Staff Perceptions on the Qualities of Meaningful Relationships with Residents at End of

Life in Long Term Care

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Abstract

Long Term Care is a place where many people die, and it is the job of the staff members to assist the resident with their dying and death experience. A peaceful transition to death is largely dependent on the relationship between resident and staff members. In order to provide the best dying and death experience for the resident, I sought to explore staff perceptions on the qualities of a meaningful relationship with resident at the end of life.

Using interpretive phenomenology as a qualitative research design and Heidegger's (1962) concept of the lifeworld as a tool of analysis, I uncovered aspects of good ethical care by listening to the people who provide it. I completed a series of nine interviews and depicted staff perceptions of the qualities of their relationships with residents at the end of life. My data analysis uncovered three qualities of staff and resident relationship that positively influenced the dying and death experience for resident. These qualities are fearlessness, meaningful time and vulnerability.

Furthermore, these findings reflect the mutual giving and receiving of care for both staff and resident throughout this relationship. Often this complex dynamic can be misunderstood or masked by what ministry standards tell us in how this relationship should look in LTC. My research exposes a different side of care at the end of life. With all the unknowns a resident is faced with at the end of life, the emotional relationship between resident and staff member can be the most comforting.

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Chapter One: Introduction

This research explores the lived experiences of staff and their perception of the qualities of meaningful relationships with residents at the end of life in long-term care (LTC). The study took place in a 151-bed municipally run LTC Home in Eastern Ontario that employs approximately 220 people. In their *Palliative Care at the End-of-Life Report* (2016), Health Quality Ontario stated that out of all palliative care patient deaths in Ontario, 11.7% died in LTC, 23.5% in community and 64.9% in hospital. Between 2015-2019 at the LTC home in this study, 20 residents have been transferred to hospital at the end of life and died in hospital when their death experience could have occurred in this LTC home. In their 2014 report, *Health Quality Ontario* stated that their main suggestion for enhancing quality in end-of-life care "included that all patients approaching the end of life have access to specialized, inter-professional, team based, integrated care" (p.42). *Quality Improvement Guide of Long-Term Care* (2012) outlines many initiatives to consider for LTC homes in Ontario. The common theme in these initiatives is the notion of working well within a team as the catalyst for good quality care (Dobrina, Tenze & Palese, 2018). The team on the floor, in direct contact with the resident and their quality of life, needs to be the staff who set the goals for the resident and in the way that they give care (Dobrina et al., 2018).

The purpose of this research project is to explore the lived experiences and perceptions of the relationship between staff and residents at the end of life in LTC. While the team and interdisciplinary approach are important components of quality end-of-life care, the focus of this study is on the perceptions and experiences of individual staff members who are part of larger teams. *The Canadian Hospice Palliative Care*

Association's (2017) latest data from 2013 stated that there were 1,334 LTC homes in Canada with a total of 147,926 beds. In Canada, residents over the age of 75 account for 82.7% of the population in LTC. Considering these facts, LTC homes are often a place where end-of-life care is administered and this will only increase in the years to come (Cable-Williams & Wilson, 2015).

Through a series of interviews, this study showcases staff experiences and their specific interactions with residents who are dying. The intention of administering these interviews is to gain knowledge of staff perceptions and document the lived experiences of their relationships with residents at the end of life. Data will be used to facilitate and implement end of life policy and procedures to enable an individualized dying and death experience for every resident in this LTC home. I see firsthand the consequences of not having a consistent approach to end-of-life care from staff not being notified that the resident is dying, to resident wishes not being discussed with all who are involved.

In contrast, I also see many unnoticed gestures of kindness and familiarity between staff and residents at the end of life that I wish to explore. The lived experiences that I am looking for will encompass both the positive and negative experiences and how a consistent approach can contribute to such a vital component of care in LTC. Being a manager in LTC has given me the opportunity to interact with staff from all departments through facilitating annual staff education, sitting on palliative committees, care conferences and daily interactions. Being active in a resident's end-of-life care from a quality-of-life perspective has afforded me the valuable experience of witnessing the continuation of care and how the approach of care could be strengthened to enhance the

resident's experience of dying and death. By creating a trusting relationship with many staff, I have listened to staff from all departments offer meaningful ways to make a resident's end-of-life care as individualized as possible.

Qualitative research has great potential to expose many overarching truths about the human experience, however, methods must be employed for the researcher to offer "rigorous, meaningful and sustained engagement initiatives while addressing broader issues of power and representation" (Rolfe, Ramsden, Banner & Graham, 2018, p.6). I will use interpretive phenomenology as a qualitative research design and Heidegger's (1962) concept of the lifeworld as a tool of analysis to understand the experiences of caregivers in reference to one another and ultimately, to the end-of-life care of a resident.

It is important to note here the theory of care ethics and its emerging role in supporting and honouring the caregiver's position in society. Bourgault (2017) writes that:

> a bureaucracy will be caring if it is attentive and responsive both in the sense that the bureaucrats who work on the front-line are capable of listening to those in front of them, but also in the sense that the way needs are defined and addressed by institutions is as reflective as possible of what the groups concerned think is appropriate (pp. 212).

Hearing staff members tell their stories and being willing to share their emotions and experiences around such an important aspect of care humbled me to my core. I started this idea for this research with a systematic query and left with a relational one. This in itself is the basis of care ethic research; that if we invest in the relationship, the system functions. I listened, I observed, and I reflected. As my data took shape, I started

to see the power of listening within a care environment and that it can be such an

important tool for change.

Chapter Two: Literature Review

In this chapter, I provide an overview of the literature concerned with staff experience of end-of-life care in a LTC setting. I will discuss some of the existing research as it pertains to this topic, specifically, staff experiences caring for a resident from the moment that end-of-life orders are written, to a resident's eventual death. I will then examine the relationship between individual staff and residents and discuss the power that this relationship holds in the dying and death experience of a resident. Finally, I will delve into the literature to help emphasize the importance of a consistent approach to the end-of-life experience. I will be including research on using a team approach to end-of-life care as a broader policy-based intervention, however, my data analysis demonstrates that the notion of a team can take many forms in LTC and is not always clearly defined. For the purpose of this literature review, I will focus specifically on end-of-life care as defined by *Canadian Institute for Health Information* (2011) as care that is delivered to a person who is actively dying and has hours or up to a few days to live. I will refer to people who reside in LTC as residents.

Living and Working in LTC

In Atul Gawande's book, "Being Mortal", he asks one of the pioneers of assisted living, Keren Brown Wilson, why LTC is not good enough, and what happened to her dream of creating homes where people lived out the remainders of their lives in safety, comfort and joy? Wilson speaks candidly about the simple yet soul-crushing issues that plague LTC. It starts with the simple activities of daily living and the notion of supporting independence by minimally assisting with such tasks as getting dressed, eating meals and walking from place to place. It's less time consuming, less irritating and less

interaction if the staff member just does it themselves instead of allowing time for independence. The resident's identity starts to creep into the shadows to be replaced by what needs to get done and when (Gawande, 2014).

This task-focused model of care compliments the ever-present biomedical model of care which is a model of care associated with the identification and management of disease and focuses on the somatic traits of the person identified by the healthcare professional (Mazzotta, 2016). The biomedical model of care has a structure based on medical scientific fact that leads to a check and balances approach to care (Mazzotta, 2016). Yet, in the last decade, LTC culture changed to become resident-focused, where the whole person is assessed, and all their domains of health are considered in their care plan (Fox, 2007). There are several movements taking shape to guide health care workers into "creating a better world for the elders, staff and leadership of many nursing homes, […] in this model we will create places where elders want to be, families enjoy visiting, providers enjoy the work they love, and lawsuits are unnecessary" (Fox, 2007, p. x).

