased for at least a year. I included this because it was advantageous that my co-participants had access to the full experience of relevant hospice palliative care services, including bereavement care. Additionally, if co-participants were still travelling through end-of-life care they might be in a emotionally-heightened, stressful state, and as a novice researcher and a non-health professional, I am not professionally qualified to provide the support for needs that might arise during our interactions.

After an individual expressed interest in participating, I met or talked on the phone with them before the study began, which was crucial for two reasons. Firstly, because co-participants were encouraged to see themselves as co-participants, not subjects, it was important that they had a full understanding of the study and that the fact that I felt they are an appropriate co-participant (Moustakas, 1994). Secondly, because research participant relationships are based on trust (Collard & Marlow, 2016), it was valuable to connect for informal unstructured conversation
beforehand to build rapport with the co-participant, which helped develop a relationship based on equality (Lindlof & Taylor, 2011). In order to further build rapport, during the conversation I explained my interest in and experience with the topic of hospice palliative care.

Before this conversation occurred, all potential co-participants were given a consent-to-participate form and were asked if they had any questions about it. In order to respect the co-participants’ time, they were given the choice of meeting in person or talking on the phone. All co-participants, other than one, chose the phone for our pre-interview connection. Because all participants were found through word-of-mouth, all were familiar with me as a community member, which added to the ease of building rapport.

My co-participants were a homogenous group beyond the geographic criteria that was set. All were middle-aged women and mothers, who were also caregiving children at home during their time experiencing hospice palliative care. Four of the co-participants used hospice palliative care in the Comox Valley and one experienced their services in the neighbouring city of Campbell River. This commonality was not intentional but rather this was the population that responded to my invitation to participate. This was an advantage in my study, as in IPA having a homogenous sample is considered ideal methodology (Smith, Flowers & Larkin, 2012), as the goal in IPA is to examine in-depth responses to a phenomenon by a specific group (Creswell, 1994, as cited by Milevsky et al., 2011). Additionally, in IPA (Smith, Flowers & Larkin, 2012) the study and its subsequent results should remain contextualized within the parameters of the sample, and any generalizations outside of a similar sample set are to remain speculative (Robinson, 2014) and should be built with the integration of further studies (Smith, Flowers & Larkin, 2012).

**Data-gathering.** Interviews took place at a neutral, private office space and began with reviewing the consent form. Once the form was signed the interview commenced. The interview
was audio recorded and took between 30 and 45 minutes, which is standard for IPA research (Smith & Osborn, 2007). It was clear within the first five minutes of my first interview that it was important to discuss with co-participants the definition of hospice palliative care. After realizing this need, I took time in that first interview, and subsequent interviews, to discuss the history of hospice palliative care and to ensure that my co-participants identified hospice palliative care as the non-profit societies they accessed, titled Comox Valley Hospice Society and Campbell River Hospice Society. For the interview, questions were broad and primarily open-ended so that participants could talk freely and feel encouraged to share their experience of hospice palliative care (Cresswell, 2013; Moster & Korstjen, 2017), in adherence with constructivist philosophy. I had some pre-set prompting questions, such as “what is your experience with hospice palliative care? What feelings come to mind when you think of hospice palliative care? What value did you find in hospice palliative care?” and used additional probing questions as necessary to elicit responses. This approach encouraged the sharing of rich descriptions, which is the strength of phenomenological studies (Smith, Flowers & Larkin, 2012). As answers from my co-participants emerged, I used imaginative variation to take questions that had already been asked, restructure them and ask them again in this new variation. This tactic within phenomenological interviewing was recommended by Bevan (2014) because it can help clarify the essence of the co-participants’ experiences and it assists the researcher in uncovering the emergent. I did find this approach beneficial, as asking a similar question with new language not only clarified the co-participants’ experiences and feelings, it often it brought forth new information.

**Bracketing.** A common challenge in phenomenological research is bracketing one's experiences (Cresswell, 2013). Bracketing, also known as *epoché*, is the process researchers employ to “set aside their experiences, as much as possible, to take a fresh perspective toward the phenomenon under investigation” (Creswell, 2013 pp. 59-60.) Therefore, in order to remain
committed to hearing the essence of the co-participants’ experiences, I took steps to acknowledge my experiences throughout the study. Before each interview I privately reflected on my pre-conceptions and experiences, and this process allowed me to move towards the co-participants’ experiences being the focus. I also kept field notes through the data-gathering process; however, my utmost priority during the interview, as recommended by Smith, Flowers and Larkin (2012), was being attentive and positively engaging with the co-participants, so that I was best able to enter their world. I made minimal notes during the interviews as I found it took away from the data-gathering processing. Additionally, giving co-participants my full attention and being a highly engaged active listener helped my push my preconceptions aside.

As suggested by Groenewald (2004), I made field notes of my reflections as promptly after the interview as possible. These notes were primarily about if the interview met my ingrained expectations and how the data related to my assumptions, which helped me dismiss these presumptions in the data analysis phase of my study. This is a typical IPA bracketing tool (Milevsky, Niman, Raab, & Gross, 2011). I also made notes of new themes that emerged during the interview process that were unexpected. It was important for me to reflect on them and evaluate if they should inform my research or if I was having an emotional response to them that was irrelevant to the research. An example of this experience was when a co-participant discussed how their experience with hospice palliative care changed their perception of death. As per IPA methodological suggestions, I made notes about my emotional reaction to this information, as it was an experience I had when a family member passed and used hospice palliative care services, yet I had not recognized this in myself until my co-participant revealed it as part of their experience. This examination was important so that I could then consider if this piece of data should inform upcoming interviews.

Data Analysis
Once an interview was transcribed I read it numerous times (Creswell, 2013; Smith & Osborn, 2007), immersing myself in the data to gain a feeling for the co-participants’ essence of the phenomena (Cresswell, 2013; Donalek, 2004). After developing an overall sense of the data, in the margin of the transcript I sequentially noted significant phrases or narratives that stood out, but I did not yet make any judgments on what deserves special attention (Smith and Osborn, 2007; Fade 2004; Alase, 2017). Once this process was completed, I went through the interview again and coded the findings. Subsequently, I put this information and the corresponding data notes into one document and began clustering the information under preliminary themes (Fade, 2004). I repeated the above process for each of the five interviews, using a different colour for each co-participant as I moved the data, to make it easy to be able continually go back and fact-check the information with the original transcript (Alase, 2017). As I added data from each interview to this master list, if there was a theme from an interview that fit under a pre-existing theme I placed it there; if not I created a new theme. Numerous themes emerged that related to the research question. Once this step was completed I established connections between the themes and merged related themes together in a meaningful way (Moser & Korstjens, 2017; Alase, 2017). As per IPA methodology, the researcher’s perspective forms part of this analysis (Donalek, 2004; Moser & Korsetjens, 2007) and the researcher incorporates their own interpretation in deciding how to cluster the data (Smith & Osborn, 2007). I regularly returned to the transcripts in order to ensure my analysis remained true to the essence of the co-participants’ narratives.

To further ensure the essences of the interviews were accurately conveyed, at this point each co-participant was contacted and presented with the preliminary extracted themes from their interview (Hycner, 1985; Martins, 2008). This step added important validity to the study (Donalek, 2004; Hycner, 1985) and supported the concept of the participant as a co-participant.
With four co-participants, this step occurred via email, because it was more convenient for the co-participants, and with one participant it occurred over the phone. All co-participants agreed with the thematic analysis as being true to their experience and the narrative they shared in the interview.

