

Community health care aides providing palliative care and their experiences of support

by

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Bachelor of Nursing, University of Manitoba, 2002

Bachelor of Arts, University of Manitoba, 1991

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**Supervisory Committee**

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## **Abstract**

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Community health care aides form the largest group of home health care providers in Canada. There is an increasing trend in Canada towards more home deaths. Home Care and the health care aides that provide this care are an integral component of this movement. An Interpretive Descriptive study was undertaken to identify community health care aides' experiences of support as they provide end-of-life care to those dying at home. Three themes emerged from the data: 1) Striving to provide the best care, 2) Connections, and 3) Loss. Findings suggest that relationships form an important part of the health care aides work and are intertwined throughout all the themes identified in this study. Health care aides in the community often feel undervalued and unsupported by the larger health care team. Comparatively little research has been undertaken to examine the unique experiences of the community health care aides providing end-of life care, compared to research on the health care aides providing end-of-life care in the long-term care setting and to research on nurses providing end-of-life care in the community. Community health care aides have unique challenges and characteristics and this study was undertaken to address this gap.

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## **Dedication**

I dedicate this thesis to my parents, Walter and Ella Misurka. I am grateful to my father for instilling in me a life-long love of learning and I am grateful to my mother for showing me that there is always a way and to appreciate “outside the box” solutions. I know you would be proud.

## Chapter 1

Palliative care is a rewarding but emotionally demanding field of health care that requires a team approach, not only for the benefit of the patients who are cared for, but also for the well being of all the team members (Canadian Hospice Palliative Care Association, 2013). As a community palliative care nurse, I had the opportunity and privilege to provide care to patients in their own homes at end-of-life. I was fortunate to be a part of a highly supportive palliative care team. I knew that if I ran into any difficulty, help was only a phone call away. As a group, we met bi-weekly to discuss concerns about clients, to talk about difficult situations, and to debrief about deaths that had affected us. In attendance were palliative physicians, clinical nurse specialists, program managers, community nurses, case managers, and psychosocial specialists. Absent from these team meetings were the health care aides who I would see in the homes of my patients. In the homes, some of the health care aides seemed eager to know what I was doing and asked questions about the client's condition and care, which I gladly answered. Other times, the health care aide retreated to another room while I was present and did not seem to want to engage with me. Some health care aides seemed quite comfortable with the care required of them while others appeared almost afraid to be in the home. I knew how much support I received from the palliative team and I wondered where the health care aides got their support, since they were not included in the activities from which I received so much benefit. As a nurse, I knew there could be and should be much more of a collaborative practice between the health care aides and nurses. I wondered what the health care aides would say is supportive and necessary to be able to do their jobs well and to the best of their ability.

In this chapter I will briefly discuss current aspects of home care, place of care and preferred place of death and some of the challenges staff face providing care to the dying in the community setting. I will also discuss the statement of the problem, the purpose of my study, some definitions of terms used in the study, assumptions I hold and the potential significance of this work.

### **Background**

The demand for home care support in general is increasing due to a number of factors and home care is the fastest growing segment of health care in Canada (Romanow 2002). It is anticipated that by the year 2046, there may be an additional 700,000 people in Canada requiring home care. This is almost double the number of people currently requiring assistance at home (Home Care Association and Human Resources Development Canada, December 2003). The majority of Canadian family caregivers for all patients at home are less than 50 years old and are still working in some capacity (Home Care Association and Human Resources Development Canada, October 2003). At the other end of the spectrum, 24% of caregivers for the elderly are over the age of 65 and seniors themselves (Statistics Canada, 2008).

While many people want to stay home to die many people who choose home as a preferred place of death are not dying at home (Agar et al., 2008; Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005). In fact, in 2012 in Canada, over 60% of deaths still occurred in hospitals (Statistics Canada, 2015). However, statistics indicate that this is changing and there is a slowly developing trend in Canada towards decreased hospital deaths and increased deaths in non-hospital settings, which includes home and personal care homes (Statistics Canada, 2015; Wilson et al., 2009).

Deaths at home are associated with the use of home care services, especially advanced home care which includes interdisciplinary teams. It has been suggested that the availability of home care services is a significant factor in helping patients to die at home when that was their preferred location of death (Gomes & Higginson, 2006; Grande, Addington-Hall, & Todd, 1998, Guerriere et al, 2015; and Murray, Fiset, Young & Kryworachko, 2009). Seow, Barbera, Howell, and Dy (2010) found that among patients receiving end-of-life care at home, use of health care aide assistance increased slowly but steadily over the weeks leading up to death with a sharp increase in use in the last month of life. Other researchers have reported that the presence of home care services eased the burden of everyday living and increased patients' quality of life (Aoun, O'Connor, Skett, Deas, & Smith, 2012; Soodeen, Gregory, & Bond, 2007). Regardless of where place of care and place of death occur, it has been suggested that it is the patient and family's experience of the care provided that has a greater influence on the satisfaction of the end-of-life experience than the actual place of end-of-life care (Murray et al., 2009). This means that any care provided, regardless of setting, needs to be of the highest quality to affect outcomes in patient satisfaction.

The subcommittee to update "Of Life and Death" recommended that the Canada Health Act should be amended to establish funding for home care for the dying (Carstairs, 2000). The Pan-Canadian Gold standard for Palliative Home Care includes access to personal care around the clock as needed as an essential component of end-of-life care (Canadian Hospice Palliative Care Association, 2006). The World Health Organization has advised that home-based care is an essential component of a nation's ability, regardless of resources available, to provide good quality care to the dying

(Sepulveda, Marlin, Yoshida, & Ulrich, 2002). Health care aides have been identified as vital to this shift to home based care (Canadian Hospice Palliative Care Association, 2006).

### **Statement of the Problem**

Health care aides form the largest group of home health care providers yet little is known about the needs of health care aides working within the setting of providing care to patients living at home at end-of-life (Home Care Association and Human Resources Development Canada, December 2003). Currently, in the setting in which this study took place, there is little contact between the formal palliative care team and the health care aides working in the homes of people receiving palliative care. Palliative care in many settings is provided for by a strong team approach consisting of multiple disciplines. The health care aides, as identified earlier, are a vital part of this team, yet historically, health care aides working in the home setting have identified feelings of isolation and of being left out of client care planning (Fleming & Taylor, 2006; Home Care Association and Human Resources Development Canada, October 2003).

Researchers have focused primarily on the needs and experiences of registered nurses. In the literature, researchers identify a need for nurses working in palliative care to be attuned to the psychosocial and emotional demands placed on them as a consequence of their work. Personal development, self care, peer support, and strong coping strategies are some supports identified as essential to a nurse working in palliative care (Petersen et al., 2010). One would assume that health care aides working in palliative care require similar support because of the similar emotional demands placed on all caregivers working in end-of-life situations.

## **Purpose of the Study**

This research aims to address the gaps in the current body of research related to the experiences of health care aides providing care to people at end-of-life living in their own homes and will attempt to identify new understandings of the experience of health care aides that will inform the development of support systems for this group of health care providers. The research question that I asked in this study is “What is the experience of support as identified by health care aides providing in-home care to patients at end-of-life?”

## **Definition of Terms**

### **Health Care Aide**

For the purposes of this study, a health care aide is defined as an unlicensed health care provider who provides help with personal assistance. Names for those who work as health care aides vary according to location but some common names for these health care providers are: Personal Care Attendant, Personal Support Aide, Home Care Attendant, Home Health Aide, Home Care Aide, Home Support Worker, and Personal Support worker (Canadian Hospice Palliative Care Association, 2006). Regardless of name, a health care aide is a health care provider who assists or provides care that the patients would do for themselves if they were able to and provides respite for families. Care most often includes homemaking and personal care (grooming, bathing, and dressing as examples) (Home Care Association and Human Resources Development Canada, October 2003)

## **Support**

When I refer to support, I am referring to practices available to ensure that one is able to perform one's work to the ideal conceptualization of that work. It could include emotional support to balance the demands placed on one from providing care. It can include education to be able to perform in an informed way. It can also include organizational practices that ensure the physical safety of each care provider.

## **Palliative Care**

In this study, I use the World Health Organization's (2013) definition of palliative care that states:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

## **Assumptions**

The first assumption that I approached this study with is that health care aides feel a sense of commitment and pride in their work. Other assumptions, based on a critical review of the literature, are that health care aides providing palliative care to patients at home can feel isolated in their work and can experience a lack of formal supports. This support may include the need for additional educational training in palliative care, emotional support, and recognition of the value of their work. I make the assumption that it is possible to gain an understanding of the health care aides' experiences providing

palliative care in the community setting through one to one interviews and that their experience is a valid source of knowledge.

### **Potential Significance**

An anticipated outcome of this research is that the knowledge generated will be used to develop ways that nursing and the larger care team might provide support to these health care providers as well as to better integrate this group into the larger care team for more collaborative practice.

The benefits of this study are that the knowledge gained from this study will contribute to the existing body of knowledge about health care aides in general and will help to inform the development of support systems for the group of health care aides providing palliative care in the home setting. In addition, the knowledge gained will help support inter-professional collaborative practice in palliative care. Additionally, the study will help palliative practitioners to understand the nature of the work that health care aides provide in the home of dying patients.

## **Chapter 2 – Literature Review**

A review of the literature is required prior to the commencement of any study to identify what is already known about the topic and to identify what gaps exist in order to support the reason for the study. In this chapter I will discuss the existing body of literature pertaining to health care aides and end-of-life. I will look at what the literature tells us about the following: health care aides in general, the nature of the work of community health care aides, community health care aides and end-of-life, health care aides working in long-term care and their experiences related to end-of-life. Following this discussion, I will identify some issues common to health care aides in all settings, followed by a discussion of what the literature says about support related to health care aides in community. My discussion of this literature review will end with a look at gaps in the body of research and why this particular study is important.

### **Health Care Aides in General**

Findings in multiple studies revealed that health care aides have a sense of pride in doing their work well and often enter into the work because of a strong desire to care and to help. These results were found both in long-term care (Bailey, Scales, Lloyd, Schneider, & Jones, 2015; Carpenter & Thompson, 2008) and in the community setting (Denham, Meyer, Rathburn, Toborg, & Thornton, 2006; Mears & Watson, 2008; Sims-Gould, Byrne, Craven, Martin-Matthews, & Keefe, 2010; Stacey, 2005). As Pfefferle and Weinberg (2008) and Carpenter and Thompson (2008) noted, health care aides in their studies reported being “called” to this work. Some studies found that health care aides in both long-term care settings and home settings experienced feelings of frustration and

guilt when circumstances prevented them from being able to provide the best care possible to their patients (Funk, Waskiewich, & Stajduhar, 2013; Beck, Törnquist, Bronström, Edberg, 2012).

### **Health Care Aides in the Community**

A study by the Canadian Home Care Association and Human Resources Development Canada (December 2003) reported that over 60% of all home health care providers (from a total group consisting of registered nurses, licensed practical nurses, occupational therapists, physiotherapists, and social workers) are health care aides. These health care aides are predominantly female (91-97%) and older (45% are over the age of 50 and only 21% are less than 40 years of age). The health care aides in that study also tended to come to this work later in life, with the majority entering the field in their thirties and forties. The number of health care aides who self-reported as being a visible minority (5-14%) matched the number of visible minorities (13%) reported by the nearest Canadian census data, which was 1996.

Work in community is isolating (Home Care Association and Human Resources Development Canada, October 2003; Mahmood & Martin-Matthews, 2008; McBride, Beer, Mitzner, & Rogers, 2011). The isolation of the work was described as both a benefit and a weakness of home care work. The home environment allowed for independence, autonomy, and challenging work, but the isolation could leave workers feeling stressed and vulnerable.

The Home Care Association and Human Resources Development Canada (December 2003) found that health care aides reported the following three most frequent difficulties providing care in the home: 1) unsanitary home conditions, 2) lack of

cooperation with care by the clients, and 3) verbal abuse from either the patient or their informal /family caregiver. Sherman et al. (2008) reported that up to 26% of the health care aides they studied had experienced some form of perceived threat to their safety.

Other researchers looking at health care aides in the community have identified the following challenges that health care aides regularly face: inadequate time to provide appropriate care (Brown & Korczynski, 2015; Cloutier, et al., 2006; Doniol-Shaw & Lada, 2011; Fleming & Taylor, 2006; Martin-Matthews & Sims-Gould, 2008; Nugent, 2007), unsafe or unsanitary environmental exposures (Sherman et al., 2008), inadequate information about clients (King, Parsons, & Robinson, 2012), inadequate communication with supervisors and other care providers (McBride et al., 2011), lack of training (Home Care Association and Human Resources Development Canada, October 2003), challenging families (McBride et al., 2011), pressure to do extra tasks (Aronson & Neysmith, 1996; Piercy, 2000; Stacey, 2005), and role ambiguity (Berta, Laporte, Deber, Baumann, & Gamble, 2013; Fleming & Taylor, 2006; Mahmood & Martin-Matthews, 2008; Martin-Matthews, 2007). In the next sections, I will discuss the following challenges in more detail: inadequate time, information sharing (communication), role ambiguity, and pressure to do extra tasks.

### **Inadequate time**

Several studies looked at the effects of the trend in home care, starting in the 1990s, towards fragmentation of care done by the health care aides, whereby tasks are assigned a standard allotment of time, with little or no time built in for transitions between tasks or for emotional/social care. This coincided with the workload of the health care aide changing to increased numbers of visits per day with decreased times per

visit (Aronson & Neysmith, 1996; Cloutier et al., 2006; Denton, Zeytinoglu, Davies, & Lian, 2002; Doniol-Shaw & Lada, 2011; Nugent, 2007; Sims-Gould & Martin-Matthews, 2010). Fleming and Taylor (2006) reported in an Irish study of home health care aides that 60% of health care aides reported 'sometimes or never' having enough time to carry out the necessary work and 47% reported that their clients 'always or usually' needed more time than was allotted. Compressed time allotments had the result of causing tension and moral distress for the health care aides because they still were striving to provide personalized care and care that they felt the person required (Brazil, Kassalainen, Ploeg, & Marshall, 2010; Brown & Korczynski, 2015; Sims-Gould & Martin-Matthews, 2010). Hasson and Arnetz (2006) reported that home care staff (RNs, LPNs, and health care aides) indicated that the most emotionally strenuous part of their work was the lack of time to complete their work.

In a study by Doniol-Shaw and Lada (2011) time constraints left health care aides in France with the dilemma of either working within the allotted time and potentially providing haphazard care or taking the time and run increasingly behind. This compression of time sometimes resulted in health care aides working through their breaks to get their work done (Aronson & Neysmith, 1996; Doniol-Shaw & Lada, 2011).

Other effects of time constraints on home health care aides included increased fatigue, increased risk of injury, increased job dissatisfaction, and decreased morale (Brown & Korczynski, 2015; Cloutier et al., 2006; Doniol-Shaw & Lada, 2011). Health care aides in Cloutier et al.'s study were concerned about being able to complete their expected working life without injury and whether they had the stamina to last.

Many of the existing studies identified that with the increased time constraints, health care aides' ability to provide emotional care to their clients was compromised (Aronson & Neysmith, 1996; Brown & Korczynski, 2015; Cloutier et al., 2006; Denton et al., 2002; Doniol-Shaw & Lada, 2011). When this happened, they were left feeling frustrated that they had not provided the best care (Denton et al., 2002; Doniol-Shaw & Lada, 2011).

In the literature, the effects of time constraints on the clients was decreased satisfaction with care from a feeling a being rushed (From, Johansson, & Athlin, 2008). Doniol-Shaw and Lada (2011) reported that health care aides found themselves providing care *for* the client, rather than helping the client to do the care themselves which would facilitate the client's independence. Elderly community dwellers in Sweden reported that good care was associated with caregivers who had sufficient time both in length of time of the total relationship and in the ability to spend additional time when unexpected events occurred that required immediate problem solving. This led to a feeling of security in this group of the elderly. Bad care was associated with caregivers who had to carry out many tasks in a short time and when relationships were not allowed to develop as when there were multiple caregivers in a short period of time (From et al., 2008).

### **Information sharing**

The literature shows that there are challenges with information sharing for the health care aides that occur in two directions. First, health care aides are not always given enough information to provide safe care. Martin-Matthews (2007) found the safety of the health care aides was sometimes compromised when their employer didn't give them enough information about the home. King, Parsons and Robinson (2012) noted that

lack of information for health care aides was sometimes lacking because of time constraints experienced by case managers or administrators. Eloranta, Welch, Arve, and Routasalo (2010) found that even in a system where a collaborative approach to care between home health care aides, nurses and general practitioners was in place, a hierarchical structure for information sharing existed with information flowing from the bottom-up (from aide to nurse to physician) with very little actual collaboration on care planning occurring.