Staff Experiences with Resident at End of Life in LTC

The biomedical model fosters and encourages a task-focused approach to care. Staff are working within a paradigm of focused tasks in a prescribed amount of time and at specific intervals throughout the day (Sussman et al., 2017). It is also relevant to note the government's role in the biomedical model approach to care. The staff's mandated documenting bodily functions and physical needs of the resident serves to diminish important social, emotional, spiritual and intellectual interactions that staff have with residents during the death and dying process (Sutherland, Wiersma & Vangel, 2019). These meaningful interactions are vital to the quality of life of the resident but can easily

be forgotten within the confines of regulated and inspected rigidity (Sussman et al., 2017; Sutherland et al., 2019).

Staff can feel limited in making decisions based on their relationships with residents that reside in their home (Sutherland et al., 2019). Specifically, staff roles in end-of-life care exist within an underlying hierarchical system that still reflects a biomedical model of care where Registered Nurses are perceived to know what is best for the resident and deliver this information to the resident (Sutherland et al., 2019). Moreover, the knowledge or opinions of Personal Support Workers is often dismissed and undervalued as meaningless at the time of end-of-life care as stated, they "sensed that the caring of bodies was viewed to be of lower status compared to clinical knowledge related to physiological functioning and medical treatments" (Sutherland et al., 2019, p. 260).

Furthermore, these separate staff responsibilities lead to differing views and understanding of when a resident is deemed to be at end of life and how care subsequently changed (Cable-Williams & Wilson, 2016). Often, this change of status of the resident's health was fraught with miscommunication, time-sensitive actions, staff interpreting end-of-life care differently and at different times (Cable-Williams & Wilson, 2016). An important aspect to a rewarding dying experience is "maintaining calm, secure environment" (Cagle, Unroe, Bunting, Bernard & Miller, 2017, p. 201). Care at the end of life such as attention to the dying patient, bodily comfort and a pain-free experience were all aspects that could easily be rectified with proper organizational support (Cagle et al., 2017).

The structure of LTC includes the harsh reality that residents will die in the facility's care. Death and dying remains a difficult and uncomfortable topic for staff to navigate with residents and with each other (Marcella & Kelley, 2015). Staff expressed that the lack of training, of recognition that people coming to die in the home and the notification process when residents do die, all solidify the belief that death is not to be discussed or communicated (Marcella & Kelley, 2015).

A study looking closely at death and grief in LTC staff even noted that the methods in sharing a resident's death symbolize an underlying unfounded fear of confronting the reality of death and dying in LTC (Marcella & Kelley, 2015). There is a notice on the wall that some may walk by, but the recognition of a resident's death is just this; a note on a wall. Researchers stated, "death is also hidden from other support staff such as dietary or housekeeping as there is no formal process of notification in place" (Marcella & Kelley, 2015, p.5). This silent recognition is a metaphor for the support that staff members feel in processing their grief while a resident is dying (Marcella & Kelley, 2015).

Often, staff members perceived they had a limited awareness when it came to the impending death of a resident (Boerner, Burack, Jopp & Mock, 2015). There was always a profound lack of communication concerning the health status of residents (Boerner et al., 2015). Furthermore, staff emotions were often overlooked or dismissed during a resident's death and dying experience (Boerner et al., 2015). This grief for staff, compounded by the lack of knowledge around a resident's dying experience made for an experience fraught with disconnect (Boerner et al., 2015).

Boerner, Gleason and Jopp (2017) explored the ways to prevent an overwhelming and stressful response in the dying and death experience of residents for frontline staff. Their research emphasized the importance of acknowledgement by management and support during the death and dying process (Boerner et al., 2017). It cannot be denied that residents have progressively shorter stays within LTC as a result of being admitted sicker and older than ever before. This truth translates to staff experiencing more death firsthand and having more relationships with residents dying within the same time frame (Boerner et al., 2017). This can have a conscious and subconscious effect on the staff and these grief processes must be recognized (Boerner et al., 2017).

Grief is a process that is easily dismissed within the confines of the task-oriented workday of staff in LTC (Marcella & Kelley, 2015). Grief is subjective and highly dependable on a person's experience of the other's death (Marcella & Kelley, 2015). A good death is perceived by staff to be pain-controlled, including loved ones and the resident being at peace, whereas a bad death is cloaked in discomfort from dying alone to being in pain (Sussman et al., 2017). The type of death has been found to be directly correlated to the intensity of the grief experienced by staff (Marcella & Kelley, 2015). If a resident's death is observed as a comfortable death, then staff and other residents are more willing to have an open dialogue about end of life (Marcella & Kelley, 2015). In contrast, if the death was perceived as uncomfortable, then an increase of support and validation is necessary (Sussman et al., 2017).

Relational Care

Staff grieving the loss of a resident, especially in an undeniably corporate system that must move residents in and out in order to maintain financial stability, largely

depends on the ability to let go (Marcella & Kelley, 2015). Being with a resident while they are dying is an enormous step in the direction of letting go and opening oneself to have the emotional space to get to know a new resident so soon after the death of another (Marcella & Kelley, 2015). Staff found that being present with a dying resident and truly honouring their lives by creating meaningful moments through laughter, belonging and intentional touch, all supported the resident in their death and the staff in their grief process (Marcella & Kelley, 2015).

Time spent with a dying resident is crucial to fostering a comfortable death for a resident and a positive grief process for the staff member (Sussman et al., 2017). Discussing a resident's death with other residents and staff honours that resident, and furthermore, offers comfort and confirmation to the other residents, knowing that their death will be respected in a similar way (Sussman et al., 2017). In our current LTC climate, it cannot be denied that a bed in LTC is a commodity and that the death of a resident opens a space for a person in need of care (Sussman et al., 2017). Talking openly about a resident who has died and recognizing their life lived makes the bed transaction more tolerable and less significant as a tool to forget and move on (Sussman et al., 2017).

There is an undeniable shift in resident populations within LTC. People are aging longer in their home, which means that by the time they enter LTC they are frailer than ever before (Banerjee & Rewegan, 2016). With the pace towards end-of-life quickening, so too the race begins to form a connection between staff and resident, in order to get to know them quicker so that when the end-of-life beckons, we know deeply what is best for a resident in our care, no matter the extent of their dying body and mind (Banerjee & Rewegan, 2016). Individualized end-of-life care takes time. The more personal history a

staff member knows about a resident, the more positive and comfortable the dying and death experience (McCleary et al., 2018). The grief response that inevitably bestows itself upon the staff member must be recognized for what it is; a sign that a relationship was forged no matter the perceived connection between resident and caregiver (McCleary et al., 2018).

Relational care, within the framework of death and dying, includes honouring the unpredictability, validating and accepting the various points of views around a resident, and cherishing the journey of understanding and mutual respect amongst all who care (Banerjee & Rewegan, 2017). Relational Care and care ethics during the end of life are closely intertwined. In the space between exists this notion of doing the right thing by a resident and how do you know it is the right care for them? Knowing a resident as an individual enables a caregiver to know what is right for them and this encompasses care ethics. De Panfillis et al. (2019) found that "morality fully emerges as a multidimensional concept. Its different meanings can be summarized by the following themes: morality is providing general care; it is knowing how to have a relationship with patients; it means recognizing moral principles and giving importance to dialogue and communication." (p.7). Yet it must be recognized that staff who practice relational care run the risk of taking too much on, trying to advocate for a dying resident to the point of sheer fatigue and stress at a time when a resident longs for their specific care (Banerjee & Rewegan, 2017).

Teamwork

The varying roles in end-of-life care have important values that are often discounted (Kaasalainen et al., 2017). Support staff, defined as anyone not involved with

direct nursing care, work considerably less with the medical needs of residents (Kaasalainen et al., 2017). They however spend a substantial amount of time in direct contact with residents. From the maintenance worker who is replacing a lightbulb, to a housekeeper emptying a garbage can, these support staff members can find themselves in day-to-day interactions with residents and just as easily find themselves having conversations about death and dying (Kaasalainen et al., 2017).