At this point, I had a list of preliminary themes, and I then began engaging with the data to organize and establish their interrelationship. Throughout the process of creating themes I attempted to use the language of my co-participants (Fade, 2004). However, it was necessary for me to use abstraction and name the themes in relation to how the data from each interview set connected (Fade, 2004). As per a recommendation from Fade’s (2004) paper on using IPA for a framework for analysing qualitative data, in creating themes I asked myself questions about a theme and looked to see if other findings answered the question. This process was also used in creating the superordinate and subordinate themes. For example, I asked myself, in looking at some data, “Was this a barrier to caregivers developing an understanding of hospice palliative care?” As a result, caregivers’ limited awareness of hospice palliative care before using their services, caregiving being stressful, doctors being the initial source of information about hospice palliative care, and caregiver interpersonal barriers became subthemes under the superordinate themes of caregivers having barriers to understanding hospice palliative care.

My findings are presented in paragraph form where I summarize and contextualize the co-participants’ narratives (Alase, 2017). In presenting my findings under the themes, I included excerpts from the transcripts, without grammatical editing, to illustrate the themes and sub-themes that emerged and to directly include the voice of my co-participants (Alase, 2017).

Throughout this process I continued to bracket my decision-making process, and
my reaction to the data. Making analytic notes is consistent with phenomenological theory, which states that the researcher’s perspective forms part of the analysis (Donalek, 2004; Moser & Korsetjens, 2007).

**Ethical Concerns**

I received approval from the Research Ethics Board of Royal Roads University. I have addressed the issue of protecting people who are vulnerable, those in the midst of loss, by only using co-researchers whose are one year out from the death of the individual they were caring for. The only ethical concern I anticipate in in conducting and analyzing my data is ensuring that my co-participants remain unidentifiable. Other than on the consent form, co-participants’ true names were not used and instead alias titles were employed.

**Findings**

The purpose of my research was to collect data and analyze how five different caregivers found meaning in hospice palliative care, and what that meaning was. My data was elicited via semi-structured interviews, where caregivers shared their experience with hospice palliative care. Based on the analysis of the data, four overarching themes emerged: caregivers had barriers to understanding hospice palliative care; hospice palliative care’s tangible services were an entrance point for caregivers to develop meaning of hospice palliative care; and caregivers found meaning in hospice palliative care as an emotional support for self and caregivers were empowered to talk about hospice palliative care.

When quoting co-participants, their words are presented in italics if they are 40 characters or more, otherwise they in quotations. Following the findings, there is a chapter discussing them. In both of these sections, co-participants are represented with pseudonyms when their words are used and when they are discussed.

**Theme 1 – Co-Participant Had Barriers to Understanding Hospice Palliative Care**
This theme discusses the communication barriers that impeded my co-participants’ understanding of hospice palliative care’s service. Co-participants’ narratives revealed the following barriers: they had limited awareness of hospice palliative care before using their services, caregiving was stressful and this was a barrier to understanding hospice palliative care, doctors were the initial source of information, and there were interpersonal barriers to accessing their service.

Co-participant has limited awareness of hospice palliative care before using their services. Before looking at what meaning was made in regard to caregivers’ understanding and experience of hospice palliative care, I asked co-participants what their level of awareness and understanding of hospice palliative care was before they became caregivers. Common sense dictates that having a lack of awareness impacts understanding of (and also engagement with) a service. All five co-participants had incomplete understandings of what hospice palliative care services could offer. Additionally, there was general confusion associated with the words hospice and palliative, including around the question of if they were different or the same. Dianne stated that hospice palliative care “wasn’t even on her radar” and April said “she had never heard of it.” Nina and Roberta thought that “palliative” was hospital care, and “hospice” was home care. Holly stated that she originally thought “hospice” and “palliative” were the same until she visited a family member who was dying in the hospital. During that time, she realized that there was a difference between “hospice” and “palliative”. She was not confident in the nature of their difference but thought that “hospice” referred to a separate building for care of the dying. All co-participants identified that, if they were asked, they would have guessed that hospice palliative care was a service for those at the end-of-their life.
The stress of caregiving was a barrier to understanding hospice palliative care.

Throughout the interviews, I did not ask any questions about the co-participants’ psychological state during their time as a caregiver. However, as co-participants narrated their experience, they shared reflections on what their mental state was during this time in their life. It was clear that the stress of being a caregiver, mixed with their own grief, deeply impacted their ability to intake and process communication about hospice palliative care.

All co-participants emphasized that caring for the patient, and also taking care of other loved ones during this time, was intense and stressful due to the logistical and emotional demands it placed on them. The stress of caregiving was compounded by the challenging domino-like impact it had on the rest of their life. Caregiving impacted co-participants’ ability to work and to care for their own children. As Roberta said, “Everything goes on hold. Your work changes. Your home changes. Everything.” This was an experience also had by April, who left her job and created a home-based business so she could better manage caregiving:

> It was just heart wrenching. I thought, “How do I call in sick when I’m going to ruin eight people's days and everybody else at work that has to cover for me?” And we just decided at that time, I can’t work. I have to say home.

April still had the stress of trying to be available for her daughter, and felt like she was failing at that because of the demands of caregiving. She explained:

> If I am not doing well the family’s not going to do well. So there was a domino effect there. So if I’m not coping with the grief and taking care of myself, how am I gonna help everyone else do that?

April’s narrative, as well as the other findings about stress, emerged despite the fact that I did not ask any questions regarding the stress level co-participants experienced while caregiving. The findings about stress emerged when I was asking questions designed to elicit information about
communication about hospice palliative care or questions such as “can you tell me more about that?” Co-participants were apologetic that they could not remember items and referred to their level of stress and exhaustion as a barrier to recalling and processing health care interactions and information. For example, Nina said that she doesn’t remember anything about anyone from a hospice palliative care organization calling her after her mom died, but she knows that happened. Nina explained that because of her trauma, exhaustion and grief, she had lack of clarity about who was providing services, and Dianne echoed this sentiment.

Doctors were the initial source of hospice palliative care information. Four of the five caregivers first heard about hospice palliative care from doctors, while one, Nina, said she was “referred” to hospice palliative care by the Canadian Cancer Society. All of the co-participants held the assumption that hospice palliative care was a phenomenon you had access to when the medical system recommended it. While residential hospice care, community care nursing, and medical palliative services do require a medical referral, hospice palliative care services do not. All my co-participants only accessed hospice palliative care when they were advised to by the medical community, and this signified that death was imminent. When introduced to hospice palliative care through this information channel, none of the co-participants subsequently felt clear on what services hospice palliative care would provide.

Co-participant had interpersonal barriers to accessing hospice palliative care. All co-participants held the understanding that hospice palliative care should be accessed only with the permission of the patient. In other words, the patient was like a gatekeeper who controlled whether or not the caregiver could access hospice palliative care. Both Roberta and Nina accessed hospice palliative care support for themselves and the patient when the patient realized that the caregivers were overwhelmed and needed help. Nina recalled about her patient:
She was proud and independent for as long as she could. Then as soon as she saw it was a lot on us because it went from me visiting every day to me being there three or four times a day and staying. Then she said okay to help.

According to Roberta, Nina and April, pride of the patient could be a barrier to accessing hospice palliative care. They reflected that receiving help could threaten the patient’s sense of autonomy and independence, and that the concept of receiving support could be uncomfortable. April’s patient had a lifetime of independence, and she felt this would impact the patient’s willingness to be supported by outside help. She wished to respect his autonomy and explained:

He was such an independent person. My grandmother passed away when I was really young so he was just always on his own. Took care of business and I think it was just really important to let him feel that that was continuing as long as possible.