The other direction where information sharing is challenging occurs when health care aides do not feel heard or feel that their knowledge of the clients is not valued. Home health care aides feel that because of the extended time that they spend with the clients and because of the close relationships that develop, they are in the best position to recognize changes in clients' condition but when these changes are reported, they are either ignored or not acted upon in a timely manner (Denham et al., 2006; Fleming & Taylor, 2006; Nugent, 2007).

### **Role ambiguity**

The nature of the health care aide's role is changing with increased amounts of delegated tasks formerly done exclusively by nursing (Cloutier et al. 2006). Fleming and Taylor (2006) noted that unclear role boundaries cause the health care aides stress.

Health care aides are told by their employers to keep within the formal limits of tasks but in a Canadian study by Berta, Laporte, Deber, Baumann, and Gamble (2013), industry experts who were high-level managers within home care described how the health care aide role was expanding exponentially and often employers were pleased when staff exhibited "extra-role" behaviours such as emotional support and other

behaviours, such as taking home a client's laundry, that went beyond the prescribed tasks. Yet, there was a concern that care aides sometimes went beyond their role boundaries and that when health care aides are emotionally attached to clients, it is difficult to distinguish between role, extra-role, and 'excessive' extra-role behaviours.

The home as a place of care increases the role ambiguity that the health care aide experiences. This aspect of role ambiguity will be further addresses in the section on relational work.

### **Extra Tasks**

Many studies reported that home health care aides performed tasks beyond which they were assigned to do because in the eyes of the health care aide, the care plan was inadequate to meet the needs of the client, often as a result of cutbacks (Doniol-Shaw & Lada, 2011; Sims-Gould & Martin-Matthews, 2010).

In the literature, doing extra was often associated with the presence of stronger relationships between health care aide and client (Brown & Korczynski, 2015; Mahmood & Martin-Matthews, 2008; Mears & Watson, 2008; Piercy, 2000; and Sims-Gould & Martin-Matthews, 2010) or when there were clients who lived alone and had no other family supports (Piercy, 2000). Aronson and Neysmith (1996) proposed that extra tasks were often not done voluntarily but rather out of a moral obligation to either provide good care or else being in too weak a position to say no to a family request. Health care aides in that study saw themselves as a "last resort" for the clients and felt ultimate responsibility for the well being of the clients. McBride, Beer, Mitzner, and Rogers (2011) reported that health care aides were often put in an awkward position when families requested extra services from them because at times the health care aide was not

qualified to do the task and other times the task requested was not in the best interest of the client. Health care aides were put in a potential conflict with the families depending on their employment arrangements.

There was evidence in the literature that care recipients appreciated the extras that health care aides did for them. Doing extras was seen as a sign of trustworthiness (Soodeen et al., 2007), a sign of good care (From et al., 2008), and benefitted families who were assured that their family member was well cared for and safe (Aronson & Neysmith, 1996). Mears and Watson (2008) found that home health care aides considered 'extras' to be little things that helped them to do their job well and made a difference to their clients.

### **Relational work**

The relational work of health care aides is foundational for many, is the reason that they became health care aides, and is a source of job satisfaction (Brown & Korczynski, 2015; Denton et al., 2006; King et al., 2012; Mears & Watson, 2008; Piercy, 2008; Sims-Gould et al., 2010; Stacey, 2005). Relationships and trust are necessary in order to provide the personal, intimate care that is often required (Mears & Watson, 2008; Piercy, 2000). Soodeen et al. (2007) noted that positive relationships between health care aides and recipients fostered a sense of independence in the care recipients, as health care aides were better able to encourage clients to do things for themselves. Soodeen et al. (2007) also reported that home care clients felt that their health care aides were "like a security blanket" and having someone in the home helped them to remain independent in their homes longer. Other studies reported that home care clients benefitted from the ongoing social contact provided by having a health care aide come to the home (Aoun et

al., 2012; Binder et al., 2009; Piercy, 2005; Sims-Gould & Martin-Matthews, 2010; Soodeen et al., 2007).

When clients had a relationship of trust with the health care aides and felt cared for, not only were their families able to attend to their own needs because they knew their loved ones were in safe hands (Lovatt et al., 2015; McPherson et al., 2014), their satisfaction with care increased (From et al., 2008; Soodeen et al., 2007).

The relationship between health care aide and care recipient was often described as one of mutual benefit as both parties drew value and dignity from the relationship (Stacey, 2005). Piercy (2000) found that home health care aides gained a sense of meaning from their work when it involved relationships and emotional care. In addition, Piercy found that status and power differentials were minimized when relationships developed, leaving both parties feeling empowered as long as boundaries were mutually set and respected.

Another aspect of relational work involved the close relationships that can arise between the care provider and care recipient. Many health care aides working in the community described their clients as either friend or like family (Martin-Matthews, 2007; Mears & Watson, 2008; Piercy, 2005; Stacey, 2005). Piercy (2005) found that health care aides used different language with different clients, ranging from “friendly” to “friendship” and finally to “like family”. She noted that health care aides and care recipients were most likely to use the language of “like family” about 39% of the time and often when a client really didn’t have anyone else in their life to care for them. In these types of relationships, there was a high level of commitment by the home health care aide to the client’s well being.

The home as a place of care strongly impacts the relationships that develop between home health care aides and their clients. Multiple researchers have described how the home as a site of care is both at once a public workplace and a private space with often blurred boundaries between formal service providers and informal care givers, and between paid and unpaid work (Aronson & Neysmith, 1998; Martin-Matthews, 2007; Sims-Gould & Martin-Matthews, 2010). As England and Dyck (2011) pointed out, during the normal course of their required work, home health aides and registered nurses provide work that “transgresses the boundaries of ‘normal’ social interactions both in relation to bodily boundaries and in the use of ‘private homespaces’”(p.211). This already tenuous boundary between public/private space and formal, paid caregiver and informal, unpaid caregiver is further blurred when health care aides do extra tasks or stay beyond the designated time as discussed earlier in this chapter, leading them further into the private realm of family/friend (Mahmood & Martin-Matthews, 2008).

Mears and Watson (2008) noted that their employers give health care aides contradictory messages. They are employed because they care, yet are cautioned to “not care too much”, told to be flexible and use own initiative, but “not too much”, and to form good relationships with their clients and respect their wishes, “but don’t let them get too dependent”. Several studies described strategies used by some home health care aides to keep clients at a safe emotional distance, but in all of the studies, it was found that maintaining an emotionally safe distance was difficult to achieve (Mears & Watson, 2008; Piercy, 2005; Sims-Gould & Martin-Matthews, 2010).

In summary, the community health care aide’s work life is changing. There is an increased movement towards making do with less so that the health care aides find

themselves seeing more clients per day with decreased time to provide the care. One outcome of this change is that the health care aides are losing the time to provide the “caring” relational work that is so important to them (Cloutier et al., 2006, Doniol-Shaw & Lada, 2011; Sims-Gould & Martin-Matthews, 2010). This emotional work is often not recognized by employers or other team members and this lack of recognition is apparent in descriptions of the health care aides work which omit any mention of emotional care or psychosocial support that they offer to their clients (Canadian Hospice Palliative Care Association, 2006; Home Care Association and Human Resources Development Canada, October 2003; McBride, et al., 2011). This lack of recognition of the emotional work that health care aides do has been noted by other researchers who have indicated that emotional work is invisible yet inseparable from the practical work that health care aides provide (Aronson & Neysmith, 1996; Cloutier et al., 2006; Piercy, 2000). In fact, Aronson and Neysmith (1996) propose that there is no vocabulary to describe the emotional aspect of caring behaviour and health care aides themselves often do not recognize the work that they are doing and as a result, this work remains invisible.

### **Community health care aides and end-of-life**

There are few studies that have explicitly focused on health care aides’ experiences of providing end-of-life care in the community. Herber and Johnston (2013) completed a systematic review to answer two questions: (1) what roles did the community health care aides perform when caring for people at end-of-life? and (2) what were some of the challenges and supports in their efforts to provide this care in the community? They examined studies from 1990 to 2011 and out of an initial number of 1695 they found nine acceptable for both quality and appropriateness to the research

questions. Out of these only five were set completely in the community setting. From this review, Herber and Johnston noted that health care aides spend a great deal of time on providing emotional care in addition to personal care. They found three challenges to the health care aides' ability to provide care: emotional attachment, role ambiguity, and inadequate training. These challenges have also been identified in studies of health care aides not specifically working in end-of-life care (Aronson & Neysmith, 1996; Berta et al., 2013; Fleming & Taylor, 2006; Mahmood & Martin-Matthews, 2008; Martin-Matthews & Sims-Gould, 2008). Herber and Johnston found that informal peer grief support groups, peer support, and task orientation helped the aides to manage the excess of emotional involvement. There were a few studies focused on the role of the home care worker in providing end-of-life care in the community (Clark, Ferguson, & Nelson, 2000; Denham et al., 2006; Devin & McIlfatrick, 2010; Ferguson, Nelson, Rhodes, & Clark, 1998; Ingleton, Chatwin, Seymour, & Payne, 2011). Of these, two focused on the MacMillan Carer (a specially trained health care aide working as part of a hospice team in Great Britain) (Clark et al., 2000; Ferguson et al., 1998). These studies showed that MacMillan Carers provide intimate care such as bathing, washing, toileting, and feeding, social and emotional support through listening, talking and companionship, and practical help such as assisting with household tasks. Ferguson, Nelson, Rhodes, and Clark (1998) reported that, like health care aides working in general home care described earlier, MacMillan Carers found themselves at several intersections that cause ambiguity in their role. They fit somewhere between a trained RN and a paid care aide as they often did more than a regular health care aide, they worked to provide both health and social care, and they fit somewhere between a formal care provider and informal care provider

because of the way they became like family to the care recipients. This same ambiguity of role was found in Lovatt et al.'s (2015) study looking at the provision of emotional labour by health care aides caring for those dying of cancer in the community. In that study, the care aides used the ambiguity of their formal role to aide in providing emotional care to their clients and families. In addition to the studies identified by Herber and Johnston (2013), there have been a few recent additional studies looking specifically at the health care aide providing end-of-life care in the community (Boerner, Burack, Jopp & Mock, 2015; Lovatt et al., 2015; van Riesenbeck, Boerner, Barooah, & Burack, 2015).

Devlin and McIlpatrick (2010) also looked at the role of the health care aides providing palliative care in the community and at the community nurses perceptions of the health care aide role. They found that health care aides reported being able to talk to their supervisors and considered them to be supportive yet 46% of the health care aides in that study reported that increased support would be helpful. Some supportive factors were mentioned such as co-workers. Aides reported that they wanted emotional support for deaths – someone to talk to. When the researchers held focus groups with the district nurses, they found the nurses thought that the aides' main role was to provide physical care—they did not recognize the emotional work that the aides did with the clients, nor did they recognize the emotional impact of caring experienced by the health care aides. Nurses were identified as a potential source of support for these aides, but it was recognized that an understanding of each other's roles was going to be necessary if the nurses were to be able to be effective in offering support.

England and Dyck (2011) reported that RNs in the community also found that at times the necessity to spend time providing emotional care meant that time allotments were exceeded. The nurses in England's study were able to advocate to their employer for increased time allotments to provide emotional care to dying patients; however, it was noted that the health care aides in that same study did not have similar power to extend the time allotments.

Several researchers identified that health care aides had difficulty coping with death and dying and experienced similar grief reactions as family members (Boerner et al., 2015; Denham et al., 2006; Devlin & McIlfatrick, 2010; and Ferguson et al., 1998). They reported this as especially difficult and painful early on in the health care aides' employment. These difficulties increased when they knew the client well.

Boerner, Burack, Jopp, and Mock (2015) found in their study that 40% of home health aides were "not at all" prepared either emotionally or informationally for the deaths of their patients and that the more emotionally prepared a health care aide was the lower the levels of grief they experienced. Van Riesenbeck, Boerner, Barooah, and Burack (2015) found that when home health care aides had knowledge of clients end-of-life care preferences or client care decisions, they were more emotionally and intellectually prepared for their client's deaths. However, in their study, 40% of home health aides had no knowledge of either.

Like the general community health care aides, health care aides providing end-of-life care also identified challenges of being asked to do extra tasks, insufficient time to complete the required work, lack of training, and challenges with travel distances (Brazil et al., 2010; Denham, et al., 2006; Devlin & McIlfatrick, 2010).

Because of the paucity of studies of studies of home health care aides providing end-of-life care, we need to turn to studies of health care aides providing end-of-life care in nursing homes, with an awareness that findings may not translate across settings, as Kemper et al. (2008) cautioned.

### **Health care aides in long-term care settings and end-of-life**

Like health care aides working in the community, health care aides in the long-term care setting also experienced grief when residents died (Beck et al., 2012; Burack & Chichin, 2011; Carpenter & Thompson, 2008; Funk et al., 2013; Marcella & Kelley, 2015; McClement et al., 2009; Moss, Moss, Rubinstein, & Black, 2003; Rickerson et al., 2005; Wilson & Daley, 1998).

Funk et al. (2013), in their study of long-term care health care aides, found that aides drew on shared beliefs to help manage their emotions related to loss. These beliefs included: normalization of death (death is expected), sense of relief (suffering is over and the resident is going to a better place), finding a fairness to the death (the resident had lived a full life), focusing on the ways they were able provide good care (to contrast with the helplessness they sometimes felt), and personal rewards (work experiences helped them to focus on the positive aspects of life). Funk et al. (2013) revealed concerns that some of these beliefs may affect the quality of care that the aides provided, for example, if health care aides believe that there is a sense of relief of suffering when death occurs, this may lead to inadequate attention to improving the quality of life of these residents.

The tension experienced by health care aides in navigating the friend/client relationship was described earlier in this discussion and so at this point, I will now only discuss aspects of this tension related to end-of-life and grief. Multiple studies found that

health care aides were concerned about the anticipated grief that would occur when their clients died because of the close relationships that had developed and attempted to remain at a distance from their patients, without much success (Burack & Chichin, 2001; Funk et al., 2013; Wilson & Daley, 1998). Adding to this tension was a strong belief by health care aides that residents at end-of-life should be treated like family, especially when residents had no family (Funk et al., 2013; Hanson, Henderson, & Menon, 2002; McClement et al., 2009; and Moss et al., 2003). Multiple studies showed that health care aides in long-term care settings use language and metaphors of family (Burack & Chichin, 2001; Funk et al., 2013; McClement et al., 2009; Moss, 2003). Berdes and Eckert (2007) noted that when aides cared for the residents “like family” it meant that they were providing a gold standard of care. Moss et al. (2003) proposed that seeing the residents as “family-like” may serve to help health care aides process their grief because this view point validates their grief that may otherwise be disenfranchised.

Like the community health care aides who were distressed by a lack of time to provide what they felt was appropriate care, many studies of health care aides in long-term care settings also found this to be the case, especially when providing care to dying residents. When they did spend time with dying residents, it was often at the expense of the other residents (Burack & Chichin, 2001; Casey, et al. 2011; Funk et al., 2013; Schell & Kayser-Jones, 2007).

Health care aides providing end-of-life care in the long-term care setting had to manage their feelings of loss and used several avenues to do so. Some health care aides turned to spiritual beliefs (Carpenter & Thompson, 2008), debriefed with or turned to colleagues for support (Beck et al., 2012; Funk et al., 2013; Marcella & Kelley, 2015;

McDonnell, McGuigan, McElhinney, McTeggart, & McClure, 2009), used self care strategies (Funk et al., 2013), found meanings in the patient's death (Carpenter & Thompson, 2008; Funk et al., 2013), or used various rituals of closure (Funk et al., 2013; McClement et al., 2009). The participants in Funk et al.'s (2013) study at times used emotional avoidance as a way to cope with grief. Barooah, Boerner, van Riesenbeck, and Burack, (2015) found that the health care aides experienced negative grief reactions when they were not told of a resident's death in a timely manner.