It is imperative that these relationships between staff and residents be brought to the forefront of end-of-life care. A staff member needs to know that their relationship mattered and that their end-of-life care was noticed and appreciated (Kaasalainen et al., 2017). It is important to acknowledge staff grief and the support they have given to a resident by having debriefing sessions where all staff who have cared for that resident can meet after their death and discuss their feelings and experiences (Kaasalainen et al., 2017). This experience makes it easier to discuss death openly with other residents and staff members within a place where death talk has been avoided (Sutherland et al., 2019). Validation of support staff who work closely interacting with dying residents needs to be a necessary tool in instilling comfort as part of the death and dying experience for the resident and staff relationship (Sutherland et al., 2019). Furthermore, interventions need to be considered for support staff to acknowledge and work through their own grief when a resident dies (Sussman et al., 2017). It is demonstrated that "perhaps having these conversations without being involved in other care-related discussions that involve the typical "care team", makes them feel less empowered and hence, more vulnerable, to distressing emotional responses in response to death and dying situations" (Kaasalainen et al., 2017, p.6)

An end-of-life approach to care is often interpreted by staff as a specific model of care as opposed to a way of being that is embedded within every interaction between staff and resident (Sutherland et al., 2019). It has been found that this concept would be difficult to attain without a genuine home-wide appreciation for the knowledge of a resident from all professions within the home (Sutherland et al., 2019). A true team approach to end-of-life care is imperative to address the upheaval of the long-standing biomedical model of care (Sutherland et al., 2019). There needs to be a dismantling of the current way of doing in order to enhance every resident's quality of life and therefore, the quality of their death (Leclerc et al., 2015). In order to begin to break down the undercurrent of the professional hierarchy, it needs to be recognized that there is mutual worth and importance on a team approach (Sutherland et al., 2019).

A team approach to care boosts the morale of the entire extended team (Clemins, Brant, Kersten, Mullette & Dickerson, 2016). Providing care during a resident's dying stage of their life by including a team approach immediately empowers and fosters instrumental input based on each staff member's relationship with the resident (Clemins et al., 2016). The power of delegating care between team members creates an underlying connection with a common focus, the death and dying experience of the resident (Clemins et al., 2016). This shared force has great potential to harness creativity from caregivers and thereby, give solutions that may not have been visible before (Clemins et al., 2016).

A team that functions cohesively with shared values and goals can create an environment where the people being cared for are living and dying in the best way possible (Banerjee & Rewegan, 2016). Not only is a team approach necessary because of

the different departmental responsibilities but the varying expertise and experiences

within the field of work offers a variety of perspectives and therefore the space for

different types of care (Banerjee & Rewegan, 2016). According to Banerjee and Rewegan

(2016), implemented interventions that involved staff facilitating dialogue around the

resident and their death and dying experience created a vital opportunity for all frontline

staff to get on the same page.

A highly functioning team encourages efficiency, mutual learning, accountability,

and respect for differing professional roles (Walsh et al., 2018). This research

overwhelmingly supports that a simple tool like a team huddle can change the culture of a

highly institutionalized place like LTC and directly affects the quality of life of a resident

and the quality of work of a staff member (Walsh et al., 2018). Discussing death and

dying in a safe and supportive environment is a widely beneficial tool to assist

professionals in processing their grief (Walsh et al., 2018). It has been established that

"delivering palliative and end-of-life care options requires significant collaboration and

teamwork" (Walsh et al., 2018, p.850). A team approach to end-of-life care plays a

significant role in learning throughout the experience (Nelson, Wright, Abshire &

Davidson, 2018). Inclusion of many different professions translates into different death

and dying experiences, from a frontline staff member's intimate closeness to a more

distant physician medical approach to death (Nelson et al., 2018; Walsh et al., 2018).

Including staff in more care conversations with other staff means that questions

can be asked and common goals focusing on the resident can be exercised (Marcella &

Kelley, 2015). This inclusion of frontline staff serves to positively influence a staff

member and contributes to their coping strategies while they are grieving (Boerner et al.,

2015). In order to have a seamless and love-infused approach to a resident's end of life and ultimately their death there needs to be a dynamic team that knows the resident (Boerner et al., 2015). These end-of-life teams, through their constant and engaging relationships with a resident, have the potential to greatly enhance a resident's dying and death (Boerner et al, 2015; Marcella & Kelley, 2015).

  Creating meaning through understanding the qualities of a relationship between individual staff and residents at the end of life is what I seek to discover with this study. I will uncover aspects of good ethical care by listening to the people who provide it. The focus of this literature review was to outline the studies that reflect a staff member's experience with end-of-life care in LTC. Through this review, I gathered new perspectives and the need to better understand the qualities that create meaning in the relationship between staff and residents at the end of life. Furthermore, I look forward to exploring the extent to which we understand one another in this relationship and how we can positively impact the way a resident experiences their own dying and death.

Chapter Three|: Methodology and Methods

This chapter provides a summary of the methodology and methods of the study,

provides an overview of qualitative research, phenomenology, selection of participants,

data collection, data analysis and ethical considerations. The purpose of my study is to

explore the qualities of a relationship between staff and resident at the end of life. The

following chapter will assist with exploring and uncovering the meaning of a staff

member's experience and perceptions within a relationship with a resident at the end of

life.

Health research owes its expansion to the approaches of qualitative research

(Morse, 2007). This type of research has provided the ideal path for offering the best in

health education to a wide range of communities (Morse, 2007). It has given us

exceptional ways to assess and seek improvement in health reform as well as why

processes fail and how we can do better. Qualitative research is vital in understanding the

caregiving realm of healthcare (Morse, 2007). It gives the caregiving professional a voice

in an often bureaucratic industry, particularly phenomenological research which

"provides insights into the meaning of caring, suffering and fatigue" (Morse, 2007,

p.716).

Qualitative research explores in-depth the practice of being human (Smythe &

Giddings, 2007). Through gathering as much information as possible within the confines

of the inquiry, I will clarify an important experience in healthcare, an interdisciplinary

approach to end-of-life care. This research, like all qualitative research, will serve to

bring forth things that count but are rarely discussed. The 'how' of my question carries

more weight than just the steps in accomplishing something, "there is a way, an

engagement, an attunement that makes a difference" (Smythe & Giddings, 2007, p. 41). I am also attempting to hold space for people at the forefront of the interdisciplinary experience at the end of the resident's life and I am looking at the truth that these individuals "hold insight and understanding in a way that connects with something deep inside" (Smyth & Giddings, 2007, p.41).

Phenomenology

Phenomenological methods are commonly executed with a solid in-depth interview that seeks to uncover the lived experience of the participant (Lopez & Willis, 2004). The data analysis is where the two prominent pathways of phenomenological methodology start to take their separate spaces and must be considered in order to infuse the study with trust from the beginning (Lopez & Willis, 2004, van Manen, 2016). These two pathways are Husserl's descriptive and Heidegger's interpretive phenomenology (Lopez & Willis, 2004). Choosing between the two will ultimately reflect on how the analysis is explored and what can be learned from the data to influence future change (Lopez & Willis, 2004).

Husserl's (1970) philosophy of proper research was to focus on the descriptive approach. Husserl concluded that the meaningful moments in a person's everyday life is worth exploring and can be objectified and therefore, can be studied (Lopez & Willis, 2001). Husserl's discussed that people conduct themselves in a way that is based on their own perceptions of the world around them, of what they experience as their reality that they rarely contemplate (Lopez & Willis, 2004). van Manen (2016) states that "for Husserl, reflection on consciousness was his big thing because Husserl's phenomenology

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aims to make a phenomenon (lived experience or element of consciousness) transparent. And thus, you describe that whatness, eidos, or essence of something" (p. 6).

To Husserl (1970), the role of the researcher in descriptive phenomenological methods is to be a blank slate concerning the objectified experience being explored. Any preconceived notions, any teachings or past experiences must be released so that the researcher ascertains, a term coined by Husserl, of "a transcendental subjectivity" (Lopez & Willis, 2004). This means that throughout the exploration of the research study, the researcher's role is constantly being scrutinized and accounted for (Lopez & Willis, 2004). Bracketing is the term that descriptive researchers use to compartmentalize their biases and the influence of their past experiences (Pringle, Hendry & McLafferty, 2011).