Additionally, Nina and Roberta also noted that information may not get to all caregivers because one caregiver may have their own interpersonal barriers to accepting it and therefore not share the information to other caregivers. For example, Nina commented that her step-father, the other caregiver for her patient, “was proud and thought he could do it all on his own,” and this could impact the information he passed on to other caregivers.

Summary. This theme draws attention to the barriers that my co-participants experienced in developing an understanding of hospice palliative care. Their experiences show they had limited understanding of hospice palliative care before it was suggested to them and that, when it was introduced, it signified that death was imminent. All co-participants felt that the service should only be contacted with the support of the patient. It was also noted that some members of the family who were also caregiving the patient might receive information about hospice palliative care and that information might not get passed on. Additionally, co-participants found caregiving exhausting and stressful and this impacted their ability throughout the process to
remember and process information. Despite the barriers to learning about hospice palliative care, my co-participants received hospice palliative care services that became meaningful to them.

**Theme 2 - Hospice Palliative Care’s Tangible Services Were an Entrance Point to Co-Participants Finding Meaning in Hospice Palliative Care**

While hospice palliative care provides a variety of support services and programs, hospice palliative care’s provision of medical beds, counselling services, and a wellness drop-in service were the three services that were mentioned in the caregivers’ narratives. Co-participants were clear that these tangible services were meaningful to them and made them feel cared for, which subsequently reduced their stress. Note that this theme therefore intersects with Theme 4 of hospice palliative care as having meaning to caregivers as an emotional support (presented below).

The three co-participants who used hospice palliative care while their patient was at home all valued the medical bed service, which included delivery and set up, directions of use, and pick up service, all without a fee. During the interview, they exhibited notable clarity in remembering this service. They valued the caring way that this service was delivered and how it made them feel supported. Holly recalled:

*Well the hospital bed was a big one. That they came and literally moved all other furniture out of the room and just installed this hospital bed and taught my brother how to use it which was super. And then of course, they came and collected it when we no longer needed it. They must have called and we told them she had passed away and 48 hours later they just came and discreetly took the bed away and I didn't have to do anything and that was great.*
Nina spoke about the comfort of the bed for the patient, and how she associates hospice palliative care in allowing her patient to be at home longer. She felt that this service gave them the opportunity to choose what was best for them and thus was nurturing. Nina said:

> It gave us more of the days of being at home, which was a good feeling, instead of more of the days in the hospital having that dying feeling, right. It’s just her home. She was in her bright living room surrounded by the things that made her happy, with her dog.

While Nina associated this service with allowing her mom to be at home longer, Holly associated this tangible service with allowing her mom to actually die at home. The bed itself was illustrative of the feelings of being supported that the caregivers experienced from hospice palliative care.

After the patient passed away, two co-participants, April and Dianne made use of the counselling services, both for themselves and their children. They felt that the service helped them in their role of caring for others. Two of the other co-participants commented that they should have used the counselling services, noting that they were too busy or tired to use it, but they also felt good knowing that it was offered. Nina recalled that someone did call her about counselling, and also spoke to her step-dad (the other caregiver). Nina was too tired to use the services and her step-dad was still in too much grief and pushed away the offer, but Nina felt supported just by receiving the call.

There are two other services that had meaning to caregivers. April used the weekly caregiver wellness program and both April and Roberta had patients in residential hospice palliative care. The meaning of these services to the caregiver is presented in theme 3, as despite being tangible services, the magnitude of their value was best illustrated under theme 3, as my co-participants spoke directly about how these services supported their self-care.
Hospice palliative care’s tangible services were easy recalled and named by the co-participants. Co-participants found value in these services beyond the tangible; they made them feel supported and were a symbol of the culture of care they experience with hospice palliative care.

**Theme 3 – Co-participants Found Meaning in Hospice Palliative Care as an Emotional Support For Self**

When asked what hospice palliative care meant to them after using these services, the words supportive, calming, a source of relief, and stress-reducing emerged throughout the interviews. The theme of hospice palliative care as a source of emotional support for the caregiver was the strongest message that co-participants shared from their experience with hospice palliative care. For my co-participants this meaning developed through experiencing support from hospice palliative care personnel, through receiving an information booklet, and for one co-participant through a support group. Co-participants also reported that the presences of hospice palliative care in their caregiving journey provided opportunities for interpersonal engagement, both between hospice palliative care personnel and caregivers, and between family members.

The word comfort emerged in four of the co-participants’ narratives. When asked what comes to mind when they think of hospice palliative care, Dianne, Roberta, April and Holly used the word comfort. Nina used the word calming, which is similar in meaning. In her narrative, Nina shared that one of the ways in which she received this feeling was through the regular phone calls from hospice palliative care:

*I don’t know if it was daily but every once a while they’d just check in with us to see if we needed anything. It was nice, sometimes it was crazy, sometimes it was obviously the wrong time, but you never can predict that. It was just comforting. It was probably after*
[the death] that I had a lot of phone conversations with them, when time would permit with two kids running around. I think before my mom died, I got more from just knowing they were there but I probably used them more after she died then when she was alive. It was a comfort just knowing they were there if I needed it. It was just the fact that I knew they were there, and I knew how to get ahold of them.

Hospice palliative care provided comfort by reducing co-participants’ worries. All co-participants struggled with feelings of fear and worry during their time as a caregiver. Co-participant Nina said about hospice palliative care:

*It was all very calming, and it brought us back down to the care instead of getting worried. There was a lot of worry on our part, and they really helped with, I guess, stabilizing that feeling.*

Roberta stated that without hospice palliative care her and her family would have had more fear. Similarly, reflecting on her experience of her patient’s final days and the role hospice palliative care played, April recalled that she was terrified because she didn’t know what to expect, and that without hospice palliative care these emotions would have been more intense. This intensity and fear, and the general stress of caregiving for the co-participants was magnified by not knowing what to expect as caregivers and for their patient’s death. However, Nina, Holly, April, and Dianne said that hospice palliative care helped them prepare and to know what they could expect. This support was stress reducing. Roberta and Dianne received a booklet, published by a palliative hospice organization, about preparing for death. Dianne stated that the booklet made her feel more prepared and empowered, and less confused. Roberta thought the book reduced fear and made her feel more empowered. Both Roberta and Dianne also valued that the booklet opened up conversation between family members and provided opportunities for interpersonal communication about death.
Caregivers also valued the role that hospice palliative personnel played by having conversations with them to help prepare for the death of their patient. April stated that she realized she wasn’t an expert on death, so appreciated there was one, as did Dianne, who expressing her appreciation for the staff’s kindness and caring. During our interview, Roberta become emotional when she was talking about hospice residential care staff and communicated her emotion:

*Well I think the staff there is exceptionally compassionate, this one makes me cry.*

Dianne and Holly, who were caregiving people dying at home, articulated that the regular check-ins from hospice palliative care personnel were meaningful. Co-participants didn’t have distinct memories of specific hospice palliative personnel although they do recall phone conversations with them and said that these check-ins by caring experts provided logistical and emotional support. Hospice palliative care helped Holly, Roberta and April feel less alone. In order to reduce her loneliness April went to a weekly service titled “Self-Care Wednesday” for short stress-reducing bodywork sessions. She also took part in counselling and participated in a hospice palliative care grief support workshop. In speaking about her experience with hospice palliative care, she said:

*I found it really helpful to know that I was not the only person in the world that felt this way. My world had been turned upside down. When someone you live with passes away, it just changes everything. But when I went to that group, everyone in that room knew what I was going through. Everyone. So that was a really comforting feeling.*

It was clear that feelings of loneliness were not expected by the co-participants and that this emotion added to the overwhelming nature of being a caregiver.
As well as helping co-participants feel less alone, hospice palliative care also provided a sense of relief to co-participants. When asked what hospice palliative care meant to them, Dianne, Roberta and Nina said that hospice palliative care meant relief. April said that when her patient was dying in a residential hospice, being part of hospice palliative care gave her a sense of relief. She explained:

*It gave us as a spot to go through it without the feeling like we were in a fish bowl. It was special. It was a safe space. I am really thankful for that.*

Residential hospice palliative care was instrumental for both Nina and Roberta in reducing their stress and making it easier to grieve. Roberta explained:

*It made you able to grieve a bit more without the stress of it. I mean, death is stressful anyway, no matter how you look at it, right? Especially in those kinds of situations when you’re watching someone die. But I think [hospice palliative care] enables you to relax a little bit and grieve some more.*

My co-participants recalled caregiving as an exhausting time when they were stressed, scared, and lonely. Despite the fact that co-participants had differing experiences with hospice palliative care, they universally stated that their relationship with hospice palliative care meant emotional support and reduced stress. Within the different co-participants’ narratives, their meaning of hospice palliative care was rooted in the experience of comfort, relief, reduced fear, and feelings of being less alone. These feelings developed through regular phone conversations, the safe environment of residential hospice care, and the provision of printed information and emotional support services.

**Theme 4 – Co-participants Empowered to Talk about Hospice Palliative Care**

In the interviews, co-participants shared how their experiences of caregiving changed their understanding of hospice palliative care, and how they would share this knowledge. Four
participants were empowered to communicate about hospice palliative care with others. April said she would actively encourage others who become caregivers to access hospice palliative care because it would help them take care of themselves. She wants people to know to:

\[
\text{Take advantage of what is available to you and that caring for yourself is just as important as caring for your loved ones. You can’t take care of them if you don’t take care of you.}
\]

Both Dianne and Holly felt more willing to discuss the subject of hospice palliative care for reasons similar to April—they want people to be better prepared for caregiving and to realize that knowledge is empowering and reduces stress. However, all co-participants expressed the belief that hospice palliative care is something that people might not want to talk about, because it is a signifier of death. Roberta explained:

\[
\text{If I admit to getting healthcare, then I admit he is dying. But you DO already know it, so admit it and then it is so much easier. There’s nothing easy about it, but it is so much smoother to deal with.}
\]

Roberta said that hospice palliative care should be “a bigger deal,” that there needs to be more societal acceptance of death in order for people to prepare, and that she wished this would happen. Similarly, Dianne said about death and hospice palliative care:

\[
\text{I think it is a conversation that we should be having more often, because everybody is going to be dying. It’s part of life. It is really important work that [hospice palliative care personnel] do, and it should be something that should be considered more when we are living.}
\]

Dianne referenced how society prepares for babies being born, as a comparison:
When you have a baby, they encourage you to take prenatal classes, and they encourage you to learn all about the things that are coming up that are going to prepare you to have a baby, but in end of life, there is no classes.

Nina said she wants people to say “yes” to receiving hospice palliative care and that people need to accept this help. However, she was unsure of how she would talk about this topic with others because it still reminds her of a sad time with her patient. While April, Roberta, Dianne, and Holly realize that hospice palliative care is something that people do not want to talk about, and that there is stigma around talking about death, they felt more aware of and comfortable with death as a universal human commonality. This awareness added to their feelings of empowerment to discuss the issues surrounding it.

All participants still had a lack of clarity about the differences between hospice palliative care services and other end-of-life medical services such as community home-care (typically provided through a nursing center and accessed with a medical referral). However, co-participants had a greater awareness that a range of end-of-life services exist that are valuable to both the patient and caregiver. They expressed passion in encouraging others to access hospice palliative care in order to be better supported through caregiving and grieving.

Summary

Through semi-structured interviews I discovered my co-participants’ meaning-making experiences of hospice palliative care. This included understanding how they developed meaning of hospice palliative care. Key findings included: data on the lack of understanding co-participants held about hospice palliative care before using their services; insight into how hospice palliative care’s tangible services helped my co-participants develop meaning; and subsequently further insight into how caregivers found meaning in hospice palliative care as care
for self. Finally, my data brought forth information on caregivers’ desire to transmit their learnings about hospice palliative care to others.

**Discussion**

The focus of my research was to comprehend what hospice palliative care meant to five different people, each of whom was caregiving for a loved one who was dying. This chapter will first present a discussion of my findings and how they correspond to the literature. Following this discussion, there is a section on recommendations for hospice palliative care communicators along with a section on limitations of my study.

**Theme 1 – Co-participants had Barriers to Understanding Hospice Palliative Care**

Caregivers had numerous barriers to understanding hospice palliative care. These included: their limited understanding of these services before using them, the stress of caregiving, the way they were introduced to hospice palliative care, and interpersonal barriers. These barriers informed the way my co-participants found meaning in hospice palliative care, and also impacted what that meaning was. I discuss both these issues in turn, below.

**Caregivers have limited understanding of hospice palliative care before using its services.** As evident in the findings, before becoming a caregiver, co-participants either did not have an understanding or had an incorrect understanding of hospice palliative care’s purpose and services. Although the findings in my study align with the literature, which stated that there is a general societal lack of understanding of hospice palliative care (Claxton-Oldfield et al., 2004), I was nonetheless surprised that my co-participants’ understanding of hospice palliative care was so limited. Additionally, it was notable that other than Holly, none of my co-participants had previous experience, even conversationally, with hospice palliative care. Holly had been exposed to hospice palliative care before becoming a caregiver, and she communicated in her narrative that she felt confident in her decision, made promptly after becoming a caregiver, to use hospice
palliative care services. While she was unsure of its purpose or what it would offer her, she understood that these services would help her. These findings demonstrated to me that an introduction to hospice palliative care before someone becomes a caregiver could inform a caregiver’s willingness to develop understanding of, and to access, hospice palliative care.

I am curious if my results would have been different with an older generation. An older generation could have the opportunity for more conversational experience about hospice palliative care, because they might be exposed to more narratives and information about dying. This would be an interesting area for future research.

The naming practice for hospice palliative care confused my co-participants. This confusion became obvious at the beginning of data collection. In my first interview, it was clear that I had to establish a shared definition of hospice palliative care with co-participants, to ensure we were talking about the same services. I was using the term *hospice palliative care*, which is used by the BC Hospice Palliative Care Association and the Canadian Hospice Palliative Care Association. However, my co-participants accessed hospice palliative care services near their homes in the Comox Valley and Campbell River, where the organizations providing these services are called Comox Valley Hospice Society and Campbell River Hospice Society. Without ensuring we had a shared definition of hospice palliative care, I could not have as effectively conversed with co-participants or confidently analyzed my co-participants’ narratives. My experience matched the literature stating that a challenge in understanding hospice palliative care is lack of consistent naming of their services which make them more difficult to discuss and understand (Pastrana et al., 2008; Weil et al., 2015; O’Conner, Davis and Abernethy, 2010).