### **Common elements for both community and long-term care aides**

Developing relationships was thought to be the key to good end-of-life care for all health care aides, regardless of setting (Casey et al, 2011; Hanson et al., 2002; Lovatt et al., 2015; McClement et al., 2009). One way in which this was accomplished was through being present (Casey et al., 2011; Devlin & McIlfatrick, 2010; Ferguson et al., 1998; Lovatt et al., 2015; McClement et al., 2009; Wilson & Daley, 1998). Beck et al. (2012) found that health care aides in a long-term care home were frustrated because "doing" was rewarded and "being" was less valued and only at the very end-of-life was there an allowance for the extra relational work of just "being with" the dying resident. At times, health care aides in long-term care were able to be present, even when they felt helpless in controlling unmanaged symptoms that were beyond their control (Funk et al, 2013).

Several studies pointed to a general discomfort among health care aides in all settings, related to talk of death and dying with their clients (Beck et al., 2012; Casey et al., 2011; LeClerc et al., 2014; McDonnell et al., 2009; Osterlind et al., 2011). Aides in several studies have identified a need for end-of-life education, including how to communicate with families about death and dying, and how to provide end-of-life

comfort measures (Beck et al., 2012; Casey et al., 2011; Denham et al., 2006; McDonnell et al., 2009; Osterlind, Hansebo, Andersson, Ternstedt, & Hellström, 2011).

### **Support related to health care aides**

Denton, Zeytinoglu, Davies, and Lian (2002) described organizational support as understanding, able to voice opinions, being heard, valued, appreciated, having personal contact with the supervisor and being able to talk openly with the supervisor. They described peer support as colleagues who are helpful, willing to share experiences, and show personal interest. Other studies measuring support have described it differently. For example, Yoon, Probst, and DiStefano (2016) described organizational support as the existence of benefits, health insurance and training.

Several studies of health care aides in the community looked at support of home health care aides from an angle of job satisfaction and retention. Most of these studies were large quantitative studies utilizing surveys or questionnaires (Denton et al., 2002; Hasson & Arnetz, 2006; Kemper et al., 2008; Yoon, Probst, & DiStefano, 2016; Zeytioglu, Denton, Davies, & Plenderleith, 2009). Of these, only two were Canadian studies (Denton et al., 2002; Zeytioglu et al., 2009) and two were American studies (Kemper et al., 2008, Yoon et al., 2016). Yoon et al. (2016) studied factors that determined job satisfaction among home health care aides. This was a large quantitative study, (N=3,274) undertaken in the US, which looked at the influence of stressors and positive support factors on job satisfaction. They identified organizational support as “financial, structural or emotional support from organizations that can lead to positive job satisfaction of their workers” (p.59) and measured organizational support by the availability of benefits, health insurance, and training. They identified factors of personal

support as respect, availability of challenging work, trust and confidence. Supervisory support was identified as the presence of clear instructions, support for career growth, feeling heard, and acknowledgement of good performance. They also looked at personal factors and job stressors such as patient assignment, communication problems with employers, misinformation about patient's health and problems with co-workers. These researchers found that a supportive environment and personal support was associated with increased job satisfaction. Additionally, the researchers found that supports, whether organizational or supervisory, helped to weaken the negative relationship between job stress and job satisfaction. This study identified areas of support from the researcher's point of view, rather than the health care aides; that is, they identified what they thought to be supportive factors and measured the existence of those factors. A strength of this study is that it was recognized that many of the studies to date looked at health care aides working in long-term care. This was a large study that looked exclusively at the home health care aide.

The two Canadian studies by Zeytinoglu et al. (2009) and Denton et al. (2002) were similar in nature and shared common researchers. The first study by Denton et al. (2002) looked at job stress and job dissatisfaction of home care workers in the context of restructuring. That study found that organizational support led to decreased stress and increased job satisfaction among home care workers. Zeytinoglu et al.'s (2009) survey of 991 mixed employees included nurses and therapists in addition to health care aides. The researchers found that casual hours and decreased pay satisfaction were associated with higher intentions to leave their employment. Like other researchers identified previously, they also found that when home care staff felt supported, by the organization or by peers,

they were more likely to be satisfied with their jobs and less likely to feel work stress.

While these two studies provide a good overview of the perceptions of support of Canadian workers in home care, there were no publications that I could find that focused on health care aides experiences specifically, only those that reported findings from the group as a whole. The educational preparations are vastly different between health care aides and nurses or therapists. Kemper et al. (2008) found that when they asked health care aides from different settings what would improve their jobs, they found both similarities and differences in the responses of health care aides at home versus those in long-term care settings. Kemper et al.'s study was an American study that analyzed the responses from 3,414 workers to one question of a larger survey. All groups identified that improved work relationships would improve their jobs. Staff in nursing homes identified work relationship factors such as being listened to, respected, and appreciated more often than home health aides, while home health aides identified improved communication with supervisors more often than staff from nursing homes. The researchers suggested that this may reflect the home health care aides' isolated working conditions where they often are not in contact with other staff so relationships are less of an issue, but at the same time, the isolation makes it harder to share information. The importance of this study is that it demonstrates the need for caution when looking at studies from different settings and to not assume that findings can apply across settings.

Hasson and Arnetz (2006) echoed this need for caution in applying findings across settings. Hasson and Arnetz's study looked at questionnaire responses of 863 mixed staff (registered nurses, licensed practical nurses, and health care aides) from both long-term care and from home. They measured competence and skill development,

emotional and physical strain, stress, and job satisfaction. Home staff in this study reported knowledge insufficiencies in a number of areas, including palliative care, more often than long-term care staff. They also reported less physical and emotional strain than staff in long-term care settings but reported more difficulty with transfers and providing toileting assistance. Similarities across settings were noted in terms of work related exhaustion, mental energy, and ratings of overall work satisfaction, as well as time pressures. The researchers found that work stress and exhaustion were inversely related to work satisfaction and that there was a positive correlation in home care between work satisfaction and skills development. The drawback to this study is that they studied mixed employees – RNs, LPNs and health care aides. The researchers noted that the differences might have been due to a difference in education levels rather than setting, as the majority of staff in the long-term care settings were licensed practice nurses, while the majority of staff in the home care settings were health care aides. Registered nurses accounted for approximately 10% of the staff in both settings. This study is important but without group sub-analyses that would specify experiences based on job role, the staff mix in the sample makes it difficult to know whether the differences were due to setting or educational level.

The use of mixed samples when studying health care aides is problematic because training varies greatly between health care aides and registered nurses. Additionally levels of empowerment differ between the two groups, as identified previously by England and Dyck (2011) who noted that health care aides were less able to advocate for more time to provide care to their clients than the registered nurses caring for the same clients.

Kendra (2003) studied health care aides and health administrations' perception of risk and found that health care aides and their administration agreed on the level of risk present but health care aides described fewer frequencies of risk than the administration did and the administration perceived that they had more in place to minimize risk than the health care aides perceived to be in place. This study is important because it points to the need for good communication between staff and administration. The researchers attributed some of the discrepancy, especially to the supports in place to minimize risk, to a lack of knowledge on the health care aide's part about what behind the scenes supports were already in place. The health care aides may have felt less supported when in fact there were supports in place that they were unaware of.

Fleming and Taylor (2006) studied 45 community health care aides using an open ended questionnaire and asked what factors about their jobs makes them consider leaving their work. Forty-four percent of those studied said they had considered leaving the work and the main reasons cited were: unsociable hours, lack of management support, workload and lack of support from clients. The previous studies discussed looked at support as it related to job satisfaction and retention. While this study also does that, it also shows the complex relationship between one's work and one's perception of job satisfaction and feeling that one's work is worthwhile. The health care aides studied acknowledged that there were aspects of the job that they would like to change and even considered leaving the work because of those aspects, yet the work itself was rewarding and provided job satisfaction. This finding suggests that just studying job satisfaction as the previous studies have done is perhaps not capturing enough of the health care aides experiences related to support.

### **Gaps in the current research**

Of the studies looking at the experiences of home care aides, several of the large studies looked at mixed groups of employees, rather than at health care aides exclusively. This raises questions as to whether the findings reflect a difference in setting or a difference in education level. Other studies have identified a danger of assuming groups of health care aides are alike that come from different settings.

Another gap is that support was often looked at in terms of job satisfaction and predetermined factors of support. The one study that did ask staff what would make their job better, asked for a single recommendation and any additional comments were not included in the data. The limitation to this is that multiple recommendations may not have been given in priority order. Also, there was no allowance for multi-factorial recommendations. In fact, 37% of home care staff did not even respond to the question, which was part of a large 8-page questionnaire on a wide range of job conditions of the health care aides (Kemper et al. 2008)

Very little research on the community health care aide providing care to people at end-of-life exists. The isolation makes the work substantially different from the experiences of health care aides working in long-term care or acute care. If we look at community, we can choose to either look at community health care aides who do not have the same emotional components associated with working with those at end-of-life or we can look to community registered nurses providing palliative care but education and empowerment levels are vastly different from health care aides. Both areas of research do not address the unique needs of the community health care aide who provides end-of-life care. Many of the studies investigating support and the community health care aide have

been large surveys. While this type of study design is important to give a good overall picture of the problem, a more intimate focused interview study will give a richer and nuanced understanding of the problem. It is for these reasons that this study is necessary.

### Chapter 3 – Methods

Munhall (2012) identifies the overall goals of qualitative research as understanding, interpretation and meaning. An assumption of qualitative research, as noted by Munhall (2012) is that people are unitary beings; meaning that the whole of the person is greater than the sum of their parts and that a person can not be broken down into pieces to be studied. This means that the person must be looked at as a whole individual, indivisible for study and cannot be understood apart from their situated context, which is the era, culture, and relationships in which a person finds themselves in. This situated context is important because it is this context that will influence a person's subjective experience. Munhall identifies other assumptions of qualitative research, notably that multiple realities and perspectives exist and humans create their own realities. Richards and Morse (2007) and Thorne (2008) note that qualitative research is the best way to answer questions when little is known about an area, when we want to make sense of a complex situation, or when we want to learn about participants' experiences, meanings and interpretations. These criteria match the research problem of this study. That is, as identified in the literature review earlier, little is known about the home health care aides experiences in general, let alone their experiences of support when providing end-of-life care. Because of this gap in understanding, we do not know what manner of support would be most beneficial or how nursing can assist in this development.

Interpretive Description is a qualitative methodology that is most appropriate to address the research question I have identified (Thorne, 2008). Thorne's interpretive descriptive approach goes beyond description to interpretation or meaning as it pertains

to the clinical situation. This methodology was developed in response to a recognition that qualitative research in nursing borrowed heavily from methodologies developed in other disciplines. Because these methodologies did not originate in nursing, sometimes adjustments to the methods were necessary to meet the needs of the nurse researcher, resulting in modifications from the original “pure” methodologies on which the research was based. This in turn, drew criticism of the validity of the research itself from the larger research community. Interpretive Description is Thorne’s solution to the need for a methodology specifically suited to nursing and clinically-oriented questions. Underlying assumptions of Interpretive Description are that there is a constructed and contextual nature to much of the health and illness experience and that there are shared realities.

### **Analytic Framework**

Thorne (2008) notes that a formal conceptual framework is not required in an interpretive descriptive study. It is important, however, to build the study on the basis of an informed critique of the current body of knowledge and using expert clinical knowledge (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004). The assumptions that I make, based on a critical review of the literature, are that health care aides providing palliative care to patients at home can feel isolated in their work and can experience a lack of formal supports. This support may include the need for additional educational training in palliative care, emotional support, and recognition of the value of their work. Nurses working in the home setting with palliative patients can experience caregiver stress and that an important way to alleviate this is to ensure that the nurse receives support from various sources. Health care aides may require similar support systems but

only by actually studying the phenomenon of support as experienced or not by the health care aides, will nursing be able to assist in providing support. I assume that health care aides feel a sense of commitment and pride in their work. I make the assumption that it is possible to gain an understanding of the health care aides' experiences providing palliative care in the community setting through one to one interviews and that their experience is a valid source of knowledge. I also make the assumption that nurses can work with health care aides to create a supportive environment for both groups.

## **Methods**

### **Sampling**

Sampling was done using both purposive and snow-balling techniques. According to Polit and Beck (2004), purposive sampling refers to choosing participants who meet a particular criteria of a study. In my study, this refers to the criteria that I had for participants who are health care aides having looked after a dying patient in the community. Snowball sampling means that one asks early participants to make referrals to other potential participants. I utilized snowball sampling when I asked each health care aide who contacted me to forward my information (poster and participant consent form) on to any other interested health care aide. Health care aides in the community in which this study took place were employed through two main avenues: the regional health authority's home care program or by private care agencies.

### **Inclusion and exclusion criteria**

Initially I intended to limit the sample population to those health care aides who had looked after a dying patient in the course of their employment in the last 24 months

because I wanted to learn about *existing* sources of support. I specifically asked that the care of the dying patient had occurred during employment to exclude situations of a personal experience. While that situation is important, it was not the focus of this study. During recruitment it became clear that the health care aides that I spoke with did not make the distinction between those clients who were formally designated as palliative and dying and those patients who were the frail elderly and happened to die during the course of their time together. Thorne (2008) suggests that a small study, such as I undertook, could set a somewhat arbitrary minimum sample size but the researcher must also acknowledge that there would always be more to learn and to study. In this case, the sample size of six, was a feasible number according to Thorne (2008). The goal was to interview enough participants to get a sufficiently rich and thick level of data so that meaningful findings could occur yet still be a manageable amount of data for the time constraints of this research study.

### **Recruitment**

I requested approval from the central administration of the regional health authority and from the area directors of private agencies to interview willing participants. I made the initial request by either telephone or email and followed with a confirmation letter explaining my research in full and included thanks for the opportunity to conduct my research (Appendix A). Once approval was received, I sent poster information to each individual office along with a supply of consent/information sheets about the study and my contact information (Appendix C, E and I). I also asked to attend any meetings where health care aides might be in attendance and present my proposed study directly to health care aides (Appendix D). I left distributed posters and the information for consent letters

with them with a request that they call me if they were interested. I posted a copy of the recruitment poster in several issues of the monthly newsletter (“Hotsheet”) that was sent to all the offices that the regional health care aides report in and was read by the staff. The health care aides who were interested in participating contacted me directly by phone. When a potential participant contacted me I asked the screening question, “During the course of your employment, have you looked after a patient at home, in the last 24 months, who was dying?” If the answer was yes then I reviewed the information about my study with the participant and asked if the participant was still interested in proceeding. If so, I arranged a time for the interview at the participant’s convenience (both in time and in location).

Recruitment went very slowly and required amendments to my original recruitment process. I discovered that the health care aides do not go into their offices very often and meetings are held only a few times a year so I was not able to speak with many health care aides directly. Additionally, I was informed that the newsletter was not widely read by the staff. I modified my recruitment strategy to request that the palliative nurses be allowed to ask health care aides that they see in the clients’ homes if they might be interested in participating (Appendix H). If they were, then the nurse would give the health care aide a copy of the poster and information about consent. This produced only a few more participants. I modified my recruitment strategy a second time. I had been told that the potential participants found the information about consent overwhelming and so did not want to participate because of that. I amended my strategy to only giving out the poster as information. When an interested potential participant contacted me, I would verbally review the consent information with them (Appendix J) and if still interested,

proceeded as initially planned. When the interview occurred, I would ask the participant to sign the consent form. Two other changes I made with the second modification was to request that the nurses give me the names and numbers of interested participants so that I could contact them directly, provided that the participant agreed in advance to this. I also changed the poster at this time because I had been told that it was too wordy. This last modification resulted in obtaining the remainder of the participants. The anxiety about participating may have been wide spread and because I was unable to speak directly with many health care aides to correct their misunderstanding about confidentiality and anonymity, this may have reduced the number of participants willing to be interviewed.

### **Description of participants**

I interviewed a total of six participants, three worked for the regional health authority and three worked for private agencies. All six had reported looking after a client who had died during the course of their contact with the client. Ages of the participants ranged from 41 to over 60, with three of the participants' ages falling in the 51 – 60 age range. There was a wide range of time that the participants had been health care aides, ranging from 2 to 30 years, with three of the participants having been health care aides for 20 years or longer. All six had worked their entire career as health care aides in the community. Four of the six participants were certified as health care aides. None of the participants had taken specialized training in palliative care. There were four female participants and two male participants. All reported having experienced a personal loss.

## **Data Collection**

Data collection took the form of semi-structured interviews (Appendix G), a short questionnaire (Appendix F), and a reflexive journal that I kept throughout the process. Interviews were as open-ended as possible to allow the participant to fully express their reality and description of their experience. Demographic collection was reviewed after the interview to ensure all questions had been answered but in telling their story, many of the participants had answered all the demographic questions. The demographic questions were intended to help situate the context that the participant was in. This demographic data included whether the health care aide had any formal education in palliative care, if they worked for a private agency or the regional health authority, how long they had worked as a home health care aide, whether they were a certified health care aide, and if they had any experience with loss due to death in their personal life. This demographic questionnaire, given after the interview, was not to assist in generalizing findings but rather to illustrate participant context.