Another hallmark of Husserl's (1970) descriptive phenomenology is that what one research participant's experiences can be teased out to find commonalities amongst other participants having the same experience, called 'universal essences' (Lopez & Willis, 2004, Archer-Kuhn, 2018). Most notably, Husserl (1970) was the first to bring forth the notion of the lifeworld. The lifeworld is the basis for the everyday normal life of the human being, before forms, labels or ideas of how things should be (Gorichanaz, Latham & Wood, 2018). This lifeworld experience is what the descriptive phenomenological researcher seeks to make sense of just as it is being lived, in the moment before the experience is interpreted (Archer-Kuhn, 2018).

Martin Heidegger (1962) believed in an interpretive approach to phenomenology which states that the researcher knows what is happening within the experience because we all experience life, the interpretive phenomenological researcher goes deeper to understand how the experience holds meaning for the individual (Archer-Kuhn, 2018).

Heidegger (1962) appreciated the notion of the lifeworld as not only a source of commonality but also to understand people's differences in experiencing the world (Lopez & Willis, 2004).

An interpretive phenomenological approach, from the perspective of my research study, looks at the qualities that make a meaningful relationship between staff and resident at the end of life. The exploration of these individual experiences at the moments of end of life are felt and lived and are enmeshed into the lifeworld of the person experiencing them (Eatough & Shaw, 2019). A lifeworld is the world that each of us know and feel, the world full of our own perspectives, our experiences and our quest for meaning and what is important to ourselves (Eatough & Shaw, 2019).

The methods of interpretive phenomenology and its dependence on an individual's lifeworld and the accrued meaning has the potential to be a great source of culture change within healthcare because of the focus on giving the researched individual a voice of meaning and purpose (Eatough & Shaw, 2019). Understanding the relationship between staff and residents in LTC at the end of life is valuable, important and full of meaning for that person. In order to find any generalizations, seeking to understand several experiences of the same experience is vital in creating any lasting understanding, shift in culture and ultimately, professional growth (Eatough & Shaw, 2019).

Being able to take the lived experiences of small group of professionals working within one LTC home and with each other, in order to provide the best care possible to a dying resident and generalizing that all professionals in LTC in the same situation experience their role this way requires a great deal of thought (Eatough & Shaw, 2019). This is where the notion of a lifeworld within phenomenological research can allow us to

create generalizations through the fact that we are all striving to be interactive, intuitive and relational beings (Eatough & Shaw, 2019). Through the use and acknowledgement of the lifeworld, we can be trusted to make assumptions on the wider human experience of this event (Eatough & Shaw, 2019).

Finding the meaning of an experience is the basis for phenomenological research. For a novice researcher, this can be a complex undertaking that requires a clear definition of the researcher's role (de Witt & Ploeg, 2006). An interpretive phenomenological approach which allows the researcher's personal connections to the research to be an advantage to any findings, as opposed to having to be left out (de Witt & Ploeg, 2006). For the researcher, being an active part in this search for meaning in an experience can be a daunting endeavor that requires continuous rigour throughout the methods (van Manen, 2017). van Manen (2017) put it best when he stated "the realization that phenomenology is the pursuit of insight into the phenomenology of lived experience should strike fear in the heart of anyone who hopes to practice it. Yet, the sheer satisfaction of experiencing moments of meaningfulness is worth the effort (p. 779)."

My question of delving into the qualities of the relationship between staff and residents during the death and dying experience requires a deep dialogue of feelings, an expression of motivations and relating to one another that could not be captured in any other form. Naturally, as a researcher begins to appreciate the human experience that is being explored through gathering detailed descriptions and understanding the more opportunity there is to grow and open to new directions and dialogue (Rolfe et al., 2018). My research and understanding of both Husserl's (1970) and Heidegger's (1962) practiced theories and philosophies on both descriptive and interpretive research, has led

me to look more closely at Heidegger's interpretive phenomenological methods. As van

Manen (2016) describes in his summary of Heidegger's beliefs of interpretive

phenomenology, that we tend to make our lived experiences into things that are tangible

and measurable and then we look at and reflect on them (van Manen, 2016). What if,

instead, we choose to solely interpret the lived experience as van Manen (2016) states:

"Heidegger tries to come to 'understanding' of the moment - this is the hermeneutic: not

to make experience into a thing or an object, but understanding something as a living

moment in its livingness" (van Manen, 2016, p.6).

Selection

Researching the lived experiences and perceptions of staff and their perceptions of

the qualities that make a relationship with residents at the end-of-life care has many

potential benefits to this LTC home. Gathering data from interviews will serve to explore

and understand the staff member's experience with end-of-life care at this LTC home.

The data, beginning with the selection of participants, will be the foundation to create a

LTC culture that honours this relationship and views it as a foundation to individualized

end-of-life care. The participants will be given the space to express their experiences and

be validated for the experiences.

Enhancing the approach to end-of-life care, better supporting staff through it and

thereby, giving the resident the best dying and death experience possible will inevitably

serve this LTC home and the wider community. Data collection consisted of 30-60-

minute face-to-face interviews with staff members who have experienced end-of-life

care. Considering that the main focus of phenomenological research is to uncover the

internal awareness of an individual with a specific experience (Willis, 2007), it makes

sense for me to collect data from a variety of staff who have close relationships with residents and value end-of-life care.

Participant names and professional roles were identified at the onset of the interview and while the collection and analysis of data was taking place. Participant names were not retained once data collection was completed. Professional roles are used in analysis of the data and the results within the master's thesis. The names of the participants will not be stored once the research is completed. The location of the interviews was private and allowed for quick entry and exit in the building. There was also an option to meet off-site at the public library or local coffee shop. The professional roles where there are only a few people in the department will not be confidential, such as the Associate Director of Care and Nurse Practitioner. This was explained to these individuals before the interview. Their names will not be used in the final thesis, but their roles and associated quotes will be.

How participants were selected, participate and share their experiences must be acknowledged in the transparency of the professional power dynamic of researcher and participant. I am a Resident and Family Services Manager at this LTC Home, and all managers are considered to have the power to manage all employees depending on the situation. Though I am asking questions based on their personal experiences to benefit their roles in the home and aspects of their work, this power dynamic must be acknowledged in order to create an interview dialogue and subsequent data collection that is honourable. This was mitigated by conducting the interviews on my own time and the staff member's own time.

Conversely, I am researching the environment in which I work, as Morse (2007) reflects on "these researchers know who to approach, and when and where to approach them, and can identify the best time, for instance, for interviewing or observing care" (p.717). It is important to note that my research does lend credence to the phenomenological theory that the lived experience that I aim to understand, is founded within a wider "situational, cultural and historical context" (Johnson, 2000, p. 144) by selecting participants from several points of years of service, age, gender and socioeconomic status. However, it must be understood that the nature of phenomenological research does not beg to know who the participants are, only if they have lived the experience that is being researched (Englander, 2012).

My recruitment poster (Appendix D) was placed on the wall in the common staff room for one week. I had nine staff members come to my office and voice their interest to participate in my research. At this point I gave them a brief synopsis of what the data collection would look like and the letter of invite (Appendix A) and informed consent (Appendix B) I would need them to sign. All nine participants were agreeable and in total, there were two Associate Director of Care (ADOC), one Nurse Practitioner (NP), one Registered Practical Nurse (RPN), one Registered Nurse (RN), two housekeepers and two personal support workers (PSW).

My selection of participants assisted in mitigating risk by selecting staff members that have not only had the lived experience that I am researching but who have also expressed their interest in end-of-life work and for a need to enhance the quality of their work. I will explain in my letter of informed consent (Appendix A), the potential risks to the participants as well as the non-denominational Chaplain being on hand to assist

anyone with any unexpected emotions that could arise from the interview. This LTC

Home also has a robust Employment Assistance Program (EAP) for all employees. I will

have this resource and contact information on hand if needed. I am researching a sensitive

topic and though my questions are focused on the professional roles of the participants,

emotional risks exist. I was aware and sensitive to the emotions of the participants

throughout the interview process.