**The stress of caregiving was a barrier to understanding hospice palliative care.** During the interviews, my co-participants regularly apologized for their inability to recall information clearly. Additionally, much of the data that was elicited during my interviews
includes the co-participants referencing their stress level during caregiving. None of my questions were about co-participants’ stress or fatigue level, yet all of the co-participants’ narratives included information on exhaustion and stress. These findings were unexpected, but important. What is notable about these findings is they illustrate that co-participants had a challenging time processing information about hospice palliative care due to psychological noise caused by exhaustion and stress. Noise refers to an external barrier in the communication process that can affect the receiver’s ability to make sense of the information being delivered to them (Lunenburg, 2010). These findings have important consequences for hospice palliative care and can be used to consider what communication tools could support more effective communication with caregivers.

**Doctors were the initial source of information.** The findings in this theme were expressed only briefly, but were done so by all participants, with directness and clarity. These results were highly meaningful to my research question and therefore I explore this theme robustly in this thesis discussion. These findings from my study have important consequences that relate to the medical system as an information channel to caregivers’ understanding of hospice palliative care as being provided by a community-based non-profit association and as a signifier of death.

When hospice palliative care was introduced in the context of the medical system, it created the false understanding that caregivers need permission by doctors to access hospice palliative care services. All co-participants connected with hospice palliative care only after the medical system recommended it, and none of the co-participants, even at the time of the interview, realized they could call hospice palliative care without a recommendation from other health professionals (other than for residential hospice palliative care, hospice-care does not require a doctor’s recommendation or referral). Co-participants did not feel they had agency in
accessing the services, and until discussing it with me in their interview they held the erroneous belief that hospice palliative care services could only be accessed with their doctors’ referral.

In recounting their experience of hearing about hospice palliative care from the doctor, co-participants had trouble remembering what they were told, however, they were clear that the introduction to hospice palliative care signified that death was imminent for their patient. This constitutes a significant misunderstanding of the meaning of hospice palliative care. Other than Roberta, whose patient died shortly after diagnosis, my co-participants were not introduced to hospice palliative care upon diagnosis of the patient. It is interesting to consider how introducing hospice palliative care in the context of the medical environment versus community could impact the understanding of the broader context of hospice palliative care. However, in the case of my co-participants it is not definitive that learning about hospice palliative care from within the traditional medical system contributed to their belief that hospice palliative care signified their patient’s rapidly approaching death.

What is important in my findings is that the doctor (and in the case of Nina, the Canadian Cancer Society) had power in shaping the initial understanding of hospice palliative care. This addresses the larger matter of the responsibility of these professionals to ensure they understand and convey a holistic meaning of hospice palliative care, and to present this topic to their patient and the caregivers at a meaningful time, keeping in mind the noise barrier. The literature points to medical experts’ lack of understanding of end-of-life care services (Ahmet et al., 2004). This is concerning when doctors are the channel through which information is being conveyed to patients and their caregivers. Our society promotes the widely-held assumption that doctors are experts, yet none of my co-participants heard of hospice palliative care early in their patient’s diagnosis.
The literature suggests that placing the introduction of hospice palliative care within the hierarchical medical system could be creating an accessibility barrier due to the use of medical language (Connor, 2005). Although I agree that this could be a barrier, my findings did not illustrate that this was the experience of my co-participants. However, it is important to note that none of my interview questions were designed to solicit information specifically about co-participants’ experience with medical language. The literature on this topic has me questioning whether my co-participants would have used more of hospice palliative care’s services if they had heard about them through a different channel – one where hospice palliative care was positioned as a community service, not a medical service. My co-participants, even after using hospice palliative care services, were still unclear about the purpose of hospice palliative care. If they had learned about hospice palliative care in a different context than from within the medical system, could greater understanding have been formed? The literature suggests this is the case; however, my study is not definitive.

**Caregiver interpersonal barriers to accessing hospice palliative care.** My study found that co-participants were aware of the potential implications of conflicting feelings between the patient and caregiver, or between multiple caregivers, about accessing hospice palliative care. In addition, co-participants were aware that information about hospice palliative care could not be channeled effectively to multiple caregivers. Both of these interpersonal barriers could impact a caregiver’s understanding of hospice palliative care. This observation is rich with potential for analysis that connects to the literature and other topics being discussed within this chapter.

There are numerous ways to consider the reasons behind communication breakdown between multiple caregivers. It can be contemplated through the death denial (Global Atlas of Palliative Care, 2004) or the hospice palliative care as a “last resort” hypothesis (Sekelja et al., 2010) that are discussed in the literature review. Additionally, it could be examined in a way that
considers whether the messages from doctor to caregiver, and also between caregivers, are being encoded and decoded effectively. In both cases, the lack of conversational norms and the lack of understanding about hospice palliative care could be making it difficult to discuss hospice palliative care. What struck me as most interesting, though, is the hypothesis that hospice palliative care support could be rejected by caregivers, and thus information is not passed on to other caregivers, because of a generational perspective. My co-participants were all open to receiving external support; however, two co-participants noted that older caregivers might not be interested in understanding hospice palliative care because they reject this type of support. They suggested that an older generation would have grown up in a medical culture where death and dying were bureaucratically managed and placed in the context of the medical system (Gill, 2007). In contrast, younger generations have grown up with a healthcare system that includes more holistic and conversational-based health services such as midwives and doulas. It is important to remember that caregiving relationships are complex and involve layers of psychological, cognitive, and practical factors (Papadatou, 2006). There could be a generational cultural barrier which is impacting willingness to take in and transmit information. This area would be worth future study. While these findings may seem trivial, they are in fact crucial in terms of pointing to opportunities to create greater societal understanding of hospice palliative care as part of today’s changing death discourse, and to improve the way hospice palliative care frames itself to different generations.

Lastly, my co-participants were clear that they would not feel comfortable proactively working to understand or access palliative care support while caregiving without consent by the patient. This was also the experience that I had with my family when they did not want to access hospice palliative care when my step-father was dying. His primary caregiver, like the co-participants in my study, felt that hospice palliative care should not be accessed until the patient
was ready. If the patient lacks understanding of hospice palliative care, how would they know when to suggest the service or give their approval for accessing them? My results indicating that co-participants do not want to contact hospice palliative care without their patient’s consent. This finding is in line with the study by Ahmed et al. (2004) which found that there is a commonly false understanding that using hospice palliative care is perceived as giving up on a patient and that hospice palliative care is for the patient only, not for the patient, caregiver, and family members together.

**Theme 2 – Hospice Palliative Care’s Tangible Services Were an Entrance Point to Co-Participants Finding Meaning in Hospice Palliative Care**

The tangible services that hospice palliative care provided had value to caregivers, but beyond that, the experience of receiving them was instrumental in how the caregivers developed a sense of hospice palliative care’s meaning. The services were the antecedent to my co-participants experiencing hospice palliative care’s culture of care for the caregiver, and their subsequent ability to understand hospice palliative care as providing emotional support for themselves. Although tangible services, such as hospital beds, perhaps seemed to only be filling a practical goal, they were important in establishing the connection between caregivers and hospice palliative care. Once that connection was made, the communication channel between caregivers and the hospice palliative care organization was established and started to function.

Interestingly, although not all caregivers used hospice palliative care’s free counselling services, it was one tangible service identified by all caregivers in their narratives as valuable, and it helped them make meaning of hospice palliative care as care for the caregivers. Hospice palliative care organizations continued to contact caregivers after the death of the person they were caring for and to remind them of this service. Co-participants had clarity about this service, perhaps because it was offered when the caregiver was dealing just with grief and not caregiving,
which meant they had potentially less psychological noise and other barriers to taking this information.