## **Data Analysis**

Interviews were audio-recorded and then transcribed by myself. Thorne (2008) suggests that doing one's own transcribing allows one to slow down and appreciate the nuances of the data and "to hear more deeply what the language contains" (p.143). Data analysis and collection occurred concurrently as per Thorne's (2008) recommendations. This allows the nature of the inquiry to evolve as new possibilities arise (Thorne, Reimer Kirkham, & O-Flynn-Magee, 2004). Thorne (2008) advises one to immerse oneself in the data as the search begins for similar themes. These themes are then grouped by similarity. According to Thorne (2008), this method of immersion and viewing the

whole for themes is more consistent with Interpretive Description than a coding method that involves the breaking down of data into fragments. Once patterns are identified, one then turns to looking for relationships between the patterns that will lead to new understandings (Thorne, 2008). It is important to always keep open to the overall picture that is being presented by the data. One does this by continually asking oneself, “What is going on here?” (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997.) This is the process that I used to analyze the data that I had collected. I first looked at each interview to get an overall view of the participant and the data. I then examined the data from the interview and identified each separate concept or idea that was present in the data. I repeated this process for the complete data set. Once I had broken the data into distinct concepts, I looked for common ideas or themes. As these came to my attention, I grouped the common concepts or themes together. I then looked at each of the themes to find out what it was that was being revealed. There was a continual back and forth process of looking at the parts or dimensions of each theme and examining them with the other themes and dimensions to see where they truly belonged. This process was similar to the thematic analysis process described by Braun and Clarke (2006) whereby one looks for patterns across a data set with a constant back and forth between the data, the codes, and the themes. Once patterns were identified, I re-examined the data to identify any relationships between the patterns (Thorne, 2008). Throughout this process, I documented decisions in my reflexive journal and also made use of multiple mind-maps throughout. In this way I am accountable for my analytical decisions made along the course of my research.

## Evaluation Criteria

Thorne (2008) identifies four principles that should be adhered to when conducting qualitative research: epistemological integrity, representative credibility, analytic logic, and interpretive authority. Epistemological integrity means that the methodology one chooses is consistent with the research question and with the strategies used to collect the data. I recognized that there are multiple realities to the experiences of the health care aides and since the realities are multiple, the best sources of knowledge about the health care aides' experiences are the health care aides themselves. It is for this reason that I chose an interpretive descriptive study that will use interviews as the primary means of data collection.

I attained representative credibility by ensuring that any theoretical claims I made are consistent with the way my study was conducted. In this study, the interpretations that I made are reflective of this group of home health care aides who provide care to those dying in the community. As Thorne, Reimer Kirkham, and O'Flynn-Magee (2004) advise, findings in Interpretive Description are "not a new truth, but a sort of 'tentative truth claim' about what is common within a clinical phenomenon" (p.4). I have not claimed to be able to extend this interpretation to health care aides working in other settings, nor even to another group of community health care aides. However, even with this small sample, findings from this study align with what is present in the current body of research.

A reflexive journal is important in qualitative research to show the decision making process as the research evolves and in this way leave an audit trail. This ensured that rigor is met and that each decision along the way was consistent with the research

question and method. I kept a reflective journal in which I documented decisions made along the course of the study to ensure that I met the criteria for analytic logic

Lastly, to meet the demand of the fourth principle, that of interpretive authority, I have not made leaps of interpretations that are not grounded in the data. Only “tentative truth claims” or “constructed truths” can be made from the data. This is a new way of understanding a phenomenon that has been transformed out of the data that the researcher has collected and analyzed (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997).

Thorne (2008) describes three additional criteria of special importance to research in applied health research. Nursing researchers, especially those working from an interpretive descriptive lens, recognize that the goal of research is to ultimately change nursing practice. This puts additional onus on the researcher because any published research will be examined to see if it can be used to influence practice, even before any formal theories have been developed. The additional criteria that must be applied to researchers working in applied health fields are moral defensibility, disciplinary relevance, and pragmatic obligation (Thorne, 2008). A study has moral defensibility when the knowledge that is being sought is necessary and will benefit those studied. My study was necessary because the group of health care aides I studied work in isolation with little apparent support. This study contributes to the paucity of knowledge existing about this group. In addition, it is the group of health care aides themselves that will benefit from the new understandings gained. This study is relevant to the discipline of nursing because there is a role for nurses and health care aides to work together and to support each other in the work that they do. The criteria of pragmatic obligation was met as I moved through the research process and kept in the forefront of my consciousness,

the possibility that my research may be applied in practice and not just treated solely as a theoretical exercise

### **Ethical considerations**

I obtained consent from the Human Ethics Research Board at the University of Victoria as well as consent from the University of Manitoba Research Ethics Board because this research study was conducted in Manitoba. I followed the guiding ethical principles outlined by the Tri-Council Policy statement that informs research conducted in association with the University of Victoria. Informed consent is vital when conducting research. Prior to beginning the interviews, I ensured that each participant understood the reason for the research, what knowledge I was looking for in conducting the research, how the study was going to be conducted, that there was full confidentiality, and that they were free to withdraw from the study at any time. I obtained this consent in writing. I employed process consent, which refers to obtaining new consent at any change in process or focus of the study from when the original consent was obtained (Munhall, 2012). I recognized that each participant gave freely of his or her time in order for the interviews to take place. In appreciation, I gave each participant a gift card of \$10 for a local coffee shop when the interview was completed.

### **Potential for harm and benefit**

Sometimes during interviews, sensitive topics may arise that are distressing to the participant. I endeavoured to be sensitive to this possibility when conducting the interviews. In the event that a participant became distressed, I had planned to offer to hold the interview or postpone it, allowing the participant to make the decision. I also

had information available to the participant on how to contact either the EAP (Employee Assistance Program) of the Regional Health Authority or a community mental health service in the event any emotional issues might have arisen during the interview. There were no circumstances that arose where these strategies were necessary.

There may be a potential benefit to the participants of this study in being heard and able to tell their story. This research study is important because the participants as a group may benefit from the results. The goal is to obtain information that will assist in developing programs and supports to assist the health care aides to be able to do their work with the dying.

### **Confidentiality**

To ensure privacy and confidentiality, interviews were conducted in a location that was chosen by the participant. Four of the interviews took place in the participant's home and two of them took place in busy coffee shops. Any identifying information was removed from the transcripts. Pseudonyms were used in all direct references to participants in the findings section of this thesis. During the course of the study, the transcript/participant list was kept in a separate location from the transcripts. Audio recordings of the interviews were destroyed after completion of the study. All transcripts and the transcript/participant list will be kept in a secure location for a period of seven years. After seven years all participant documentation will be destroyed.

### **Limitations**

A limitation of my study is that due to the nature of the study (an interview lasting 1 or 2 hours) and the limited time in which I had to complete the study, I was not able to

capture every experience of health care aides providing palliative care in the home setting. It was difficult to find health care aides willing to participate. Some of the health care aides I interviewed expressed a concern that their views would get back to their employers and they would face repercussions as a result. I attempted to minimize this fear by reassuring the participants that their information would be kept confidential and anonymous. I do feel though that I interviewed enough participants to get a good understanding of their common experience as recurrent themes appeared in most of the interviews. It is possible however, that those who did participate were particularly confident and may as a group have a different reality than those who chose not to participate.

An unexpected limitation that I encountered was that the participants I interviewed were often unable to separate their experiences providing care to palliative patients from non-palliative clients. All the participants answered that they had looked after a dying patient, but in answering the questions, they shared experiences from all aspects of their caseloads and it was sometimes only after some questioning that I was able to tease out if it was an end-of-life situation that was being described. Some of the participants I interviewed shared that they often did not know which of their clients were palliative since their supervisors did not generally share this information with them. The participants all had a mixed caseload and those clients who were not formally declared to be palliative were often the frail elderly who by their very nature were at risk of dying unexpectedly. In sharing their stories, it became apparent that the participants did not make this distinction and so their experiences blended together. It was often hard to decipher if the information shared related to palliative situations or district home care

situations. However, loss is loss and the effect of grief on the participant was the same or even increased when that client was not expected to die, as a palliative client would be. Additionally, the participants identified several areas where support was lacking- some of these areas related directly to palliative patients and some to their general working conditions. Regardless, the information gleaned is still valuable in our attempts to understand the health care aides' experience of support.

## Chapter 4 – Findings

The intention of this study was to explore support as experienced by health care aides who provide care to dying people living in the community. As previously discussed in the Methodology chapter, there were some challenges with this study. The participants all had experienced death associated with their work, but because none of the participants worked exclusively with palliative patients, many of the experiences that they shared with me could not be confidently applied as reflecting an end-of-life situation or that of a situation where death occurred unexpectedly as might occur for a frail, elderly client living at home. In fact, the participants themselves did not appear to make the distinction between the two groups. Loss was loss, and to the participants, the effect on them was the same. Similarly, the stresses they encountered daily as part of their work were present regardless of the type of client.

I identified three major themes from the data. These themes are: 1) Striving to provide the best care, 2) Connections, and 3) Loss. Striving to provide the best care involved six dimensions: 1) making the client comfortable, 2) protecting - keeping the client safe, 3) working outside their scope of practice, 4) self care, 5) time, and 6) information-sharing. The theme of connections has the dimensions of being present, developing bonds, and relationships with the larger care team. Finally, the theme of loss has the dimensions of anticipating the loss, feeling the loss, and managing the loss. While the participant's efforts to connect and develop bonds with the clients formed an independent theme, the effect of the participants' relationships with the clients was evident in all of the themes. Additionally, there are connections between each of the themes and this will be discussed further on in this chapter.

### **Striving to Provide the Best Care**

The participants were unanimous in their goal to provide the best care possible for their clients. As Mary put it, “I’m doing the best job that I can do and working hard, and to me, that’s all I am concerned about.” All of the participants spoke about wanting to do their job well, not only for their client’s benefit but also for their coworkers’. As another participant suggested, striving to provide the best care instilled confidence that he was contributing positively to the lives of those he cared for, and at the same time, worked to encourage his coworkers to also strive to do their very best:

I do my job well because I think it’s in my best interest as a worker. As a worker, if I do a good job, it helps me. It makes me comfortable and it’s known that I am doing that job out there. It’s given me that confidence to be a positive part of each and every person’s life and even my co-workers because I am bringing another co-worker with me who is coming in the next day or even the next. So I am bringing in other workers with me because if I am doing a good job today and they see I am doing a good job and have no complaints, they will want to keep up with me.

Striving to provide the best care involved six dimensions: 1) Making the client comfortable, 2) protecting - keeping the client safe, 3) working outside their scope of practice, 4) self care, 5) time, and 6) information-sharing. These dimensions describe strategies that the participants used to help them provide the best possible care for their clients. The last two dimensions have additional factors that include barriers to the participants’ abilities to provide what they felt was the best care possible.

### **Making the client comfortable**

All the participants spoke about wanting to keep their clients as comfortable as possible and most described it as their main role. For many, this involved taking the time to attend to details such as ensuring heated car seats were turned on when transporting a client home from the hospital, holding a hand when family indicated that this action was comforting to the client, and wanting to act in ways that would respect cultural differences. Making the client comfortable also extended to paying close attention to the subtleties of care as described by Peter:

So like it's meeting the needs. Making sure that they're comfortable. Like you know if you want to be turned – OK. Tell me where it hurts and how are we going to turn it and how to manoeuvre the turn to make sure that we don't have that screeching pain when we turn. So we blend everything into what's best for the client and how you deal with it to make sure that his comfort is being met in the positive way.

Providing emotional comfort was important to many of the participants and some spoke about putting the client's emotional needs first, regardless of the participant's own emotional state. As Peter put it, "I am always asking them about their morning, their overnight, so it's not about me anymore." This same participant described coming in to a home just after a death and needing to keep calm while comforting the family as they waited for the body to be picked up:

But a lot of time, the main people that we deal with is the family and then you know you have to phone the family, or you'll sit there with the mom or the wife

and she starts crying and then you have to be able to keep that calm skill about you and simply say, “You know, it’s going to be ok. He’s at rest. He’s at peace.”

One participant talked about wanting to treat clients as she would like to be treated and used that as a guide to providing care. Another participant commented that part of making a client comfortable was ensuring that they were “well-dressed and well taken care of”. When clients were made comfortable, many of the participants indicated that they felt they were meeting their goal of doing the best job possible in caring for their clients.

### **Protecting - keeping the client safe**

Most of the participants spoke about being protective of their clients and of being on guard for their clients’ safety and well-being. According to the participants, potential threats to clients’ safety came from the client’s own questionable choices or from other care providers.

Some participants spoke about being vigilant for their client’s well-being and safety through careful observation of their behaviours. This close attention to their clients was not only a way in which the client’s comfort was optimized as described earlier, but also used to watch for changes that would be detrimental to their clients. Mary described noticing something “off” about one of her clients and described her client as confused, which led Mary to believe something might be medically wrong with her. She made plans to return to see this client a short while later. Shortly after Mary returned, the client had what appeared to be a seizure. Mary said, “You know, I thought, had I not come back to see her or anything, she more than likely could have died there. So I was there, I called the paramedics.” Another participant, Jane, described monitoring

her client closely and applying an oximeter after her client returned from the washroom and asking him to do his breathing exercises to ensure a return to a safe and stable respiratory status.

Several participants spoke about being concerned for their client's safety related to choices being made by those clients that put those clients at risk. Bonnie worried about a client wanting her to leave the door unlocked when she left: "But it is always kind of safety. You don't want them to leave the door open because sometimes people walk in and you know they steal things from these people when they are sleeping. It has happened." Another participant described a situation where a client was putting herself at risk by choosing to drink excessive amounts of alcohol, which resulted in injuries from falls and challenges in medication management. This participant experienced considerable distress because she was not able to adequately ensure the safety of her client, even though it was beyond her control.

Part of keeping the client safe related to a perceived need, on the part of some participants, to protect their clients from other care providers. One participant felt the need to ensure that the community nurses were providing safe care:

The others I know right off the bat they are good and they know what they are doing. They talk. They say "How are you, how's the patient?" You know and then they go and I show them where they are, whatever, and then I watch them because I don't trust anybody so I watch what they do."

The participants felt they had a responsibility to protect their clients, even though some of the areas for this concern fell outside of their role as care provider and also outside of their ability to make the changes required to keep their clients safe.

### **Working outside their scope of practice**

Sometimes in an effort to provide what they felt was the best care, participants advocated for their clients in ways that fell outside of the scope of their role. Bonnie described a situation where she was concerned about a client who did not answer her door. She returned back to the client's apartment a total of three times (which was against agency policy) before she finally asked a caretaker to let her in. She found the client on the floor and called an ambulance. She said:

But she was lying there for at least two or three hours on the floor. You can't leave them like that. It's just cruel. I mean, you wouldn't do that to your worst enemy...but I didn't follow the rules because I was more concerned about the person.

Sometimes working outside of their scope occurred when participants took on roles resembling more like family than care provider as in the case of Bob who felt that his client was not performing in speech therapy as he knew he could and was frustrated because he could not attend the treatment sessions with his client to ensure that his client did his best. Another example is the participant who was hired to provide transitional care to her client when that client was placed in personal care home. The participant did not feel the client was getting the care that she needed and so contacted the family and told the family, "Listen, if you do not take your client out of here, she's going to die. There's no two ways about it, she is going to die."

Many participants, in striving to provide what they felt was the best care, completed tasks like taking out the garbage, that were not specified on their assigned task list in an effort to make things better for their clients even though they knew that they could be

disciplined for providing the extra help. As one participant said: “It’s about improving. How we can improve and make things better for the people that we are seeing; in the long run, not the short-run, the long term.”

All these examples of care come from a place of wanting to provide what the participant felt was “best” for the client.

### **Self care**

All of the participants practiced some form of self care to help them cope with the day-to-day stressors of their work, realizing the necessity of self care if they wanted to continue to be able to provide the best care for their clients. Self care included seeing a counsellor when the demands of work built up, practicing hobbies, talking to colleagues, friends, and family, exercising, getting out in nature, and walking. These personal sources of support helped the participants to do their job well. As one participant explained, doing these acts of self care allowed her to give each client her “100%”. Mary described the effect of self care after a workday:

Cause there’s times when you are feeling really stressed out or kind of down about things and you know what? I will go for a 5 km walk and feel much better by the time I am back. So, yeah, it makes a big difference. A big difference.