Data Collection

Interpretive phenomenological research is concerned with a research system that

has "purposeful phenomenological and hermeneutic orientation; this involves thinking,

making decisions and executing them in a way that fits with such a stance" (Eatough &

Shaw, 2019, p.51). Any phenomenological exploration of an individual's lived

experience can only be truly captured through the interview process (Kvale &

Brinkmann, 2009). The interview process allows for a variety of meanings of a specific

phenomenon and it is the commonalities that are constant across interviews that form the

true understanding of the phenomenon (Kvale & Brinkmann, 2009). It is vital in

interpretive phenomenological research to recognize that the interview is about opening a

floodgate of meaning and that this meaning does not have an end (van Manen, 2016).

Attempting to discover some hidden meaning that will finally bring a stop to your need to

explore does not exist in phenomenological research (van Manen, 2016). A semi-

structured interview supports the necessary phenomenological characteristic of

description which fosters open ended questions that permits the researcher and participant

to have a free-flowing dialogue with questions to guide the individualized lived experience (Kvale & Brinkmann, 2009).

The participants allow for a purposeful data collection that will capture all the lived experiences of the same phenomenon. I had six interview questions with probing sub-questions (Appendix B) that guided the dialogue and allowed me to gain as much individual description of the phenomenon as I could. I exercised purposeful sampling for this research study. Participants received the official findings of the collected data as well as access to the final copy of the thesis.

The researcher's role needs to be accounted for throughout the research development as a tool to create an honest and transparent method that assures the reader that every attempt was made to create a trustworthy source of information. This is most apparent in the participant selection process and the data collection. The researcher must keep their role in the research at the forefront of every decision throughout the research method. Frequent check ins, confirmation on data received and providing a safe and respectful interview will all hold significant weight for the reader (Rolfe et al., 2018).

Participants were informed of their right of withdrawal through the letter of informed consent, given to them before the interview. All participants were able to exercise this right of withdrawal at any point throughout the research. The procedure involved letting me know that they would like to withdraw at which time we would discuss the use of their data, if any has been collected. If the participant wished to remove themselves and the data entirely, this will be granted without any reprisal of any sort. Throughout the research project, data was stored in a file on my personal drive on my computer and password protected.

Data Analysis

Phenomenological research tells a story about an experience and it is within this story that the researcher teases out and emphasizes the pattern of consciousness of crucial meanings that are common throughout the data (Giorgi, 1997). As the researcher, I work and live within the staff stories of end-of-life care, this allowed me to hone in on my intuition and means that I have been embedded in these lived experiences and when it comes to the collected data, I had the insight to find what I know is there.

It is imperative that at this point in my analysis, that I revisit the original typed transcripts so that I can confirm that my choices of sections and commonalities are valid and true to the expressed experiences (Kleiman, 2004). The substance of my outcomes is weighted in the lived experiences and the ability to go back to the original transcripts and find immediate and clear links to the essence of the phenomenon (Eatough & Shaw, 2018). Once this practice is completed, I will reflect on my own role and work within my own research study. This reflection is constructive in its scope, a practice that assures the reader that every aspect of the phenomenological approach has been considered and accounted for (Kleiman, 2004).

Lifeworld as a source of reflection for phenomenological research and in my specific case, as a tool for rejuvenated healthcare practices, must begin to be looked at as the foundation of all scientific inquiry and any true understanding of the human experience must reference the lifeworld (Gorichanaz et al., 2017). Any analysis of human experience must start with the lifeworld where any new knowledge or understanding of the world must be rooted, where the human experience begins (Gorichanaz et al, 2017). The lived experience is one part of the lifeworld, as Gorichanaz et al. (2017) state "lived

experience can be identified when a question is asked of the lifeworld, when we direct ourselves toward a phenomenon of the world, singling it out for reflection" (p.884).

Interpretive phenomenological methodology has the power to completely shift the healthcare paradigm into a system that starts with the human experience and uses the lived experience to create the system (Eatough & Shaw, 2019). The acknowledgement of the meaningful effect of the lifeworld in this endeavor is how I seek to understand the power behind the lived experience to create something better than what is (Eatough & Shaw, 2019, van Manen, 2016).

Ethical Considerations

Phenomenology is an intensely philosophical undertaking that does not bind itself to the rigour of analytical research (van Manen, 2016). Phenomenology, interpretive, is not about drawing conclusions, finding truths or making claims, it is more focused on finding the meaning in the lived experience (van Manen, 2016). In the case of my research, I will be finding the meaning in the lived experience of the relationship between staff and resident and how this meaning influences the end-of-life transition. I will be seeking to intimately know the experience, surrounded by the human senses and basic human needs and how the experience is interpreted by all the ways that we are human. The lengths that a researcher is willing to go to give credit to her research interpret the extent to which the reader will identify their own experiences within the collected data. This collective experience is what any researcher seeks to explore and there are many considerations that can be done during the data collection to make this possible (Thomas & Magilvy, 2011)**.** In the following ethical considerations, I will be using de Witt and

Ploeg's (2006) recommendations for addressing rigour in interpretive phenomenological research.

Balanced Integration

Secure and convincing research that produces useful knowledge needs to have a balanced integration (de Witt & Ploeg, 2006). There are variables that compliment this component of rigour and they all concern the proper use of the philosophical foundation of the method (de Witt & Ploeg, 2006). The researcher must balance the rich meaningful data collected from the participants and comfortably refer to the tenets of, in this case, interpretive phenomenology (de Witt & Ploeg, 2006). The research participants lived experience and its interaction to time, self and other with the understanding and inclusion of the lifeworld (Eatough & Shaw, 2019). Using the lifeworld as a pathway to understand the meaning of the experience is imperative for the rigour of the study. "These lifeworld features provide a useful lens through which to examine the concrete particulars of an individual situation and say something about its more universal features" (Eatough & Shaw, 2019, p.51).

Along with using the lifeworld as a reference point throughout my data collection and analysis, I will also go back and reference the philosophical basis for interpretive phenomenology (van Manen, 2016). Hearing the voices of nine different staff members will give me an in-depth understanding of the lifeworld's influence in interpretive research. In van Manen's (1990) definition of lifeworld, he interprets that all humans no matter their position in the world relate to "four key themes, lived space, lived body, lived time and lived human relation" (p.882). The understanding of these themes throughout my interview process and data collection will assist me in sticking to an

interpretation of the lived experience, so exploring an experience and all the human senses involved rather than trying to discover something in it and quantify it (Gorichanaz, et al., 2018). Throughout the research process I will deepen my understanding for historical basis of phenomenological research as van Manen (2016) writes "understanding of the roots or primary resources of the methodology being used, needs to be heeded by all qualitative researchers as it impacts the quality and trustworthiness of qualitative research" (p.7).

Openness

Along with balanced integration, openness speaks to the research journey. Being open by including a conversation in the selection, data collection and data analysis between researcher and the research process is a sure sign of openness (de Witt & Ploeg, 2006). I will interview nine staff members and ask six open ended questions in order to gather data that supports my research question on how their relationship with the resident influences the resident's dying and death experience.

In my participant selection process, it will be necessary for each participant to have lived through a resident's death and dying experience. This will be outlined in my recruitment flyer placed in the staff lounge. Creating an open space of learning and understanding between researcher and participant during the interview informs the data collection within the phenomenological approach (Willis, 2007). Interpretive phenomenology requires insight, on behalf of the researcher, on how to maintain a continuous dialogue of transparency and how decisions in the research process were made (de Witt & Ploeg, 2006). The more this transparent dialogue is emphasized and accounted for, the more openness is substantiated for within the examination of the

research (de Witt & Ploeg, 2006). The goal is not to look for truths that describe the world outside the person but to dig deep into the essence of that individual's experience and give meaning to the inner understandings that they have created (Willis, 2007).