**Theme 3 – Co-participants Found Meaning in Hospice Palliative Care as an Emotional Support for Self**

Through their experience of using hospice palliative care services, all of my co-participants developed meaning of hospice palliative care as emotional support for the caregiver, not just the patient. This theme was extremely pronounced and was interesting, as it is not the dominant societal conversation about hospice palliative care. Part of my findings relate to the type of communication that influenced how the co-participants developed an understanding of what hospice palliative care is and what it offers. This section highlights the role that two communication channels played in the development of meaning. First, I discuss the role of hospice palliative care personnel, and subsequently I discuss the impact that an information booklet had in how hospice palliative care came to hold meaning for the co-participants.

Co-participants’ comprehension of hospice palliative care shifted throughout their process of experiencing hospice palliative care service. It grew from a vague understanding of hospice palliative care as end-of-life care, to a knowledge and passionate appreciation of hospice palliative care as predominately about care for the caregiver. This meaning developed initially through communication with hospice palliative care personnel about tangible service delivery and then grew through the subsequent interpersonal conversations with hospice palliative care personnel. Additionally, the narratives of two co-participants stressed the value of a booklet that is distributed by the Canadian Hospice Palliative Care Association called *A Caregivers Guide*. The booklet provided caregivers with information about what was happening to their patient physically, what to expect as they moved towards death, and advice for pre-death and post-death. The intended audience for this booklet is the caregiver, as opposed to the patient. Caregivers were
able to take in this communication on their own time, in a non-hierarchical environment. As a result of these communication strategies, the information in the booklet helped my co-participants make sense of what was occurring, and prepared them for what was to come. The information they received from this booklet empowered them and reduced their stress. The booklet also played a role in facilitating conversation and making meaning of death and hospice palliative care. The booklet helped caregivers and family develop shared language and understanding on a topic that does not have societal conversational norms. This subsequently he

In addition to facilitating a personal hermeneutic process, the booklet supported conversations between caregivers. In their narratives, co-participants emphasized how greatly they appreciated the emotional support that hospice palliative staff provided. This support was experienced through conversations. Talking about grief with family can help caregivers cope (Pennebaker, 1997, p.29). Reading the booklet and using it as a tool to engage in a conversation assisted caregivers in cultivating a shared meaning with others and in negotiating their own meaning of caregiving and hospice palliative care. My co-participants could not recall the content of most of these conversations, but nonetheless their conception of hospice palliative care was significantly informed by communication with hospice palliative care personnel, who placed little demand on the caregivers and checked in regularly with them. The hospice palliative care personnel helped caregivers feel supported and prepared them for the patient’s death and therefore was significant in how meaning of hospice palliative care was made and what that meaning was.

It is interesting to compare and contrast how caregivers made meaning of hospice palliative care based on interactions with hospice palliative personnel versus their primary care physician and emergency doctors. The medical community has been criticized for engaging in communication with patients and their family in a style that is impersonal and formulaic, as
compared to treating communication as a dynamic process that requires thoughtful attention (Goldsmith et al., 2011). My study results affirm that there are differences between the experience of receiving information from a doctor versus through hospice palliative care. While my co-participants did not state that the communication between them and the doctors was impersonal and formulaic, their narrative did not express that the doctors were instrumental in helping them develop correct understanding or personal meaning of hospice palliative care, whereas my findings demonstrated that communication with hospice palliative care personnel was instrumental in how caregivers develop meaning of hospice palliative care. The communication with hospice palliative care personnel was interactive and provided opportunity for an ongoing semi-consistent feedback loop which allowed caregivers to express their emotions and ask questions. This interactive communication made caregivers feel supported and cared for. This is concurrent with the literature that suggests sense-making of a phenomenon occurs when there is trust between communicators, and this trust is impacted by there being space for questions and conversation (Jordan et al., 2009). This interactive mode of communication leads to more successful decoding of information than communication experienced in a more typical linear learning model in the medical system (Jordan et al., 2009). Regular communication between hospice palliative care personnel and the caregivers allowed the message of hospice palliative care as emotional support for self to be being received.

My study revealed there was a difference in the communication context — the doctor provided information in the context of a time-restrained medical system, and hospice palliative care provided it outside of the traditional frame of the medical system, through informal phone conversations and in residential hospice care. Additionally, the destination for the message was also clear, in that the caregivers knew it was for them — to support them.

**Theme 4 - Caregivers Empowered to Talk About Hospice Palliative Care**
After experiencing hospice palliative care, my co-participants had an expanded understanding of what it was. This new comprehension included, most notably, hospice palliative care as care for the caregivers. These findings, which were pronounced amongst all five caregivers, surprised me. The co-participants valued services that also assisted the patient, such as the home medical bed. However, interestingly, tangible services such as these were not mentioned when they discussed what they would like people to know about hospice palliative care. The caregivers in my study want people to know that hospice palliative care can provide valuable support that allows the caregiver to be able to better care for self. As a result of their experience as caregivers using hospice palliative care, co-participants felt empowered to talk to others about hospice palliative care, as well as death and caregiving, despite the societal stigma surrounding this topic.

This voice of bereaved caregivers is important, and can be effective, in raising societal understanding and awareness of hospice palliative care and helping others make meaning of this phenomenon. As evident through the theory of social constructivism, the way a subject gets talked about can impact societal understanding of a phenomena (Littlejohn & Foss, 2009, p. 892). Through conversation, those who have used hospice palliative care as a caregiver can help socially construct meaning and awareness of hospice palliative care. Additionally, research states that informal interpersonal communication plays a powerful role in health behaviour, because it facilitates meaning making, and human beings act in accordance with meaning (Cline, 2011). Therefore, the voices of bereaved caregivers sharing where meaning was made for them with hospice palliative care can help hospice palliative care become more widely understood.

Summary

My findings were consistent with the literature that states there is a general societal misunderstanding of hospice palliative care and that there are challenges in understanding it. My
co-participants noted that there is value in increasing the understanding of hospice palliative care so that more caregivers receive support. My co-participants were introduced to hospice palliative care through the medical system. Hospice palliative care’s tangible services were how caregivers first began interacting with hospice palliative care and these services were a way hospice palliative care began to mean something to the caregivers. However, it was through communication with hospice palliative care personnel that caregivers began to understand hospice palliative care as emotional care for self. Co-participants in this study are still not confident in their knowledge about the scope of services offered by hospice palliative care and about how hospice palliative care fits into the landscape of end-of-life services. However, co-participants expressed passion about talking to others about why hospice palliative care is an important service. My findings, and health care communication literature, point to the value of interpersonal communications in developing understanding of hospice palliative care. This greater understanding can lead to earlier and increased access to hospice palliative by caregivers and be beneficial in building community support for hospice palliative care associations.

**Recommendations for Hospice Palliative Care**

The results of my study elicit many suggestions for hospice palliative care communicators to consider in the efforts to increase understanding of their purpose and services.

- **Naming.** The findings in this study revealed that the naming practices for hospice palliative care confused my co-participants. These findings can be used to emphasize the need to use consistent and accessible naming in hospice palliative care communication, particularly among geographically neighboring hospice palliative care associations.

- **Reminder to doctor.** The findings in my study revealed that caregivers hear about hospice palliative care from their doctor. These findings could be used as a reminder to...
doctors that they play a pivotal role in how hospice palliative care is understood by caregivers. Doctors can aim to channel information to both the patient and all caregivers in a conversational fashion to increase the effectiveness of communication about hospice palliative care.