The participants recognized that because of the stressful nature of their work, they needed to look after themselves and to provide their own self care and support in order to provide the best care possible for their clients.

## Time

There were two types of work schedules experienced by the participants. Some of the participants worked in respite situations where they would stay in one client's home for the entire day or partial day, while another group worked on "runs"; that is, they would go from client to client, performing set tasks and once the task was done, would move on to the next client. These runs were tightly scheduled and as a result, the participants who worked in this setting had the stressor of time that the other group did not. This was a significant stressor for these participants.

Many of the participants expressed concerns that they were not given enough time to adequately provide the care their clients needed. One participant described being given only five minutes to ensure that a client was given the correct medication. This involved first finding the medication in the home, washing his hands, checking to ensure that the right medication was given, and ensuring that the client swallowed the medication. He explained his frustration:

So we know there's a lot of frustration out there. We don't know how to deal with it and I know for a fact that if something isn't done one of these days, we're going to have a tragedy on our hands and who's to blame? I don't know.

It was expressed by several participants that they did not feel that their employers appreciated the amount of time required to complete the assigned tasks. As Bonnie pointed out:

Well sometimes the supervisor doesn't always understand. They just got their rules to follow too but if they had to be in our shoes and see all the clients they expect us

to. To be here, here, here at that time, that's impossible. I tried that so many times.

They don't understand that.

Some felt pressured to fit in additional calls into an already tight scheduled. As one participant shared:

So last week when I was called to do a call – “Can you fit in a call at 10:30?” I said, well no I can't. I have my palliative care client that I have to do a bowel routine and I am supposed to be there at 1030 and it's already ten to eleven and I am not there yet. How can I fit it in? “Oh well, he's on your way”. No – because you said it's a half hour call. You know and I know it's going to take me more than half an hour.

Several participants spoke about taking the time that they needed to provide care in the way they felt care should be provided and then working through their breaks to get the work completed. Mary explained, “We don't get a break. On paper, they show a half hour break but we seldom ever get that half hour break...you just basically go and you do it until you are done.” The constant rushing created stress for the participants. As one participant shared:

I'm telling her [my supervisor] what's going on here and I really can't get a positive feedback from the people I'm communicating this with. You're feeling tense. A lot of times your chest starts squeezing. You know you're not having a heart attack but you can't really describe that feeling to her...You have a tense situation here and then you have to go to another tense situation because instead of being on time, you're late and they [the clients] are looking at you like “Why are you late?” and then it becomes an argument. Now you have a tense situation and

you really have to sit back and say ok, I understand why I'm late, but I also understand that you as Mr. Smith do not know why I am late, so I have, my whole persona has to change to comfort. "OK, well you know we had a little mishap. We had to take a little bit more time, we had to do this." So now you have to put the situation into a calming mood and then take it from there.

This example shows the advanced understanding and communication skills that this participant has developed in being able to positively resolve this potential conflict. Again the participant's focus was on providing the best care and ensuring that the client's needs were put first, even when system barriers existed that hampered that care and left the participants feeling that they were on their own, unsupported, to manage these situations.

Participants were concerned about the effect of the tight schedules on their clients.

As one participant shared:

Mrs. Jones paid her give [sic] to society. She did her job. She's old now. She's 90. She needs that extra 5 or 10 minutes to make sure she has her breakfast, not throwing in a slice of toast and saying you know the person who's going to come at 12 is going to wash her dishes. No, we should be able to go inside and find out that Mrs. Jones gets out of bed, make sure she gets a proper wash and make sure she's sitting comfortable. We are losing that because we are not giving the workers the proper times to do the proper work that is supposed to be done.

The lack of time produced frustration because it limited the participants' ability to provide what they felt was the best care possible for their clients. While not directly identified by the participants as such, the lack of time meant that the participants' ability to provide the necessary emotional care, identified earlier as important to the participants,

was affected. The participant who had to take time to diffuse a tense situation because he was late or had to sit with a client's spouse after a death are examples of emotional care that are not factored in to the time allotted for care. Participants expressed frustration at a system that they feel does not hear their concerns about the time required to safely provide care.

In contrast to the experience of those participants working on "runs" was the experience of participants who spent extended amounts of time in clients' homes. These participants found that they had adequate time to provide all the care required. As Bob explained, "They [his employer] give me lots of time to do things. Like you know we are not on a schedule as such. We have to be there. Once you get to the clients home, you phone that you're there." The difference between the two work environments was striking. In the respite situations, the participants felt supported in their attempts to provide the best care because of the amount of time available to them. Participants who worked in the "run" environment always felt rushed and were worried about the effects of the time constraints on their clients, feeling that the clients were not getting the best care possible.

### **Information-sharing**

Sharing information was an important strategy to ensure that the participant's ability to provide the best care for their clients was maximized. For participants, getting information about their clients was important in securing their sense of confidence and supporting their ability to provide the best care possible. Sharing information took several forms. There was sharing of information between health care aides providing care to the same client, between health care aides and community nurses, and between the health

care aides and the larger organization that employed them. There were both positive and negative experiences within each of these pairings.

Sharing of information between health care aides was done for a few reasons. Participants believed the reciprocal nature of sharing information helped them to support their colleagues in their efforts to provide quality care. For instance, some participants like Jane, described how she would provide information to her co-workers because of her knowledge of the client: “If my co-worker is doing something not proper, I will tell them, because maybe I take care of one client longer. I know this client a lot more than my co-worker. I will tell them how to do something.”

Some participants shared information with other care aides caring for the same clients in an attempt to support their own efforts at providing good care. Mary shared how being able to talk with a colleague and exchange information about their shared clients facilitated her ability to do her work well:

A lot of my needs are being met because I do know my co-worker and we are able to talk about clients. We are able to talk about concerns and if I didn't have her to talk to, then I don't know where, what would you do? When she retires, I am going to find it hard...She'll phone me and say you are going in on Wednesday morning. She [their shared client] is going to the doctor at 10. Can you switch things around so you can see her earlier? So I'll do that or if there is a problem with somebody she will give me a heads up and say this had been going on. You know, that makes such a difference in being able to do a good job.

The second type of information sharing occurred between health care aides and the community nurses who were involved in the same client's care. At times, this sharing of

information took the form of watchfulness as the participant carefully monitored the tasks that the nurses were doing. One participant described such a scenario. Jane said, “Sometimes I will remind them...because if some nurses are first shift with the client and maybe she forgot something because I will take care of this client all the time. I know everything so will remind her what he/she forgot.”

Participants who appraised their working relationships with the community nurses as supportive seemed to recognize that sharing information had to be tailored to the care aides’ scope of practice. For instance, Bonnie gave the example of information related to medications suggesting that this was helpful for her practice but that detailed pharmacological information was probably not needed. What seemed most important is that the participants wanted information that would allow them to perform their work to their best ability. They appreciated, for example, knowing when a client was diagnosed with dementia as such information would be helpful in informing how they approached clients and engaged with them in care. Information about things outside their scope of practice, such as medications, was not felt to be as useful to some participants. When the nurses shared their knowledge about the client situation or provided teaching about aspects of the client’s care, the participants felt supported and were more confident in their attempts to provide the best possible care for their clients.

Information did not always flow freely between the participants and the community nurses. One participant blamed the community nurses for the lack of information provided to health care aides, but acknowledged that nurses working within the publicly funded health care system did not have responsibility for sharing information or training

care aides who worked with private home care agencies. As Bob said: “We have to be trained and they aren’t responsible for training us.”

Participants reported that their relationship with community nurses varied considerably and as a result, the amount of information shared between them varied as well. Some participants expressed that they had a good relationship with the nurses – easily able to share what they saw in their client’s condition and felt heard and valued. When they felt that the nurses listened and heard their concerns, the participants felt supported in their work. As Bonnie said: “They [the nurses] are really good because you can talk to them and you kind of bounce off these situations.”

Information sharing between the health care aides and the larger care organization was often uni-directional. Mary was frustrated by not being considered part of the larger care team responsible for the client and shared how this influenced her ability to have access to information that would be helpful to her practice. She described an incident when she was required to call an ambulance on a client’s behalf. Mary was unable to answer the ambulance attendant’s questions about the client’s health conditions because she had not been given that information. She was left with the only option of giving the EMS staff the case manager’s phone number for more information. Associated with this event was the lack of information given to Mary upon the client’s return home two days later. As she said, “Nobody talked to me about what it was, what happened. You know, what to do, what her condition was. We are given nothing. Absolutely nothing and that’s not the way it used to be.” Mary explained that in the past, the care aides were given much more information. She shared that there used to be block meetings where the care aides and the coordinators would meet to discuss the clients. She said, “We were

given enough information that you went in there and you felt like you had a bit of a heads up. So if someone was confused and they started saying things to you, you had an idea of what was going on.” She further emphasized: “I think I could provide better service if I really knew what I was dealing with.” Another participant described feeling shock and remorse when she unwittingly put a client at risk by leaving the home when told to do so by the client. She later found out that the client had Alzheimer’s but she had not been told this by her supervisor when she was given the assignment. She said, “Why couldn’t they [her employer] tell me that she had Alzheimer’s? If they had told me, I would never, never have left her alone.”

Examples such as these demonstrate how a lack of attention to the perspectives of the care aides left them feeling not only unheard but unsupported, as well. Participants felt that they had knowledge about their clients that was valuable, especially since, of all the health care providers, they spend the most time with the clients. Participants were frustrated when this knowledge was not recognized or valued. Additional frustration occurred when the participants were kept out of the loop with regards to information that the participants felt necessary to provide excellent care to their clients. When participants’ concerns were not listened to, they experienced feelings of distress and sometimes felt that they had let their clients down. Without relevant information to inform their practice, the participants suggest it is challenging to provide the best care possible and leaves them feeling unsupported in their attempts to do their job well.

Striving to provide the best care possible for their clients seemed to be a primary motivator for the behaviour and actions of the participants in this study. Participants felt a need to protect and watch out for their clients, even sometimes to the point of breaking

rules to do so or providing care outside of their role. When the participants were able to keep their clients comfortable and safe, and could find ways to work within a system that seemed to produce, at times, barriers to providing quality care, they felt that they had done their best and had provided excellent care. As Peter summarized, the work is particularly rewarding when acknowledged by the clients that they serve:

Today, to tell the truth, I had a beautiful day because at my last call today, a wife and husband said to me, “Thank you so much for doing a fantastic job for us on a daily basis.” So I know when that happens, I know I can leave there. I can drive home without a care in the world and that’s how I look at it. It’s the last time you leave that house and how they say thank you and how they appreciate it. It’s that appreciation from somebody that makes your day and makes your day feel a lot better.

### **Connections**

Making connections was an important component of the participant’s work and the relationships that developed impacted many parts of their work. Many participants referred to the relationships with their clients as friendships or “like family”. Participants also described the relationships that they had with the larger care team. Connections had three dimensions: being present, developing bonds, and relationships with the larger care team. Being present is one way that participants described making connections, as they provided an opportunity for clients to talk, share stories, or to sit in silence with each other. The participants also described developing a bond with their clients – as either a process that happened naturally or one that was intentional in an effort to create a therapeutic benefit for the client. Sometimes that participant used shared experiences as

basis to develop that bond. Making connections with their clients seemed important to the participants who valued the relational aspect of their work. The third dimension of connections, that of the relationships the participants had with the larger care team, served to either increase their confidence in their ability to provide the best care when there was strong supportive relationships or alternatively, when those relationships were poor, had a negative effect and made the participants feel, as one participant said, “like second-class citizens”. When participants were not heard, and their concerns and knowledge dismissed, they felt like they did not matter. This resulted in distress for the participants because the core motivation to do this work is the desire to do the best that they can for those that they care for. When they feel they are not heard or valued, their ability to do their job well is compromised.

### **Being present**

Most of the participants expressed some form of being present with clients. Being present took the form of physically “sitting with” the client in silence or being there for the client if they wanted to talk. One participant said, “I guess it’s being with them. You know, just to know that there’s someone else here. ‘I am here if you want to talk. Even if I don’t understand you, go ahead and talk anyways.’” Another participant practiced presence after taking the lead from her clients. In one case, a client told the participant that she did not have to clean his apartment, that just sitting was okay and so she said:

After that I will mind maybe if I am doing something in front of him. Maybe he will feel uncomfortable. Dying people need quiet...I just sit with him there.

Sometimes talking with him but most of the time he talking with me. He told me about all of his family members and what they are doing.

Sometimes being present came from a sense of feeling that there is nothing more that can be done in the face of the client dying, but as one participant described: “Even if I can’t do nothing for them, what I can do is touch them.” Another participant described staying by his client’s side even while the client slept to ensure that when the client woke up, the client would be aware that he was present:

I didn’t leave his side. I stayed there because even though I was there for him and I wanted to make sure that when we sending that message, it’s not me going off over here to look at television. It’s me staying here waiting for you...and being present at that time when he wakes up and “oh yeah, I am still here” and so we carry on another conversation.

Whether through physical presence, conversations, touch, or silence, the participants described *being present* as an important part of their everyday work with clients in palliative care. Many participants felt that being the person that the client could talk with was an important part of their care work, sometimes to the point that their clients missed them on their days off as this participant acknowledge: “He [the client] always says to me, ‘You know something? I never have this conversation with anybody else. I feel so relaxed and when you are on your days off, I feel a loss.’”

### **Developing a bond**

Almost all of the participants talked about developing bonds with their clients. Sometimes this was something that happened naturally because of their shared time together, and sometimes the participants made an intentional effort to develop bonds with their clients. As this participant suggested, sometimes barriers existed to developing that

bonding relationship, but with perseverance, these barriers can be broken down, even in challenging situations:

But I always find though that even though they're miserable, if you are nice to them, so often, they will soften over time. It takes time but they will soften over time and you can kind of break down those barriers and develop a relationship with them and maybe that's part of the challenge that I like with some of the more challenging ones.

Sometimes shared experiences were used to develop a bond. One participant's husband had died some years prior. This experience helped her to connect with the clients who also had spouses die. She used this experience to help her to have conversations with the surviving spouse about the grief that they were experiencing. Another participant had a father that had died from Alzheimer's and expressed that this gave him the ability to relate to sons who were also caring for a parent with Alzheimer's.

As with being present, developing bonds with their clients seemed to be something that was very important to the participants and some considered it to be essential to their ability to provide quality care. Many participants spoke of the friendships they developed with their clients, considering the importance of these relationships and their belief that their work was more than just doing the tasks. As one participant put it: "I tend to become friends with them. I am not so cold as to just be there." Another participant described the bonding as something that was beneficial to the client and to himself as the care provider:

And so you're meeting his needs, to show him that you are not afraid to touch him or you're not afraid to be with him in his safety zone because sometimes some

people put up a wall and I said after the first two days we notice those walls coming down and for this plan that we had. It wasn't a six-month or an eight-month plan. It was like two months but in that two-month span we have really gotten to know one another. We really had that opening. As I said, we built, we bonded and it was a positive thing for him and I.

Almost all of the participants used the word friend in describing their clients. As one participant explained: "You try to develop a friendship with them and they [the family] were, I don't know, stand-offish about that part of it. They didn't want to develop a friendship because they knew what was coming." In interviewing this participant, there did not seem to be acknowledgement that perhaps the family was trying to keep things on a professional level. Yet another participant described an encounter with a client that was therapeutic and client-focused, revealing the deep connections that had been made between himself and the client:

I sit between last week and now, and I could show that we just became really good friends and we are speaking now as friends so like I say, let it out. Just feel free to tell me what is going on in your life and then we'll build on that. That way, you'll help me to understand a lot more of what is going on in your life now and I said it will help me to deal with you plus whoever comes into this system again, that needs somebody. In this case, him and I, we carry on our conversation. We go back to his childhood, to his mother. We spend our lives and then we sat...so we sat blending both lives together.

Making friends with their clients seemed a natural part of care work to the participants, but at the same time, a tension existed in trying to balance being friendly

with not getting too close. Bob explained: “I know what’s involved so I don’t take it too personal and I try to distance myself as much as I can. But still, they’re human. They’re your friends.” Some participants appeared less able to navigate the tension between the two sides of “not too close” and friends better than others. Bonnie described a situation with a client with dementia in which she was warned by a colleague to watch herself—that the client would “turn on her”. Bonnie said:

And to me that’s what I felt, that she turned on me. I thought, well, how can you do that? I’ve always treated you fairly. I’ve tried very hard...I kind of felt that I was doing my best and she wasn’t nice about it.