These interviews will be digitally recorded for me to be able to actively listen, engage with the participant and create a relaxing environment. From the digital recording, I will transcribe into text form. In my effort to remain transparent and effect openness, my conversation with the interview participant will include the fact that I have been contemplating the relationship between staff and resident during the resident's dying and death experience for many years. I know there is a need to draw out these experiences from the staff members. I will emphasize that I am seeking their individual truths and all aspects of their experience is vitally important.

Concreteness

Concreteness, along with the following resonance and actualization deal with the conclusion of the research (de Witt & Ploeg, 2006). Concreteness is experienced when the reader can position themselves in the phenomenon and all their senses are triggered and their lifeworld can embrace the how of the phenomenon (de Witt & Ploeg, 2006). Using the notion of the lifeworld experience, I will interpret the data to include my own experiences with the phenomenon and allude to this in the results for the reader to identify with (de Witt & Ploeg, 2006). My interpretive phenomenological data analysis of the lived experience will produce data that will be familiar to many readers in the healthcare fields, particularly professionals working in LTC. Furthermore, death is certain for all of us and is something we can relate to and contemplate with.

It is important to outline the participant's professional background and their lifeworld within the context of LTC in order to offer the possibility of the research outcomes to be applicable to similar people in similar experiences (Rolfe et al., 2004). This concreteness is one of the more notable traits of interpretive phenomenological research. Can your study represent another location with other people? The more the reader believes this to be possible because of your in-depth descriptions of people, place, traits, gathering data and analysis, then the more concrete your research is (Rolfe et al., 2004). My research will interview nine participants that work at this LTC Home and whose positions exist at other LTC Homes. I will interview people of different ages, years of service and genders in order to capture as many generalizations in the interviews that I can. Another note on concreteness is that it is often up to the researcher to emphasize this concreteness by keeping the participant focused on sharing all aspects of their lived experiences and often drawing them back to the inquiry at hand (Gorichanaz, et al., 2018).

Resonance

Interpretive phenomenological research is a concentration on "what people tell us through a turning away from facts to meanings" (Eatough & Shaw, 2019). The feeling that resonates with the reader expands the meaning to be wide reaching because it touches something in the reader and grants insight into their own lifeworld (de Witt & Ploeg, 2006). I will be selecting the participants to participate in this research that are articulate and freely express themselves.

I am interviewing staff members on the sensitive topic of dying and death. My questions are work related and focused on the relationship between resident and staff and

the dying and death experience. These interviews do have the potential to evoke powerful emotions for the participants. It must be noted that language is also a point of interest for this research. As an advanced professional in the field, the language used in interviews must be adaptable, open and relatable to the participant (Rolfe et al., 2018). This will add lived experiences that the reader will relate too and the highly emotionally charged experiences will hold the weight to resonate deeply within the lived experiences of the reader.

For many of the participants, this could be the first time that their opinion on enhancing end-of-life care has been sought and validated. Working in LTC is a stressful job that requires a high degree of work and life balance. Coping mechanisms can include a wide spectrum of self-protection. My interviews have the potential to uncover this self-protection and I will acknowledge and be prepared that this is a real possibility. These emotions are part of every human experience and the way the questions are explored and expressed need to be taken seriously if resonance is to occur.

Actualization

It is common knowledge that care at the end of life is an ongoing quality improvement project at this LTC Home. Staff members want a change and a more predictable process once a resident is deemed end of life. End-of-life care is an important yet often overlooked area of healthcare and I truly believe that the chosen participants will talk openly about the topic and want to find a solution for our present way of supporting residents and fellow staff members at a resident's end of life.

The existing understanding of staff and resident relationships around a resident's end-of-life care is lacking and it needs improvement. By having staff members share their

lived experiences allows for a strong foundation to build upon. Lopez and Willis (2004) state "in interpretive phenomenology, it is the interpretation of the narratives provided by participants in relation to various contexts that is foundational" (p.729). The results of this research will be evident and tangible within a renewed quality improvement initiative around end-of-life care which, in turn, could improve dying and death experience for each resident. This exploration will allow me to begin to appreciate the meaningful substance of relationships, dialogue, expressions of feelings that is within the contemplative realm of all our lifeworlds (van Manen, 2016).

My data analysis consisted of rereading the transcripts for each staff member I interviewed. With my initial reading, I concentrated on putting myself back to the interview and the atmosphere that inspired such rich dialogue. I listened to the audio recordings and reread the transcripts a few times while focusing on the content and context of the interview. Throughout this process, I took notes about things I observed and reflected on and highlighted any emotional responses.

With my notes and reflections in the margins of my transcripts, I focused on teasing out emerging themes and working on paraphrasing each meaningful quote in order to dig deeper into my own experiences and that of the participants. Here, I was able to clearly see the connections between the entire transcript and the individual quotes, the feelings of the participants were richly conveyed and purposeful in their ability to answer my research question.

The qualities that make a meaningful relationship between staff and resident at the end of life were clear and concise due to the common passion for my research question across all interviews. The transcripts spoke volumes and the notes taken for each

highlighted quote created a relationship between themes and a recognition and appreciation for the foundations of the lifeworlds of interpretive phenomenology. The relationships I found between the themes of each participant's feelings and reflections on their own experiences were exciting and inspiring. The transcripts developed into an answer to my research question and I will forever be grateful and honoured to have these experiences shared with me and to be given the opportunity to write their truth.

Chapter 4: Findings

This phenomenological study presents the lived experiences of the qualities in a relationship between staff and resident in this Long-Term Care Home. A variety of experiences are given to assist the reader in fully understanding the research participants. The narrative of their experiences is outlined throughout this chapter using quotations.

This chapter will present the phenomenological essences that were obtained from nine in-depth interviews. I will begin by giving a brief work history of each interviewee. The findings of this study enable understanding of the relationship between staff and resident and the enhancement of the dying and death experience in three ways by depicting that (a) staff level of vulnerability directly influence the quality of end-of-life care (b) fearless conversations and attitudes around dying and death are important in providing good end-of-life care and (c) meaningful time is vital to good end-of-life care. With the found essences and the tenets of interpretive phenomenological research which are lived space, lived body, lived time and live other, as a foundation, I will describe the staff qualities in a relationship with resident and how it enhances care at the end of life.

This research consisted of nine staff members from all areas of our home, seven females and two males. The questions were focused on their experience of relationship with residents and how this assists the resident in their dying and death experience. The following is a brief work history of each participant. It is important to reflect on their years of experiences and their insight into their relationship with resident at the end of life.

AB is a housekeeper who has been working at this LTC home for five years. KJ is a housekeeper that has been working at this LTC home for thirty-six years. KJO is a

registered nurse who has been working for thirty years. CW is a personal support worker who has been working for thirty-one years. JM is a registered nurse and presently the Associate Director of Care at this LTC home and has been working for forty-three years. KM is a registered practical nurse and presently an Associate Director of Care at this LTC home and has been working for twenty years. DM is a registered practical nurse who has been working for ten years. CL is a Nurse Practitioner who has been working for fourteen years. LC is a personal support worker who has been working for nine years.

Vulnerability

In the first essence of my research, participants repeatedly expressed that their experiences with dying and death directly influence their own personalities and the way they assist residents in their dying and death experience. Participants were asked about their own experiences with dying and death and their feelings surrounding end-of-life care. This first essence of this phenomenological research was understood through vulnerable lived experiences that staff have found themselves in, their comfort around dying and death has expanded and has allowed them to understand the experience of a comfortable and dignified resident during the dying and death transition.

LC describes an experience that she had in her first few years of personal support worker work as:

> I just thought I'm going to go and sit in the room there. We had the light on and the music on and he woke up and opened his eyes as clear as anything and lifted his head and looked, he looked straight ahead and if I've ever seen anybody see a light it was him all I said to him was that's for you. He looked at me and he took a breath and he put his head down and he was gone. That to me that gave me my

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own personal peace. I'm reassured that they're going somewhere you know better or more peaceful. It was just strange; he lifted his head and his eyes like I said had been glazed over for days and he looked straight ahead, and it was like you could see him see a light.