- **Community engagement.** Because caregivers and patients are first hearing about hospice palliative care in the context of the doctor-patient relationship, hospice palliative care is not being positioned as a community service. While hospice palliative care organizations need to remain mindful that the doctor-patient relationship or doctor-caregiver relationship is currently the primary channel in which hospice palliative care is being introduced, these organizations need to continually seek out other opportunities for community engagement. Increased community engagement will help patients and caregivers understand they can proactively seek out information and support through hospice palliative care directly. Additionally, increased community engagement by hospice palliative care will offer opportunities for conversation, and which can lead to an increased understanding of hospice palliative care on a community level.

- **Highlighting the role of personnel.** The finding in this study that hospice palliative care helped reduce the stress felt by caregivers can serve as an affirmation to hospice palliative care providers that their work has a positive impact on caregivers. One of the ways that hospice palliative care reduced the stress of caregiving was through caregiver interactions with hospice palliative care personnel. Therefore, hospice palliative care communicators could increase the message that hospice palliative personnel are caring experts who provide education and emotional support. This can be done in numerous ways; for example, highlighting the role of the personnel on their website.
• **Distributing information booklet.** This study found that the provision of a booklet about caregiving had positive results not just for the caregivers but also for advancing a better understanding of hospice palliative care generally. Co-participants found that this booklet ignited valuable conversations about caregiving. Therefore, hospice palliative care organizations should continue to ensure their booklet, which stimulated conversation, is being distributed effectively.

• **Messaging about support for the caregiver.** The interpretations of the data suggest that there is value in ensuring hospice palliative care prioritizes the message that hospice palliative care is support for the caregivers and family, not just the patient. Communication that included more information about support for the caregiver would assist in positioning hospice palliative care as more than a service for the final days of a patient’s life. It could increase caregivers seeking out information and support, and reduce the problem of caregivers feeling as if they need the patient’s permissions to do so. Additionally, providing information about how stressful caregiving can be, and the domino effect this stress can have by impacting a caregiver’s ability to parent and work, could help community members understand how hospice palliative care supports the wellness of the community beyond services for the dying. Finally, it is worth noting that caregiving is a topic that could have less conversational stigma, and that it could be more identifiable to people. Therefore, the message of hospice palliative care providing support for caregivers broadens the opportunity for conversation and for increasing the understanding of their services.

• **Ongoing connection with caregivers.** Caregivers indicated that it was meaningful to know that counselling services were available and expressed regret that they did not take
advantage of these services after their patient passed away. They suggested that they were just too tired and were not ready to face their grief. This suggests that it would be advantageous for hospice palliative care organizations to extend communication with the bereaved, offering these services. Meaning is consistently being negotiated, and therefore continued connection could impact further meaning making and understanding of the role of hospice palliative care.

- **Value of phenomenological studies.** This study could serve as a reminder and affirmation of the value of health communicators continuing to learn from their audience, and doing so with phenomenological research. Outside of the discipline of psychology, phenomenological research is a rare approach in health communication; however, it provides a rich opportunity for communications professionals to understand their audience (Babrow & Mattson, 2011) and this opportunity needs to be used more (Cline, 2011). By continuing to research where meaning is made to users of their services, hospice palliative care can continue to build communication that assists in raising societal understanding of their services.

**Conclusion**

This interpretive phenomenological study revealed how meaning was made, and what meaning was made, in regard to hospice palliative care for a small group of co-participants. Through in-depth open-ended interviews with caregivers, I solicited data through caregivers’ narratives about their experiences with hospice palliative care. The findings reveal information that can be used by hospice palliative care organizations to create communication that will help build public understanding of their services. The themes that emerged were: caregivers had barriers in developing understanding of hospice palliative care; the tangible services that hospice palliative care offer were an entrance point to caregivers finding meaning in hospice palliative
care; hospice palliative care became meaningful to caregivers as a service that provided support for themselves; and caregivers felt empowered to talk about hospice palliative care after using their services.

My study points to the need to increase understanding of the term *hospice palliative care* so it can be differentiated between other end-of-life service. Caregivers, even after using the services, failed to have a confident understanding of the term *hospice palliative care* and of how to access the service. Findings also revealed that co-participants were stressed and fatigued and this needs to be considered when medical professions and hospice palliative care providers communicate to them about hospice palliative care. Caregivers also were reluctant to seek more information or engage with hospice palliative care if the patient was not supportive. They also noted that other interpersonal relationships, specifically those with other caregivers, could hinder the development of an understanding of these services, as information might not be being received by all caregivers, due to generational barriers and differing attitudes about caregiving. It was also clear that, although caregivers were introduced to hospice palliative care within the traditional medical context, it was through hospice palliative care interactions, primarily informal regular conversations, that hospice palliative care began to mean something to them. For my co-participants, hospice palliative care became profoundly meaningful as emotional support for the caregiver. This was a pronounced difference from their initial vague and limited understanding of hospice palliative care as services for end of life.

It was valuable to discover that co-participants in this study are notably passionate about what hospice palliative care now means to them and that they very much want people to know that hospice palliative care is not for only the patient only, but also for the caregiver and family members. Co-participants reported that they felt invested in sharing this information with others, and that they held a conviction that more conversations about death and caregiving in today’s
society are necessary. While the findings and analysis from this study demonstrate barriers for increasing understanding of hospice palliative care, they also highlight opportunities to increase understanding of hospice palliative care and the empowered voice of the caregiver.

Limitations of the Study

This thesis does have its limitations. The sample population in this research study is small, with all participants living on Vancouver Island. Co-participants were all middle-aged women who were also parents and employed. All were white except one. None of my co-participants had socio-economic barriers or their own health barriers to accessing hospice palliative care. All co-participants were caring for an adult patient and none were left widowed from the death of their patient. My small sample size did not allow for comparison between regions, cultural differences, or differences on the basis of sex, class, or age.

The nature of phenomenological study design is that it examines a small sample in depth, in order to develop a deep understanding of the phenomenon from the participants’ lived experience (Moser & Korstjens, 2017; Skinta & Brandress, 2017; Mapp, 2008; Milevsky, Niman, Raab, & Gross, 2011). Therefore, this study does not claim to be representative of the total population. My analysis is not meant to be definitive and overreaching. In order to address validity, throughout the study I employed numerous methods such as bracketing and reviewing interview data and analysis with the co-participants in order to ensure that my interpretations were grounded in the co-participants’ accounts of their lived experience.

Opportunities for Future Research

The study examines what hospice palliative care meant to five different caregivers and how that meaning developed. My sample was homogenous, which points to an opportunity to explore the meaning of hospice palliative care among other sectors of the community with
different lived experiences. In my call for co-participants, all responses came from middle-aged women. A future study could explore if the meaning of hospice palliative care is impacted by gender, and also could look at different generational perspectives. Furthermore, future studies on hospice palliative care could consider the role of cultural and societal barriers, and the impact of being marginalized, in developing understanding and finding meaning in hospice palliative care.