Bonnie had been treating this client as a friend, rather than a client. This participant was also wary of sharing too much information with clients that might then be shared with the other residents of the building. Feelings of protectiveness developed for Bonnie who said:

But I’ve tried not to get close to them but sometimes you can’t help it because you realize they need help and you’re the only one that comes because maybe their family doesn’t come. They depend on you. Even if they forget your name, they know your face.

Another participant maintained a friendship with a client even after that client was moved to a personal care home. This participant did not acknowledge that the friendship might be outside of the therapeutic caregiver relationship.

The connections that the participants made with their clients was beneficial not only for the clients but also for the participant as often the feedback from their clients helped to show the participants that their work was valuable. As Peter explained:

You know I appreciate the little subtle things that they say to you when they are around. It makes you feel that your job is worth everything that they said. Like you know the upper boss does not see the positive feedback when you are in the house. They have never seen [heard] the kind words that a lot of people say to you.

Making connections with clients was integral to the participants' ideal of what their role was as care providers. They believed these connections to benefit clients therapeutically, and help to establish important knowledge that informed their plan of care. Many of the participants were careful, articulating a desire to not cross professional boundaries with their clients, but even so, sometimes their actions were questionable. Interviews suggest that at times, participants may be drawn into relationships with their clients that move beyond the provider / care recipient role. Although it seems that these boundary crossings were done with the client's best interest in mind, the implications of this on clients and participants was not explored.

### **Relationships with the care team**

In addition to making connections with clients, the participants spoke about their relationships with members of the larger care team. At the core of the participants' relationships with the larger care team was the concept of value. The relationships the participants had with the care team worked to either show the participants that they were valuable members of the care team or that they were not valuable and did not matter.

Several participants spoke about the support that they received from other members of the team, whether that was fellow health care aides, community nurses, supervisors, or even the benefits offered by the care agency that showed the participant that he or she

was valued. For example, Mary found that talking to another care aide in the same block was very supportive. She shared:

To be quite honest, I think that if I did not have that relationship with my co-worker, I probably would have a huge amount of job dissatisfaction, a huge amount. I think that it's so helpful being able to talk to somebody because otherwise I mean there is the whole confidentiality issue and who do you talk to?

Sometimes relationships between health care aides were hampered by mistrust between health care aides from different agencies working with the same client. One participant described tension she experienced when she and staff from a different agency were all involved in the care of one client. She said:

I was so disappointed in the other workers...and one, like, because they were from [Agency A] and I was from [Agency B], they shunned me right off the bat. I wasn't their friend. No matter what I said to them about the person I was working for, didn't matter...and I felt like I was dirt to them because that's how they made me feel.

Some participants expressed frustration that other members of the care team did not value their knowledge about their clients. This frustration was sometimes directed at the community nurses, as Bob explained:

They [community nurses] don't ask us at all about the client. They ask the parent or the spouse about the client but the caregivers – no. At least maybe because when I have been there, I haven't been there that long and the time when I am dealing the nurses they didn't take my advice because I wasn't there long enough and now the nurse...I don't even the see the nurse anymore.

Bob went on to say: “like we can give them advice on what they should do and that but they don’t, they aren’t ...we are like second-class citizens. They don’t talk to us at all.”

It is in this context that health care aides feel unsupported in their attempts to ensure that his or her client receives safe, competent care from others involved in the care. For example, Mary described a situation with a nurse regarding a client she was concerned about:

I am really quite concerned; you know I was caring for him this morning. He seemed much more weak. His breathing was not as good. And the nurse just basically brushed me off and she just said, “He’s got an appointment with the doctor on Tuesday.” And he actually died that evening...and whereas I felt something needed to be done with this guy now. And that wasn’t the case...When I came the next morning and found that he had died, you know, that evening, I just couldn’t believe it. I was so upset.

Supervisors were found to be both a source of support and a barrier to support depending on the situation. One participant found that his supervisor was someone to which he could turn to for support and described his workplace as a place where “you can talk to them [his supervisors] about your clients. You don’t have to keep it all bottled in. You just talk to someone about it and they listen to you.” This same participant went on to describe how the company he worked for provided several other types of supports, such as a gym for staff to use, frequent training sessions and lectures, and being emotionally supportive in terms of recognizing what was going on in their employees’ home lives and by giving time off for family reasons. These types of supports helped to increase the participants’ feelings of being a valued member of the team.

Another way that the participants felt valuable occurred when they were given special privileges or assignments because of their exemplary work record. One participant described being sent on an out of town assignment. The participant was given an expense account for the overnight trip and given the responsibility to drive the client to his hometown and back. This participant was proud of being chosen to do this assignment and felt it reflected the trust that his employer had in him.

Some participants expressed that being heard would contribute significantly to their feelings of being supported. As one participant said: “Feeling that you can talk to your supervisor or you know, whomever, so that you are being heard and not just being kind of shut out and pushed away. I mean that would be very helpful, very supportive.”

Sometimes the participants felt their supervisor was not hearing them. One participant described a situation where a client had access to her own medication, which was frequently taken incorrectly. When the participant brought this forward to her supervisor, her concerns were dismissed. As she said:

I phoned my supervisor and talked to her about it but to me this is just a med error waiting to happen. And you know what? My boss just kind of said to me, “Oh she’s really not that confused and she’s just putting it on”...I just – I don’t get it. And again I think we spend more time with the client than the supervisor does. They have no idea.

Not being heard in this way led to feelings of helplessness and caused distress to some participants. Because of the close relationships that the participants had with their clients, they felt that they were uniquely qualified and should be recognized as an important source of information about the clients. However, participants did not always

feel that their concerns or knowledge of the client were heard, either by the nurses that cared for the same clients or by their supervisors. As Peter emphasized: “They [the larger care team] don’t see us as a significant part of the care team. Because if you saw us as that part of it, you’d consult with us a lot more”.

Many of the participants described a relationship with their employers as one of inequity. The participants described feeling as if their input was not valued, that they themselves were not valued and that they were treated as an inferior member of the team. Several participants described being reprimanded by supervisors for complaints received from either other staff or from families, before checking with the participant for their side of the story, such as when Bonnie said a nurse reported her to her supervisor for not washing her hands when in fact she had washed her hands prior to the nurse arriving. When this happened, the participants described feeling as if they were not trusted and not respected. It made them feel as if their supervisors were taking the “others” side rather than theirs, their own employee. The fear of being reprimanded before being able to tell her side, led one participant to always do what the family wanted, even if she didn’t agree with them. As she explained, “Even if sometimes I think they are wrong, but I have to agree with them. Otherwise they complain on you. They make you get into trouble. Some family members are not very kind.”

Sometimes employment practices contributed to the participants’ feelings of inequities. One of these practices was the manner in which some of the participants were paid, which was based on the actual time allocated for each visits. If there were gaps between calls, that time was not considered time worked, resulting in the participants needing to be on the job longer than 8 hours in order to receive a full day’s pay of 8

hours. As mentioned earlier in the section on Time, many participants took the time needed to provide care, which meant that they were working through the “gaps” and not being credited for doing such. This led to feelings of inequity and resentment. As one participant shared:

I started at 6:00. So if there is no client from 8:30 – 9:00, I am still at work. It’s like a policeman or a mailman if he misses my house and he doesn’t drop some mail inside, doesn’t he get paid? So why is it different for the home care workers?

Some of the participants believed that if they were truly respected and valued as a team member, their concerns would be addressed. One participant expressed his frustration at the inequity he saw in his workplace:

Even in that 9-hour day you can’t even take a washroom break. Everyone in the office can take a washroom break. These workers have to find a McDonalds or they have to find or beg a client or sometimes a client will even say, “No, I don’t want you to use my bathroom.

Employment factors such as these contributed to the participants’ feelings of being inequitably treated and not truly on a par with the rest of the team. When relationships with members of the larger care team were poor and unsupportive, the participants felt as if they were not as valuable, leading to feel that they were not really a part of the same team. Peter summarized how he and his fellow care aides felt when he said:

It’s the home care workers – very, very dedicated to what they are doing. They want to work. They want to be treated fairly and they want to make sure that somebody out there is really...I think that what they really want is to be supported.

To be given the chance to be on the team that you say we are supposed to be on. They do not feel like they are a part of anybody's team.

### **Loss**

As many of the participants felt deeply connected to their clients, they expressed concern about the losses that they might feel when they client died. Concerned about being emotionally affected by the loss, some of the participants, as mentioned, felt a tension between developing connections and not getting too close. Several of the participants mentioned that they had not taken educational courses offered in end-of-life care that were available to them because they were afraid that this might mean that they would be put into more end-of-life situations, which they were not prepared to cope with. When asked if she had taken extra training in palliative care, one participant replied: "No. I hate the thought of being with them and all of a sudden you come back and they are gone. Can't do that. Can't do that...the idea of seeing them and all of a sudden they are gone." There are three dimensions to theme of loss: 1) anticipating the loss, 2) experiencing the loss, and 3) managing the loss.

#### **Anticipating the Loss**

As discussed previously, almost all the participants referred to a tension they experienced at wanting to get close to the client, but not getting too attached to them. The discomfort in this attachment was related to the anticipated emotional pain the participants would experience when the clients died, as indicated by Bonnie: "But I just hate the part when you come back and he's not here any more. And that kind of hurts so I try not to get close to any of them".

Sometimes the loss reflected a loss of the client's personality, such as when Alzheimer's took its toll. Joanne described the stress of needing to repeat information multiple times to a client with Alzheimer's and when asked how she coped with that, she replied: "I find it very hard because I see them slip away, you see, and I get so attached to the people. That's my problem, I get too attached to them."

Robert spoke about his need for distance as something initiated by his employer: "They [his employer] don't want us to become too close, too attached, because if you do then it is hard emotionally." Some participants found it challenging to manage this balance, recognizing that it placed them in vulnerable positions: "when I am so close to the people, they are like my mother, you know. So it's bad." This same participant also spoke about being treated like a member of the family. This role reversal between a health care provider and family worked to increase the sense of loss that she felt.

Some of the participants felt powerless at watching the decline of their clients. Others explained that their work would be better if people did not die, while acknowledging that this was part of the work, and a natural part of life. Still, as one participant mentioned: "the worst part, that I know they're getting worse and they're eventually going to die. In a perfect world, everybody would be alive, ok?" When asked what would make it easier, she replied, "People not dying." This same participant was grateful that all of the deaths of her clients had so far occurred on weekends when she does not work.

An overriding sentiment expressed by most of the participants was that of being unprepared for the death of their client. This took either the form of shock and surprise when the death occurred, with participants using words like "Shocked", "can't imagine it

happened so fast”, “unprepared”, and “couldn’t believe it”, or not having the knowledge to be able to recognize when death was approaching. Not having the ability to recognize when death was near appeared to cause considerable stress to the participants, especially since they saw a mix of clients, some of who were formally designated as “palliative clients” and others who were receiving care for other reasons. As Mary explained, this stress was often times related to not knowing what to expect and what the deterioration was going to look like. In this sense, it is difficult to prepare oneself for what is to come:

I mean we have no idea and that could be with any of our patients, not just end-of-life, but definitely for end-of-life, more so. When I think of this lady that the nurse and I are going into right now, I mean, I said, “you know what? Any day, I think that any day now we are going to go in there and find her dead. You know because she is just so incredibly frail right now. But it’s the not knowing what it’s going to look like and what’s the deterioration going to look like too. When you don’t know what you’re really dealing with.

Without advanced preparation, some of the participants felt at a loss in knowing what to expect. One participant shared that she was sometimes able to look to the palliative nurse to help her navigate this phase of her client’s life. She described one such encounter:

This nurse was amazing. Like I had never been with someone who died before and did not know what to expect or anything and she was so good. I mean she stayed there and she looked after everything... That situation was new to me and she just kind of took control and was there to support me and show me what needed to be done.

Apprehension associated with anticipating the loss was increased because of the participants' fear of grief. Some participants were cautioned by their employers to not get too close but as we saw earlier, the participants had very close relationships with their clients and many had difficulty managing this balance. Not knowing what to expect increased the participants' apprehension of the loss they knew was coming. Sometimes, the nurses were able to facilitate and guide the participants so that they felt supported.

### **Feeling the Loss**

Participants talked about feeling sad and affected by the deaths of those that they were caring for. Some participants worked hard to put their feelings aside and maintain composure, a skill that was seen as important to be able to provide care to those clients who were still alive. Peter described the need to stay positive so that other clients would not see the loss that he was feeling:

Sometimes you want to cry or you go to your car and you can feel the tears coming down...I just lost a friend. I don't really want to tell Mr. Jones [his next client] that I just lost someone else... I want to go to Mr. Jones and say, "Hey, how are you doing?...So you always have to keep up that positive front.

One participant described a situation where she was hired to follow a client into the hospital and while that participant was temporarily out of the room, the client died. The participant described feeling quite distressed when she returned and witnessed the staff preparing the body, as was the practice in that hospital of binding the hands and feet post-mortem. She had not been told that her client had died prior to witnessing the binding. Years later, this participant said she was still traumatized by the event.

Participants experienced additional feelings of loss when they became involved in relationships that extended beyond the completion of the paid caregiver time period. Bob described a friendship that he maintained with a previous client after that client had been transferred to a nursing home. Bob would visit this person weekly to take him to the legion for a game of shuffleboard and in between two visits, the person had a heart attack and died. As Bob explained:

You know it's kind of a shock because you're going to see the client all the time and suddenly they are not there anymore. It was kind of, not upsetting, but difficult at first. Cause he looked healthy. He looked fine.

Cumulative losses had effect on at least one participant who said:

At first in the block I found it very hard because in the block you see quite a turnover...when I think of the number of people who have died, it's probably the most people that I ever have die in my whole twenty years that I have been with home care.

These participants all described their experiences of feeling the loss of their clients and mentioned that having a client die was particularly hard when they did not have chance to say goodbye. It appeared that often the participants were ill prepared for the death and were surprised when it happened, which added to the depth of emotion associated with the death. Some of the participants pushed aside their feelings so that they could continue to care for their remaining clients. The participants cared for many frail elderly clients at home who, even though they may not be formally declared to be a patient at end-of-life, they were, in fact, all palliative in a sense.

## **Managing the Loss**

The participants used various strategies to cope with the losses that they experienced. Personal faith practices were important to some of the participants who found comfort in prayer, giving them strength to help others. Another participant spoke about taking a positive approach to his other clients, even when he had just lost someone who was close to him. Still others talked about how thoughts of their clients remained alive in their memories. This participant, Jane, went on to share that she learns from her clients who have died. She said, "Somehow I should learn from them very much. I most importantly need to cherish my life from their experience. I am younger than them. I am healthier than them. I need to cherish my life." Jane was able to take something positive from the pain that she was experiencing. Being able to create a sense of meaning from the loss, as Jane did, seemed to be a supportive factor in managing her grief. Yet another participant shared that when she has had a client who has died, she goes home and bakes, and as she bakes, she takes any sadness or stress from her day away: baking allows her to turn something difficult into something positive that she can then share with others.

Talking with co-workers was another strategy used by some participants who felt this to be a source of support because they had all experienced client losses and could understand what each other was going through.

Needing some form of closure was important to some of the participants. Sometimes closure was obtained by attending funerals. One participant expressed a concern that he was not told when the client he had been seeing had died and had only found out by reading the paper. This appeared to be a barrier to this participant's ability to gain closure to his losses. Another barrier identified was a participant's perception that

his supervisors did not recognize the bond he had formed with his client and that there was no ability to accommodate a need for regrouping before his next client of the day.

Sometimes grief was shared as in the case of Mary and the surviving spouse of the man who had died. Mary was very fond of the client and said that his death really impacted her. She continued to care for the wife and through talking with the wife about her grief, she also able to process some of her own grief in a mutually beneficial way.

All of the participants expressed being affected by the losses of their clients in some way. The deep connections that they made with their clients amplified the feelings of loss. The participants used various forms of self care, such as personal faith, sharing with colleagues, going to client funerals, and reflection, to process the losses that they had experienced. Some felt hampered in their ability to mourn their losses by some organizational limits and policies, such as not being informed about clients' deaths, and time constraints that kept them moving from client to client, even when there had been a death that needed to be processed. While loss was a part of the everyday work of these participants, many of them did not anticipate or feel prepared for the loss and the associated feelings. Some avoided opportunities for continuing education on end-of-life care, afraid that this would lead to being placed in more end-of-life situations. There seemed to be little recognition that most of the clients they see are at end-of-life, and that the information learned at an end-of-life course might be beneficial in any of their client interactions.