CL described how she is seen through the eyes of a dying resident:

I do become a familiar comfortable face and sometimes at the end of life in resident can recognize me and can feel safe and comfortable with me then I can provide them with that degree of comfort even if it's just recognition in a pleasant smile and it's a smile that they've seen through the last couple of months or years.

DM discusses the needs of the resident at end-of-life care and that staff may understand the resident's body in more complex and present terms than even the family when he states:

It makes a difference I might know some things about them that not even family knows because they live with us and we see them pretty regularly, so we know the needs that need to be met. Sometimes we know better than family as to what that need is based on their behaviors based on if their agitated or you know so I think that's in our favour as far as making our palliative care what it should be.

LC also touches on her own presence at end of life and the importance that her presence holds at that important transition, she knows she offers something that the resident needs, she expresses:

I'm a PSW so I think besides family that's there with them, I'm the next person in line that's there when somebody's passing away or hopefully because not to say I wouldn't be in there, but I know if I'm there I'm confident in the care that they had

right? So, I take care of them right from holding their hand in death to making

them look presentable for family to come in and see them.

KJ poignantly expresses his years of experience and his honour of seeing residents to the

end, here he expresses handling a dead body and the privilege he feels to be that person:

So, when the funeral guy came in there, he said do you have a problem? I said no

I don't have a problem, so I helped him put Bob in the bag because Bob didn't

have any family, his daughter was out West, so I felt so bad because he had no

one he had nobody there right? So, I helped them and put him in his bag and

zipped him up. It didn't bother me I was blessed, I felt blessed doing it.

Lived experience research assists us in seeking to understand that in the presence of

another, we find our own vulnerability, CW explores this when she states:

I'm still treating them like a person when they're going as if they were still alive.

Some people are more tippy toe and so I'll still go in and say hey how you doing?

You know caring and then you know what I'm still treating them as a person.

She continues by adding that her experience has taught her from knowing the resident

and understanding their bodies progressing through the disease process, the resident will

still remember how you care for them:

They're used to your behavior. They're used to the way you treat them in and

you're still consistent with them. They're going to know who you are, and they

may forget your name, but they still know who you are. So, I mean you get to

know, if you're in a section long enough, you get to know everything about them

from where they came from the time their normal till the dementia, the declining

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they'll still know who you are and how you're treating them 'cause you're

validating them as a person regardless.

Furthermore, the recognition that the body has deep meaning and is paramount in the

dying and death transition. A well-cared for body can directly influence the dignity of

death, KJO describes:

There's nothing worse than have someone dying and they look like they're dying

so get them done up it's a celebration put their lipstick on don't let them die

looking like they're dying get their nice quilt out get their nice stuff on you know

if they wore jewelry all the time they want their hair done they want their teeth in

those little things to the families mean a lot.

Cl describes a space where vulnerability resides, within the comfort that exists in the

relationship is where the empathetic care is created:

It truly does depend on which staff members are working at the time of our

resident's death and how comfortable they are with death and dying and how

comfortable they are with that resident. How deeply they know them how much

they got to know them and how much they chose to get to know them, so I think

as much as I'd like to think that care is always the same it's not and it really is

dependent on the staff members who are working at the time of death.

AB discusses the privilege of knowing when a resident is at end of life, that at times, she

may not be told and how this vulnerability of expressing herself can evoke shame, she

states:

Oh, how do I find out? If I'm lucky enough the PSW tells me or one of the RPNs,

that's how I find out. Not always though, there's been times when you walk in a

room and they're not breathing. Or the signs on the wall kick you in the gut when

you walk in the door.

KM speaks candidly about the role of management and supervisors to embrace the

experience of end-of-life care when she states:

> Going out there after death and going and having conversation with the staff too
>
> because recognizing them knowing that we're human too and that recognizing
>
> that there's a disconnect and how staff perceive what we do for them and with
>
> them. I think just going up and acknowledging that these people, the residents
>
> mean a lot to them. You know if they need to talk about it or they need to leave
>
> work. I think we don't recognize that enough.

It is important to note here that the quality of vulnerability can sometimes be imposed

onto you, without warning and without guidance. These experiences shape any future end

of life care not only because one learns but also because one cannot forget. LC describes

one of these experiences:

> So basically, it's just I'm sitting on here with your arm around a dead man. Trying
>
> to hold them up and holding him up. He was like six foot something. He was big g
>
> uy, skinny. He had palliative cancer so, but I'm alone alone by myself right before
>
> breakfast, not even my section. I went and answered the bell because of it ringing
>
> so long and then I had to   go straight from there into the dining room and I held m
>
> yself together till I got on my break and then I fell apart and I called my mom.

KM also speaks in a vulnerable and honest way when she reflects on the process for staff

after a resident dies and our ability to honour the relationship in such a fragile time:

> Sometimes there's years of relationships with some of these people and it's just
>
> expected that the staff just go on their everyday where some people can, and some
>
> people don't. We don't ask those questions enough, we don't consult people and
>
> come in and ask. It's not talked about; it's posted and then it's done and over with.
>
> I think if staff could know that there was something available to them. I don't
>
> think we do that very well.

Fearlessness

In the second essence of my research, I found that space has a role in enabling

participants to express the importance of having conversations about dying and death

with residents and fellow staff. These conversations are vital in enabling residents and

staff to deepen their relationship and build a trusting foundation. CL describes this feeling

when guiding a resident through her dying wishes:

> It's those intimate conversations that reveal somebody's fears and the important
>
> things in someone's life and what they might want to do or what they might not
>
> want to do those conversations don't arise in the hallway they rise when you're
>
> sitting quietly and intimately in somebody's room or perhaps when you're bathing
>
> someone or perhaps when I'm examining someone that's when those more
>
> intimate topics come up.

DM describes the LTC space as being a backdrop for this conversation, to start stating the

obvious:

We could really bring it to the forefront, palliative care is this is what it is and this

is what we expect and this is you know what we're here for because ultimately

nobody is here to get well and move on. People are here, this is their last stop.

LC adds to the idea of creating a space where dialogue about death is supported and safe

for the resident, she describes here about an experience of being with a resident on her

last night before she had her MAID (Medical Assistance in Dying):

I knew what was happening she didn't know I knew what was happening but that

night I took her for a nice bath. I dragged the big tree from the TV room with the

lights on it into the tub room and the CD player and put that on and gave her a

bubble bath. She said, 'do you know what's going on'? I said 'yes' and she said,

'what do you think of that'? I said 'I think you're very brave person for making

that choice to do what you're doing. I don't disagree with you at all'. I like to make

a difference; I want to make a difference before they're gone.

DM discusses physical space and its connection with comfort and familiarity and

validating the resident's need to die in a familiar space:

I can enhance it because they're going to be around people that they recognize

hopefully or hear a voice and they're familiar with that voice whatever the case

may be. So, we keep them in a setting that's kind of known to them and you know

because they've lived here prior to them getting ready to die.

CW adds to this:

You get to know their likes and dislikes. If they like sleeping on their left side or

the right side so, you'll know not to put them over there because they were never

comfortable there anyway. They like certain music, or you know they don't like

the overhead lights so we'd bring the night light in or a little table light or

something 'cause they never did like that so why would you do it now?

CL clearly outlines what it means to know someone at the end of their life and how that

knowing enables trust and that trust diminishes fear. At this point the resident and staff

are depending on one another. CL describes her experience with one resident:

This resident and I were quite close in that because she had complex medical

needs. I was in to see her a couple times a week. She also relied on me in an

interpersonal level and really confided in me and became very close to me almost

like a friend. So, I think that at the end of life that allowed her to really truly trust

me into surrender her death experience in my hand. I think that we both you know

trusted that we were doing the right thing and that created an air of support and of

comfort and nobody was scared.

LC has honest conversations with residents around their own death by using the dying

experience of another resident. She makes a promise that she knows she will keep which

offers comfort and validation:

There's been times before people die where you know they may express that they

would like to die, and I've said before well it's not time for you to die yet but I can

promise that when that time does come I will be there and make sure you go with

the most dignity in the least and her pain I don't want anybody to die in pain so I

make the promise that if I'm here they'll be taken care of.