On a broader scale, future studies could look at how conversations impact the understanding people hold around phenomena and how conversation can shift these frames of meaning. Cline (2011) suggested that the role interpersonal communication can play in shifting health attitudes and behavior is under-acknowledged and researched. There would be value in researching how interpersonal communication and conversation can impact society’s understanding of hospice palliative care and other end-of-life related services. Finally, as discussed in the literature review, the place of dying and death in current North American culture is shifting, and future research could explore how this shift is impacting stigma and conversations around death and caregiving.
References


Paul, S., & Sallnow, L. (2013). Public health approaches to end-of-life care in the UK: An online survey of palliative care services: Table 1. *BMJ Supportive & Palliative Care*, 3(2), 196–199. https://doi.org/10.1136/bmjspcare-2012-000334


Appendix A: Invitation to Participate

INVITATION TO PARTICIPATE

I would like you to consider being part of a research project that I am conducting. This project is part of the requirement for a Master’s Degree in Communication at Royal Roads University. My name is Karen McKinnon and my credentials with Royal Roads University can be established by calling XXX.XXX.XXXX ext. XXXX. My research has been approved by Royal Roads University in accordance with The Canadian Governments’ Tri-Council Policy on ethical conduct for research involving humans. I will be submitting my final report to Royal Roads University in partial fulfilment for my Masters of Communication. I will also be sharing my research findings with hospice organizations, professional journals and conferences. Results of my research will be publicly accessible and access and distribution will be unrestricted.

The object of my research is to look at what hospice palliative care means to individuals who accessed hospice palliative care and were the primary caregiver for an individual who is now deceased and has been deceased a minimum of six months. Looking at where the meaning was made in regards to hospice palliative care for these bereaved carers has important conceptual significance when it comes to hospice palliative care’s understanding of how their work resonates with others. Practically, this information can contribute to the expansion of effective rhetoric, which can increase community awareness and understanding of their services. This increased understanding can assist in gaining community support for fundraising and in facilitating earlier access to their services by palliative patients and their family.

My research will use a method called interpretive phenomenological analysis, and I will be conducting one-on-one interviews with open-ended questions. In my research method, those that I interview are called co-participants, because their voice is so important. In order that you feel comfortable with me, I will want to meet with you informally before hand. This meeting doesn’t guarantee or commit you to participating. During this meeting, we will ensure that you fit the criteria for participation, review the consent to participate and ensure all your questions are answered. This information meeting will take between 15 and 30 minutes. Before this meeting I will email you the consent form so you can review it.

The research interviews will take place face-to-face in a professional office in the Comox Valley and will take approximately an hour to an hour and a half and questions will aim to capture what hospice palliative care means to them and how that meaning came to be. After the interview, via telephone, you will have the opportunity to hear and confirm that my analysis captures the essence of their experience. Co-participants will also have access to my final research findings once my final thesis has been accepted.

During the interview, information will be audio-recorded and in my report it will be summarized and analysed. Participation in the research, throughout the interview, and within the analysis will be confidential and remain anonymous. At no time will any specific comments be attributed to any individual.

If you choose to participate in this research project, you are free to withdraw at any point before your information becomes part of an anonymous data set, which will happen after our phone call where I confirm that my analysis captured the essence of your experience.

If you would be interested in participating, I encourage you to contact me so I can answer any other questions you may have and ensure that your participations is a good fit for you, and
for the research objectives. If you contact me to discuss participation and then decide not to participate, your information will be maintained in confidence.

Sincerely Karen McKinnon
XXX-XXX-XXXX
Appendix B: Research Consent Form

RESEARCH CONSENT FORM

My name Karen McKinnon, and this research project is part of the requirement for my Masters of Communication at Royal Roads University. My credentials with Royal Roads University can be established by telephoning XXX.XXX.XXX ext. XXXX. In addition to submitting my final report to Royal Roads University in partial fulfilment for a Master of Communication degree, a copy of the final report will be housed at the university and availability through UMI/Proquest and Thesis Canada. I will also be sharing my research findings with hospice organizations, professional journals and conferences. It will be publicly accessible and access and distribution will be unrestricted.

This document constitutes an agreement to participate in my research project, the objective of which is to increase understanding of where meaning is made in hospice palliative care to the bereaved carer. This work has conceptual significance when it comes to hospice palliative care’s understanding of how their work resonates with others. Practically, this information can contribute to the expansion of effective rhetoric, which can increase community awareness and understanding of their services. This increased understanding can assist in gaining community support for fundraising and in facilitating earlier access to their services by palliative patients and their family.

The research will consist of one-on-one interviews with open-ended questions and is foreseen to last approximately 1 to 1 ½ hours. Additionally, participants will be asked to have a phone conversation with the researcher after the interview to confirm that the initial thematic analysis captures the essence of the interviewee's experience, this will take approximately 15 to 30 minutes.

The one-on-one interview will aim to gather data in regard to what hospice palliative care means to individuals who meet the following criteria:

- Are 19 years-old or older
- Used hospice palliative care for themselves as the carer, or for the person they were caring for.
- Are bereaved a minimum of six months, which means the person they were caring for has been deceased a minimum of six months
- Identify as a primary caregiver for the deceased
- Were not a carer for the deceased in a professional capacity

Interview information will be audio recorded and the researcher may make some notes during the interview process. All documentation will be kept strictly confidential and anonymous. An electronic copy, of the interview will be kept with the researcher until the thesis has been accepting via Royal Roads University, once it has been accepted the original recorded data and any transcriptions will be destroyed. The consent form will be kept separate from the interview data analysis, which will use codes and no names, in order to protect the anonymity of those interviewed.

If at any time you wish to remove yourself from the study before your contribution is part of the anonymous body of data you are welcome to withdraw. Your contribution will be considered part of the anonymous body of data after you have a phone conversation with the
researcher to confirm that the initial thematic analysis of your interview captures the essence of your experience with hospice palliative care as it relates to the research.

While the researcher is aware of the potentially emotional nature of the subject matter, the researcher is not a counsellor and should support be needed co-participants can reach out to the Crisis Line Association of BC at XXX-XXX-XXXX.

Your participation in this study is confidential. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence.

By signing this letter, you give free and informed consent to participate in this project and confirm you meet the criteria for participation.

Name: (Please Print): __________________________________________________

Signed: _____________________________________________________________

Date: _________________________
Appendix C: Guiding Questions For Interview

As per interpretive phenomenological analysis [IPA] methodology my questions were broad and open ended so that participants could talk freely, and feel encouraged to share their experience of hospice palliative care. In-line with interpretive phenomenological analysis, the researcher had to stay open and responsive to emergent data and responsive to the co-researcher. Therefore, these questions served only as guide and prompting questions were used at the researchers discretion.

-What did you know about hospice palliative care services before this experience of being a carer?
-How did you hear about hospice palliative care?
-Can you tell me about why you accessed hospice palliative care services?
-What is your experience with hospice palliative care?
-What value did you find in hospice palliative care?
-What would that have looked like if you haven't had hospice palliative care services?
-What feelings come to mind when you think of hospice palliative care?
-How did using their services impact you?
-What would you like people to know about hospice palliative care services?

I also used prompts, such as:
Can you tell me more about that?
Is there anything you would like to add?
# Appendix D: Themes and subthemes

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<thead>
<tr>
<th>Co-participants had Barriers to Understanding Hospice Palliative Care</th>
<th>Hospice Palliative Care’s Tangible Services Were an Entrance Point to Co-Participants Finding Meaning in Hospice Palliative Care</th>
<th>Co-participants Found Meaning in Hospice Palliative Care as an Emotional Support for Self.</th>
<th>Caregivers Empowered to Talk About Hospice Palliative Care</th>
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<tbody>
<tr>
<td>Caregivers have limited understanding of hospice palliative care before using its service</td>
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<td>The stress of caregiving was a barrier to understanding hospice palliative care</td>
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<td>Doctors were the initial source of information</td>
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<td>Caregiver interpersonal barriers to accessing hospice palliative care</td>
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