### **Summary**

In summary, three main themes emerged from the data: 1) Striving to provide the best care, 2) Connections, and 3) Loss. It was clear that the participants were driven by

their desire to provide the best care possible and to do the best job that they could for their clients. They attempted to do their best by making the clients comfortable, keeping them safe, sometimes working outside their scope of practice, and sharing information. Sharing information was not only a strategy to providing the best care for their clients, but when information was not shared with the participants, it became a barrier to their ability to provide the best care for their clients. The lack of adequate time was also identified as a barrier to the participants' ability to provide what they considered to be best care for their clients.

The participants believed that making connections was an important part of their role and they did this through being present and developing bonds with their clients. Within the theme of making connections was the dimension of the relationship the participants had with the larger care team. This relationship was at times supportive as when the participants felt heard, and that their contributions were valued. Other times, these relationships led them to feel as if the team believed them to be inferior and not as valuable as other members of the team.

The participants all expressed feelings of loss during the course of their work. This loss was expressed in three dimensions: 1) anticipating the loss, 2) feeling the loss, and 3) managing the loss.

Effects of relationships were interwoven throughout all the themes. The participants considered their relationships with their clients to be essential to provide best care. These same strong relationships led them provide care at times in ways outside of their scope in role, prescribed tasks, and time allotted. Their focus on providing the best care for clients with whom they have a strong caring relationship with factored into the

frustration and distress they experienced when they felt that their knowledge and concerns were not valued. This led to frustration because of all the health care providers in the home, they felt they knew the client the best, provided the most intimate care, and were often the client's "confidante". These same strong caring relationships created situations where the participants became like family or friends, which added to the grief that the participants felt when these same clients died. When participants were not given access to information about their clients, they not only did not have enough information to provide best care, they were also not always able to prepare themselves for the inevitable deaths. When the participants were not able to provide care of the quality that they felt should be provided, feelings of distress emerged. This distress was related to feeling devalued and not part of the team. Relationships impacted their entire work experience from their daily interactions with their clients to the way that they were able to process or not process their feelings of loss. In many ways, the participants were often left feeling unsupported by the larger care team and isolated in their attempts to provide the best care possible for their clients.

In the next chapter I will discuss how the findings of this study align with the existing larger body of research and the implications of this study for nursing, education, health care organizations, and research

## Chapter 5 – Discussion

The purpose of this study was to learn about the experiences of support of the health care aides who provide care to people living in the community at end-of-life. Three themes emerged from the study: striving to provide the best care, connections, and loss. Findings from this study reinforce the current understanding of how working in the home has unique challenges. The participants in this study, like others studied, are committed to their work and strive to do their best. Health care aides often develop strong relationships with their clients and many use the language of friendship when describing their relationship with their clients. Home as the place of care is at once both a private personal space and a public workplace and this causes ambiguity of roles. While other researchers have identified these links (Mahmud & Martin-Matthews, 2008; van Riesenbeck et al., 2015), this study illuminates just how all encompassing the effect of relationship is for the health care aide.

Relationships run through all three themes identified in this research. Relationship begins with the very reason the health care aides choose the work; that is, they care about people and find the emotional connections satisfying. Many health care aides believe that developing a relationship is a requirement of their work and the key to quality care. It is this relationship that helps them to do the best that they can and helps to make the clients feel truly cared about but it can also leave health care aides vulnerable to increased anticipation of emotional overload when the clients die and can increase the level of grief that the health care aides experience.

Two aspects of the findings that I would like to particularly focus on are: 1) the relationship that the participants have with the larger care team and the associated feeling

of value; and 2) the tension that the health care aides feel between getting close, but not too close and the apprehension surrounding end-of-life scenarios.

### **Relationships with the team and value**

Participants in this study did not always feel like they were valued and respected members of the larger palliative care/health care team. Contributing to this belief were incidents when the community nurses did not seek the participants' knowledge about their clients, when the nurses or their supervisors ignored the participants' concerns about their clients, and when the participants were not given enough information to adequately care for their client. It was acknowledged that the relationships with other colleagues, nurses or supervisors were variable and at times could be quite supportive. Feeling supported occurred when the participants felt listened to, when their knowledge about their clients was seen as valuable, and when supervisors showed that they recognized work done well.

This finding of health care aides feeling like their knowledge about the clients was not valued lends support to multiple studies from both long-term care settings and home settings. Home health care aides feel because of the extended time that they spend with the clients and because of the close relationships that develop, they are in the best position to recognize changes in clients' condition but when these changes are reported, they are either ignored or not acted upon in a timely manner (Denham et al., 2006; Fleming & Taylor, 2006; Nugent, 2007). This undervaluing of the health care aides' knowledge also occurred in long-term care settings (Barack & Chichin, 2001; Carpenter & Thompson, 2008; Hanson et al., 2002; Pfefferle & Weinberg, 2008; Spilsbury & Meyer, 2005).

The research literature has many studies that show that health care aides do not believe that employers value or recognize the emotional work that they do. Findings of my study show that participants value the emotional work that they provide to their clients, are able to notice subtle changes as a result of the relationship that has developed and are distressed when these changes are brought forward but ignored. As we have discussed earlier in the literature review and findings, time constraints impact the health care aides' ability to develop relationships and as a result, their ability to provide emotional care is hampered. This sends the message from the organization that the emotional work that health care aides do is neither recognized nor valued. Several researchers have indicated that emotional work is invisible yet inseparable from the practical work that health care aides provide (Aronson & Neysmith, 1996; Cloutier et al., 2006; Piercy, 2000). In fact, Aronson and Neysmith (1996) propose that there is no vocabulary to describe the emotional aspect of caring behaviour and health care aides themselves often do not recognize the work that they are doing; as a result, this work remains invisible. It is often omitted from descriptions of health care aide work (Canadian Hospice and Palliative Care Association, 2006), yet we know that this work is being done.

Devlin and McIlpatrick (2010) noted that health care aides in the community did not always feel supported by the community RNs and the RNs viewed the health care aide role as primarily providing physical care. The health care aides were not seen as providing any kind of emotional care so the impact of that work on the health care aide was not recognized by the RNs.

Devlin and McIlpatrick (2010) noted in a study looking at health care aides providing care to palliative clients at home that the organization recognized that care recipients identified the importance of continuity of care providers and relationships but when care needs increased, different staff were brought in to meet scheduling demands. This left the care recipient needing to adjust to new care providers and the health care aide feeling devalued and interchangeable.

Participants in my study noted that there was often a contradiction between what was said by the organization and what actually occurred. The formal message was that the aides are part of the health care team, but when their input wasn't solicited or their concerns ignored, this sent the message that they were not valued. The impact of the larger organization not recognizing the level of emotional care provided also impacted the participants' grief. Anderson and Gaugler (2006-2007) found that health care aides working in long-term care were able to achieve personal growth from their grief when the relationship between the health care aide and the resident/client was acknowledged and suggested that failure to acknowledge the health care aide's grief may hamper the grieving process. In my study, there was often no accommodation made to allow the aides to grieve. Participants expressed that there was a need to put their immediate feelings aside and remain positive so that they could carry on with the remainder of their day and to not let their next client of the day know that they had just experienced a loss. This finding supported several studies in long term care (Funk et al., 2013; Osterlind et al., 2011) and in the home setting (Devlin & McIlpatrick, 2010; Ferguson et al., 1998).

The need to put aside one's immediate feelings in order to carry on has been well documented in the literature on emotional labour (Hochschild, 1979). Hochschild defines

emotional labour as working to manage an emotion, whether that be working to show an emotion that isn't there, as in smiling and being pleasant when one has to in the course of employment (shop clerk needing to remain positive in the presence of an angry customer) or suppressing an emotion such as when a nurse suppresses the expression of grief while she is in the presence of grieving family members. James (1989) elaborates further and speaks to the work required of hospice staff who must regulate their emotions. James explains that patients in hospices often express a variety of difficult but very appropriate and expected emotions such as anger, despair, or frustration and the staff must be witness to these emotions, which are not typically present in a workplace. James proposes that this emotional work is as hard as physical labour. This emotional labour is often done alongside personal care. Nurses say that their education did not prepare them for the emotional work required in nursing, let alone in palliative care (Henderson, 2001; Hopkinson, Hallett, & Luker, 2005). Health care aides do not have nearly the educational preparation that nurses do. There is no standard educational or training requirement to become a health care aide, nor are there any standards of practice (Pan-Canadian Planning Committee on Unregulated Health Workers, 2008). If nurses feel unprepared to provide the emotional care required, it is not surprising that health care aides feel unprepared.

The Pan-Canadian Gold Standard for Palliative Home Care states that palliative care is to be provided by a strong interdisciplinary team (Canadian Hospice and Palliative Care Association, 2006). We need to support the health care aides to be a part of this team. As participant Peter said. "We all just want to be part of the team that you say we are on".

### **Apprehension of emotions at end-of-life**

The participants described a constant tension between being friends with their clients and yet not crossing the line to caring too much. The participants in this study were concerned about the effect that their client's death would have upon them and many were unsuccessful in maintaining this boundary effectively. This tension and apprehension were so strong that several participants actively avoided education about end-of-life issues because they feared being put into more end-of-life situations that they say they were ill equipped to handle emotionally because of their relationships with their clients. I had expected to find grief related to deaths of clients; however, I did not expect to find this apprehension of emotions associated with end-of-life that I saw.

In addition to feeling apprehensive about their ability to manage their emotions, several participants were concerned that they did not have the knowledge to recognize when death was approaching. The participants indicated that they would feel better prepared if they knew when death was approaching and what to expect. This fear was not unique to this study. Boerner et al (2015) found that the less prepared health care aides were for a death, the greater their grief was. Van Riesenbeck et al (2015) took this further and found that knowledge of the client's goals of care was associated with better death preparedness. In my study, the relationship with the team comes into play here. Participants shared that they were seldom told when a client was palliative and that the end-of-life was near. Sometimes the community nurses were able to guide them about what to expect, but that appeared to be the exception rather than the rule.

It becomes clear that telling a health care aide to "not get too attached" or "watch your boundaries" is not only unsupportive but is fruitless and undesirable. As

demonstrated in the literature review, there are many reasons why a relationship between a health care and the care recipient is not only necessary, but also desirable. What is clear is that the health care aides are in dire need of support to be able to navigate the tension that exists in developing a relationship but not letting it go to far and how to handle and manage the emotions that are a part of providing care at end-of-life.

There appear to be opposing views with regards to relationships in health care. Some researchers and authors say that managing emotions is just a matter of keeping good boundaries. It appears that in reality, boundaries and emotion management is far more complex. Carmack (1997) describes how caregivers learned to manage this balance over time using techniques such as awareness, setting limits, monitoring oneself and self care. Those who were successful at balance had a clear understanding of what was in their control versus what was not and were not unduly invested in outcome. Health care aides are the largest group of providers and spend the most time with the clients and are ideally situated to provide emotional care and dignity care that is so important at end-of-life.

Relationship and connection are interwoven throughout all the findings. Participants strive to provide the best care and believe that providing emotional care to their clients is an essential component of doing their best. At times, they feel unsupported in their efforts to provide what they feel is necessary for good care. This leads them to do extra tasks and spend extra time with their clients. They begin to see their clients as family because they feel at times that their clients have no one else. They may feel that the care plans are inadequate, such as the example of taking out a client's garbage when that wasn't specified. When their relationship with the larger care team is

unsupportive and they do not feel heard when they bring their concerns forward, they are left with feelings of distress and feeling devalued. When the participants feel that they have not done their best, even when circumstances are beyond their control, this leads to distress. It also perpetuates behaviours such as doing extra tasks and working beyond their paid time because the health care aide begins to feel as if they are alone out in the community. They are alone in managing their grief, which leads them to avoid end-of-life situations.

### **What this study contributes to the current body of research**

This study lends support to several different topics of existing research: the effects of home care restructuring on the health care aide, the importance of relationship to the health care aide, the experience of the health care aide as a self-perceived non-valued member of the team, the unpreparedness of the health care aide for the deaths of their clients, and the degree to which they experience grief.

New material that this study brings to the current body of research is the extent to which relationship with their clients impact their whole work experience, from the strategies they utilize to provide the best care to the importance of developing bonds with their clients and to the loss that they experience. This research further emphasizes the isolation of this work. The health care aides are not part of the collaborative care team and generally work unsupported in their attempts to provide safe quality care. They are generally unheard and undervalued. Their contribution toward the emotional care of the clients goes unrecognized and they are left to fend for themselves when grief occurs.

### **Implications for nursing**

Nursing has a role in supporting health care aides in the community, not only in palliative situations, but in all situations of care at home. Community nurses, especially specialty palliative nurses, can provide one-on-one teaching with health care aides about clients and can interpret what they are seeing, especially in end-of-life situations. Working together, nurses could not only teach health care aides about death and dying but could also help to mediate when the health care aide/ client relationship is getting too close. Nurses are in the best position to engage health care aides in collaborative care of clients as the health care aides spend a large amount of time with their clients and can provide nurses with valuable information about the clients. As van Riesenback et al. (2015) and Boerner et al. (2015) noted, when health care aides are included in care planning and are prepared for their clients' death, they experience lower levels of grief responses. Nursing can be of great assistance here. When health care aides know a client's end-of-life wishes, they are in a better position to ensure that those goals are met. Nurses experience grief just like health care aides do and because of this shared experience, can offer support to the health care aide. It has already been shown that one reason that health care aides turn to each other is because their colleagues know what they are going through (Denham, et al., 2006; Marcella & Kelley, 2015).

### **Implications for education and training**

Health care aides would benefit from specialized training for end-of-life care, including dealing with dying and loss, communicating with clients about death, how to know when death is near, and what to report to others. Research shows that most training

for health care aides in end-of-life is inadequate (Herber & Johnston, 2013; Denham et al., 2006; Devlin & McIlfatrick, 2010).

Van Riesenbeck (2015) found that increased preparedness for death by home health care aides was associated with a personal awareness of their own end-of-life preferences and also an awareness of the client's end-of-life preferences. Increased positive attitudes toward death have been associated with increased education level and with increased experience with end-of-life experiences (Leclerc et al., 2014; Ferguson, 1998). Health care aides need to be supported in exploring their own ideas around death and dying so that they increase their comfort level. This could be undertaken in small groups of discussion.

Health care aides will be developing relationships with their clients due to the nature of the intimate personal care that is provided and as a result, will need education on how to navigate the balance between caring and crossing the line into over-involvement. It is vital that health care aides be supported in their work with clients so that they are able to manage this level of emotional involvement. If it is not managed, then there is great capacity for professional boundaries to be crossed and for burnout of health care aides to occur.

More effort needs to be put into giving the health care aides the skills to manage the emotional work that they do. Carmack (1997) and Ablett and Jones (2007) both suggest that maintaining emotional balance and learning to be resilient can be taught. Scheid (in Stacey, 2005) suggests that contrary to common belief that burnout among direct care workers is a result of the intense emotional labour that they do, health care aides find relief in work that fosters deep emotional ties with clients. She suggests that

burnout is the result of a suppression of a worker's emotional labour rather than a result of over-involvement. So the answer is not to advise the health care aides not to get involved, but rather to give them the skills and supports necessary to process the emotions safely. Health care aides need education in understanding grief, normalizing their grief, and the opportunity to debrief.

### **Implications for health care organizations**

Health care organizations have a responsibility to better align their actions with their stated policies. As one participant remarked "You say we are the jewel in the crown and that our opinion matters and then you tell us to shut up." Several other researchers noted this discrepancy (Bowers, Esmond, & Jacobson, 2003; Pfefferle, & Weinberg, 2008). Existing research clearly shows the importance of the health care aide/care recipient relationship for quality patient care and for patient satisfaction, as identified in the literature review. Organizational practices need to align with this fact. Health care aides are the largest group of health care workers and spend the most time with clients in the home. Their ability to affect the quality of care is enormous.

Several studies looked at retention of health care aides and several identified job satisfaction and strong supervisor support as factors that kept health care aides in their jobs. The need for health care aides is growing phenomenally, as discussed in chapter one and competent health care aides need to be supported so that they will stay in the vocation and not leave for other work. Organizations need to acknowledge the impact of caring on health care aides and provide appropriate support.

Several researchers caution that threats to a worker's ability to form and maintain relationships with clients (such as increased workloads, changing caseloads, variable

work schedules) form the biggest issue in home care (Denton et al., 2002; Martin-Matthews & Sims-Gould, 2008).

Health care aides need to become a part of the formal care team and knowledge needs to be shared in both directions in order for the health care aides to feel supported in their work. To this end, nurses and case managers need education in putting collaborative care into practice. Palliative care works because of a strong team effort both for patient care and for mutual support of each other. Mutual understanding of grief helps members of the team to support each other. When the largest component of the team is left out, we do a disservice to our clients.

### **Directions for future research**

We know that health care aides have identified a need for increased support and education. In particular, areas needing further study in broad terms are grief and emotional coping of health care aides. Future research needs to look at the effectiveness of various interventions for support such as does mindfulness training or resilience training help the health care aide to find balance in their emotional work? Does education about end-of-life and communication training help to prepare health care aides to be better prepared for the deaths of their clients? Which education methods work best – small group learning with demonstrations of communication techniques, computer based learning programs, or mentor/buddy experiences? Future research needs to focus on the unique needs of the health care aides who provide end-of-life care to those living in the community. Community health care aides providing end-of-life care have unique needs and these need to be addressed.

## Summary

This study was undertaken using an interpretive descriptive approach to understand how health care aides who provide palliative care in the community experience support. A total of six health care aides were interviewed. Data was analyzed and three themes were identified: striving to provide the best care, connections, and loss. Striving to provide care included dimensions related to ways in which they were able to enact this care. It also included two dimensions that at times were barriers to providing this care (information sharing and time). The theme of connections emphasized the importance of connection that the participants had with their clients. It also included how their relationships with other members of the care team often left them feeling devalued and isolated. The third theme of loss had three dimensions: anticipating the loss, feeling the loss, and managing the loss. Findings showed that participants were very nervous about experiencing the death of their clients because of the close relationships that had developed and many avoided further education in end-of-life care because they feared that this would put them in more end-of-life situations.

Relationships are central to the participants experience and drive their behaviours. This can be positive such as when it leads to being able to provide excellent care when they know the client so well that they are able to notice subtle change and avert untoward events. This can also be potentially harmful as when they are put in vulnerable positions such as when they have gotten too close to a client without the associated organizational support to manage the emotions. Because of the isolation of the work in community, health care aides can feel as if they are working out on their own, unsupported by the larger organization.

The population of Canada is growing older and there will be a huge increase in demand for home care services in the near future. People want to stay at home to die and health care aides are essential to the ability of the health care system to be able to deliver this service. An army of qualified, well-trained health care aides is going to be needed. This army will need to include a large component of health care aides trained in end-of-life care, comfortable with being with the dying. The public expects palliative care to be delivered by knowledgeable, caring staff. There are already large numbers of committed, caring health care aides working in the community; all they need now is the support to be able to be the best care providers that they can be.

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## Appendix A – Letter to Agency Managers

Dear (Name of Manager),

My name is Florence Misurka and I am a graduate student in the School of Nursing at the University of Victoria. As part of my studies, I am conducting a study looking at how supported health care aides feel in providing in-home care to patients at end-of-life. There is very little research looking at this issue and yet health care aides spend many hours looking after people at home who are dying. I am interested in speaking with **health care aides** who have looked after a dying patient in the home setting within the last 2 years. I hope to gain an understanding of the health care aides' experience of support (emotional, educational, and organizational) that will inform the **development of support systems** for this group of health care providers.

I am **requesting your permission to attend any meeting** you might have already scheduled with either the health care aides or their supervisors so that I could take a few minutes to speak with them about my study and to invite their participation. If no such meeting is planned in the near future, I am hoping that you might be willing to speak with me and help me figure out how to best contact health care aides who might be interested. I will be following up with you in about a week's time by phone to discuss the study and address any questions that you might have.

Thank you for considering my request. If you have any questions, I can be reached at xxx-xxx-xxxx, or at xxx-xxx-xxxx or at email \_\_\_\_\_. I will be working under the supervision of Dr. Kelli Stajduhar, who can be reached at 1-xxx-xxx-xxxx, or email \_\_\_\_\_. I expect that data collection will be completed by June 2015.

Thank you for your time.

Sincerely,

Florence Misurka, RN, BN, CHPCN(C)

**Appendix B – Recruitment script for managers of agencies**

Florence Misurka, RN is a student at the University of Victoria completing a Masters of Nursing degree. She is interested in learning about the health care aides' experiences of support as they provide in-home care for people at end-of-life living at home. If you are interested in sharing your experiences with her, please take a copy of the enclosed Participant Consent form that gives more information about her study and her contact information. Participation in this study is entirely voluntary and completely confidential.

### **Appendix C - Recruitment letter for Health Care Aides**

Hello,

My name is Florence Misurka and I am a student at the University of Victoria completing a Masters of Nursing degree. As part of my studies, I am required to conduct a research study. I am interested in learning about your experiences of support as health care aides as you provide care to people dying in the home setting.

This research is important because very little research has looked at the experiences and needs of the health care aides working in the home setting with palliative patients. My hope in conducting this research study is to use the information obtained to aid in the development of support systems for health care aides.

If you are interested in sharing your experiences of providing care to people who are at home and dying, please take a copy of the informed consent letter that I have. If you still wish to participate after reading the letter, please contact me at the number listed on the letter. I would also be happy to answer any questions that you might have. I would ask that you participate only if you have looked after a dying patient within the last two years.

The interview will take between 1 and 2 hours and will occur outside of work hours at a time and location convenient to you.

Participation in this study is entirely voluntary and confidential. Your supervisors will not be informed of your participation. In appreciation of your time and participation, I will give a small honorarium in the form of a \$10 gift card to Tim Horton's.

Thank you.

## **Appendix D - Recruitment script for meetings with health care aides**

Hello,

My name is Florence Misurka and I am a student at the University of Victoria completing a Masters of Nursing degree. A part of my studies, I am doing a research project to better understand how supported you feel when you provide care to people dying in the home setting.

This research is important because very little research has looked at the experiences and needs of the health care aides working in the home setting with palliative patients. My hope in conducting this research study is to use the information obtained to aid in the development of support systems for health care aides.

I am interested in hearing from health care aides who in the last 2 years have looked after a person at home who was at the end of their life. My intention is to learn from you. If you are interested in participating and would like some more information, please speak with me at the end of this meeting or give me a call at xxx-xxx-xxxx. My contact information is also available on the poster that is available.

Thank you for considering my request. Your perspectives will be very helpful in informing how to best support health care aides in the important work that they do.

### Appendix E- Recruitment Poster

Are you . . .

- A health care aide who works in the community and has provided end-of-life care to a patient in the last 2 years?
- Willing to share your story?

If so...

I would like to hear from you!

I am a masters of nursing student at the University of Victoria and I am conducting a research study to see what kinds of supports are available to health care aides providing palliative care in the home setting.

This research is important because very little research has looked at the experiences and needs of the health care aides working in this setting. My hope in conducting this research is to use the information obtained to aid in the development of support systems for health care aides.

What's in it for you?

- The chance to have your story heard
- The opportunity to help influence the work environment of health care aides in the community
- A \$10 gift card to Tim Horton's

## If you are interested...

Please call Florence Misurka at xxx-xxx-xxxx or email at \_\_\_\_\_ to hear more details about how to participate. Remember, all participation is confidential and anonymous.

Thank you

**Appendix F – Questionnaire for Context**

How long have you worked as a health care aide?

How long have you worked in the community as a health care aide?

Are you certified as a health care aide? Yes or No

What is your level of training?

Have you had any specific training in palliative care? If so, what was the training and how long ago did you complete the training?

In which age group are you: 20- 30 years, 31-40 years; 41-50 years; 51-60 years, over 60 years?

Are you male or female? (Please circle).

Do you work for the Winnipeg Regional Health Authority (please write out in full) or for a private agency? (Please circle).

Have you had any experience with loss due to death in your personal life? Yes or No

## Appendix G – Interview Questions

Can you please share with me:

How long have you been a health care aide?

Tell me about your training and how you came to be working as a health care aide?

Have you had any specific training in palliative care? If so, what was the training and how long ago did you complete the training.

When was the last time that you looked after a patient who was dying?

Tell me about an experience you have had caring for a dying patient while you were working.

What was it like caring for the dying person?

What is the most stressful part of providing care to palliative patients and how do you cope with that stress?

Questions related to being part of a healthcare team:

When you hear the word “support” from the health care team, what comes to mind for you?

Where do you find support and what does (or would) that support look like?

Can you tell me about a time that you felt supported by other healthcare providers as you work?

Can you tell me about a time that you did not feel supported in your work?

What helps you to do your job well?

What hinders you in providing care to the best of your ability?

What is your relationship like with the palliative nurses that visit the clients at home?

Can you describe a time that you had a significant encounter (positive or negative) with one of the visiting nurses and how did you feel?

Do you feel that the visiting nurses are supportive of your work? If so, what specifically do they do that supports you? If not, what specifically is unhelpful or unsupportive?

Is there anything that you would change in your working environment and if so, what would that be?

Is there anything else that you would like to tell me about your work?

## **Appendix H – Information to nurses for help in recruitment**

My name is Florence Misurka and I am a graduate student in the School of Nursing at the University of Victoria. As part of my studies, I am conducting a study looking at how supported health care aides feel in providing in-home care to patients at end-of-life. There is very little research looking at this issue and yet health care aides spend many hours looking after people at home who are dying. I am interested in speaking with health care aides who have looked after a dying patient in the home setting within the last 2 years. I hope to gain an understanding of the health care aides' experiences of support (emotional, educational, and organizational) that will inform the development of support systems for this group of health care providers.

I am requesting your help in providing information about my study to the health care aides that you see during the course of your day. If you are in the home of a palliative client at the same time as a health care aide, I am asking that you give the health care aide a copy of the poster about my study and relay the importance of this study.

If the health care aides have questions, please encourage them to call me and I will gladly answer any of their questions with no commitment required of them. If the health care aide is interested in participating, please ask their permission to pass on their contact information to me. When I contact them, I will explain the study in more detail and then if they were still interested, we would make an appointment to meet in person. The health care aide can also call me directly using the contact information on the poster, if they feel more comfortable with that method.

If you have any questions, I can be reached at xxx-xxx-xxxx or email \_\_\_\_\_. I will be working under the supervision of Dr. Kelli Stajduhar, who can be reached at 1-xxx-xxx-xxxx, or email \_\_\_\_\_.

Thank you

## Appendix I – Consent form



**University  
of Victoria**  
School of Nursing

### *Participant Consent Form*

#### **Experiences of Support as identified by Health Care Aides providing in-home care to patients at end-of-life**

You are invited to participate in a study entitled

#### **Experiences of support as identified by Health Care Aides providing in-home care to patients at end-of-life**

conducted by Florence Misurka, RN, BN.

I, Florence Misurka, am a graduate student in the School of Nursing at the University of Victoria. As a graduate student, I am required to conduct research as part of the requirements for a degree in Nursing. I am conducting this research under the supervision of Dr. Kelli Stajduhar. You may contact Dr. Stajduhar if you have further questions by calling xxx-xxx-xxxx or by email at \_\_\_\_\_.

#### **Purpose and Objectives**

The purpose of this research project is to gain an understanding of the experiences of support as identified by health care aides providing in-home care to patients at end-of-life. My goal is to use the knowledge generated to inform the development of support systems for this group of health care providers.

#### **Importance of this Research**

Research of this type is important because it addresses a gap in the current body of research. Very little research has looked at the experiences and needs of health care aides, regardless of setting and even less has looked at the experiences of health care aides providing end-of-life care in the home setting. Health care aides are the group of health care providers who spend the most time with patients at home and have the potential to experience the most intense emotional stressors, yet little is known about their needs with regard to support. It is anticipated that the knowledge learned from this research will inform the development of support systems for this group of health care providers.

#### **Participants Selection**

You are being asked to participate in this study because you are a health care aide who has provided end-of-life care to a person living in their home during the last 2 years of your employment.

#### **What is involved?**

If you consent to voluntarily participate in this research, your participation will include a single one-to-one interview lasting approximately 1- 2 hours at a time and location convenient to you.

An audio recording will be made of the interview and I will take some written notes during the interview. I will transcribe the audio recording myself.

Please be advised that information about you that is gathered for this research study will not be identifiable as belonging to you.

### **Inconvenience**

Participation in this study may cause some inconvenience to you, including the time and location of the interview. To compensate for this, I will arrange the location and time of the interview to your convenience.

### **Risks**

There are some potential risks to you by participating in this research and they may include feeling some emotional distress in talking about your experiences. To prevent or to deal with these risks I will stop the interview if necessary to give you a chance to compose yourself, reschedule the interview for another time or continue with the interview and ensure that you have contact information for follow-up emotional support.

If information is revealed by you that pertains to activity of an illegal nature, such as abuse towards a client, I am duty bound to report this information.

### **Benefits**

The potential benefits of your participation in this research include a feeling of “being heard” in the telling of your story. Society would benefit because we know that the need for home care services is increasing in general and with the aging population in Canada, the need for increased home care services at end-of-life is also increasing. The health care aide who feels supported in all aspects of his or her role will be able to provide quality care. The state of knowledge benefits from this study because this study addresses a gap in the body of knowledge currently available. Information about the health care aides who provide palliative care at end-of-life in the community setting is sparse and this study will address this gap.

### **Compensation**

As a way to compensate you for any inconvenience related to your participation, you will be given a \$10 coffee shop gift card. If you consent to participate in this study, this form of compensation to you must not be coercive. It is unethical to provide undue compensation or inducements to research participants. If you would not participate if the compensation were not offered, then you should decline.

### **Voluntary Participation**

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be used only if you give permission to use the information already collected. If you withdraw and ask that I not use information already collected, all information you have given will be destroyed.

### **On-going Consent**

It may be possible that the data that I collect may be used in a future study. There is a section at the end of this document where you can indicate your decision regarding this. If you do decide to allow the use of your data in future research, your data will be completely anonymous and confidential. This means that any identifying information will be deleted.

### **Anonymity**

During the course of this study, I will identify each participant by a pseudonym. There will be a master list containing the name of each participant and the pseudonym assigned to his or her interview data. This master list will be kept in a locked location, separate from the interview data. The list will be destroyed once interview analysis is completed.

### **Confidentiality**

Keeping the participant name and pseudonym separate from the audio recordings will protect your confidentiality and the confidentiality of the data. Pseudonyms will be used in all documentation. Any identifying information will be omitted or changed in any publication of the study.

### **Dissemination of Results**

It is anticipated that the results of this study will be shared with others in the following ways: a written thesis and oral defense of the study, presentations at scholarly meetings, published articles, and the Internet (masters theses at the University of Victoria are available online and can be accessed by the public). I will also send a letter summarizing the results to all participants who request a copy.

### **Disposal of Data**

Once the study is completed, all electronic data on the laptop will be erased. The remainder of the data, the paper documents, audiotapes, and the backup flash drive will be kept for a period of 7 years. Once this period is finished, paper copies will be shredded. Audiotapes and the flash drive will be erased and then destroyed by incineration.

### **Contacts**

Individuals that may be contacted regarding this study include my supervisor, Dr. Kelli Stajduhar whose contact information appears at the start of this document.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

---

*Name of Participant*

---

*Signature*

---

*Date*

### **Future Use of Data**

I consent to the use of my data in future research: \_\_\_\_\_ (Participant to provide initials)

I **do not** consent to the use of my data in future research: \_\_\_\_\_ (Participant to provide initials)

I wish to be informed in the event my data is requested for future research: \_\_\_\_\_ (Participant to provide initials)

*A copy of this consent will be left with you, and a copy will be taken by the researcher.*

## **Appendix J – First discussion with participants**

Thank you for your interest in participating in this study. My hope in conducting this study is to gain an understanding of health care aides experiences of support as you provide in-home care to people at end-of-life. My goal is to use what I learn to help develop programs of support for health care aides.

Very little research has looked at the experience of health care aides who work in the home setting and I believe that the health care aides as a group have important knowledge that we can learn from.

In the last 2 years, have you provided care to a person at home who was at end-of-life? If it is ok with you, I would like to give you some information about the study so that you can make an informed decision about participating in this study.

If you agree to participate, we would set up a time for an interview that will take between 1 and 2 hours. This would take place out of work time but at a location and time convenient to you. Participation is entirely voluntary, anonymous, and confidential. No one will know that you are participating. You can choose to withdraw from participation at any point in the process. I will make an audio recording of the interview to aid in my analysis at a further point in the study. These recordings will be kept for 7 years in a locked cabinet and then will be destroyed along with any other data such as hand written notes. In compensation for your time, I will give you a gift card in the amount of \$10 to Tim Horton's. Are you still interested in participating? If so, let's set up a time to meet.