 CL candidly discusses how honest conversations with residents can greatly assist in end-

of-life care:

I think really our prior interactions I very much knew what her desires and needs were at the end of life and so it was very it was my instinct to just go back to our conversations we had had and follow what she had told me were her wishes and put on music and hold her hand and make sure she had a chance to see her friends because those are all things that she had told me in the past in the context of her intimate conversations.

CL further states:

And I think without taking the time to allow them to express these feelings and without allowing myself to be vulnerable enough to receive the information I wouldn't gain the knowledge I need to best look after someone at end of life.

It is important to acknowledge the concern of pain at end of life and how, at times, it can be managed too late and the feeling that staff cannot accept this as a possibility. DM clearly states:

I'm not big on people being palliative for three weeks. That's not fun. I think the shorter it is with comfort in place is the ideal way.

How do we make it shorter? I've thought about that too. Sometimes I think we start palliative orders too soon and then we run into a case where someone's on hydromorph for three weeks and they're slowly just dying and you know, what are we doing here?

This essence of fearlessness includes staff to staff interactions and a respect for the relationships and that there are people caring for this resident that just simply know them better. CW describes this frustration:

Ok, she looks comfortable because you were not in there for the last 15 minutes trying to move her and hearing them moaning. You can hear them groaning, you can see them tensing. We know they're uncomfortable. This is why we are asking you to give them something, but just to come in and look at them and say, Oh well they look comfortable and not, you know what I mean? To not take our word for it.

Meaningful Time

In the third essence of my research, I found that meaningful time at the end of life is vital to a good death. As the researcher, I was repeatedly moved by the staff experiences of end-of-life care. The stories and expressions of feelings were in home practices that I was not aware of. Whether personal or team focused, good care is happening and more often than management assumes it to be. The lived experiences of time for manager and staff in relation with one another and resident and how all these intertwined relationships helps or hinders a residents' dying and death experience is described here.

CW discusses her lived experience with time as frustrating and devaluing in that there is not enough time to give the care needed to the dying resident and other residents who need everyday care:

It would be just nice to maybe have an extra hand for a few hours to get when they start the process with their families or if it's a family that never deals with them and then comes in and has 150 questions you don't always have the time. Then you try to put it off to the other staff and they don't have the time and like I

would love to take the time to explain things to you, but you know, I have 12 other residents, you know.

CL also discusses the need for extra hands while a resident is dying, she states:

They would have the dedicated attention of a staff member that is not constantly thinking about what else they should be doing. They can focus their entire attention and love and grief into that dying resident. And be with the family and spend time doing some counseling with the family and spend time reminiscing about stories that they maybe want to share with the family that the family doesn't know about without having to think about the different tasks that they should be accomplishing instead.

LC also brings up that not having enough time is demeaning and devaluing, she states:

When somebody is dying it would be nice to have more time to care for them personally you know not like just going every two hours to turn them over in bed and clean them up and clean their mouth. That's not the way I like it, ideally there should be an extra person there so one person can just dedicate their time.

Many participants brought forth the need for more time with residents at the end of life, LC states:

I should not have to search the building for supplies at the end of life it happens a lot. That's a common one so like there's not like an end-of-life cart. I think that would be like a big thing. I don't know that there's you know just having that stuff necessary and ready or not having to go and find it because of the time it takes. You have limited time and then you have more time with the resident that's it.

DM discusses how he carves out time to be with residents and deepen rapport, he knows how important this is, he declares:

> We need more time with these people. When I come onto a day shift, I don't really spend time with any of them I don't have the time. Nights is better because if there is one or two that are restless and up I can sit with them I can have a sandwich and a drink with them I can ask him what's going on they don't always have to tell me but you get that opportunity to sit down and just be a person with them. I'll tell you why I think we need to spend more time with people I can't walk and hug CR without having to come down and hug CB and if CH gets wind that she got a hug then she wants her hug they're all starving for just that human touch that human connection of just sitting and being a person, not a nurse, not here's your pills or do you need to use the bathroom.

As a manager, KM brings light to this issue of time and alludes to the task orientation of frontline staff as a mindset and not necessarily a requirement when she discusses taking the time to be with a dying resident:

> I think the supervisors can bring this piece in taking the time not just when you have your meds like let's go in there together because I think people need support and they need to know that it's not always go go go and do these things it's OK to take those times.

CW draws on her own experience to express her absolute comfort around dying and death:

> I mean I'm always open because some staff will say how come you're so comfortable it's like well I don't know I've been dealing with it for so long. I don't

say that it's that either just because I still doing it for so long, I think I've always

been comfortable even as a teenager when I was dealing with it. It was something

I respected because it's something that's going to happen to all of us.

CW also touches on trying to encourage other staff to get to know the residents as individuals:

These residents have their own needs. They're all personal, they're all different.

You can't approach Joe the same way you would approach Jean you know what I

mean and you try to give them those little tidbits on how to work with them and

it's like I already know I do this somewhere else it's like OK good luck to you so

yeah a wall will go up and then you know what it'll take a long time before that

person would get my respect back.

KJo adds to this by describing the connection with the individual resident:

And I think it's more of a personality thing, how you jive with the residents and

how you just click and I think sometimes when they pass away especially if you

see them every day in your full time and you feed them dinner every night and

they pass away it's very hard but it's also very rewarding to help them and see

them go comfortably.

KJ exemplifies lived other by sharing a ritual that he practices when residents are dying:

See a lot of residents will tell you their stories right so it's like you just whisper it

back in their ear and tell them the story that they had told you. Go be with your

husband you loved him so much and love to go fishing, go be with him. Like SW

she loved her husband and horse races, she always talked about horses all the time

so I whispered in her ear go be with him and get on the horse that's what I said to

her and her daughter started crying 'cause they could hear me.

CL describes feeling comfort from providing good care and finding purpose through the

end-of-life care she provides:

At the end of the day, I come to work to do good things. I come to work to make a

positive impact on people and I do truly think that in that instance, I was able to

make this woman's last moments on earth extremely comfortable and fulfilling

and peaceful and I take great comfort in knowing that I provided that to her.

DM describes his experience as an honour to take care of someone that you are attached

to:

I mean I get to know residents well enough that you get attached you know and to

be part of their last days on earth is kind of an honour really is to be lucky enough

to be there with them when they're passing right? How many times do people pass

away in this building and families are not here and we are?

LC adds to how this honour goes both ways; the resident also feels honoured to have

someone they know with them:

I feel it's important that the residents know you it is important that they know who

you are when they're dying there's nothing worse, I don't know that there would be

anything worse than dying and not knowing the person or having built rapport

with that person.

DM discusses his role at end of life as much more than providing medication, end-of-life

care is so much more than that:

When I come into a room that is the dynamics everybody's looking at me like I'm

the one that's going to make grandma comfortable or you know I'm the one that

can enlighten on where we are what we're doing and why we're doing it. That's

what I'm here for. I'm not here to whip that cart around and push pills into people's

mouths, that's not what I'm here for, I'm here for something much more serious

than that and that's end-of-life care.

KJ illustrates this seriousness with end-of-life ritual:

If a resident passed away, we always went in the room and kissed him goodbye on

the forehead, we always did that as a team, we always did that they always kissed

him on the forehead and then went and told him that we love them and when they

passed away, we always did that downstairs that was kind of the bond we had so

we did that as a group.

LC talks about how dying and death is not a part of schooling, supporting that experience

is what enables comfort around dying and death:

I've talked to nurses about it in the PSW school we don't talk about death. I mean

as a society we don't talk about death, it's a scary thing like I've had young PSWs

say to me I didn't know people died here. Like it's crazy right like we take it for

granted but I think that you just know when you're going to see people die. You're

going to see death, you're going to see, like it eventually will happen, and you will

be there.

JM touches on, what she thinks, is a necessary approach to end-of-life care. A team

approach that recognizes everyone's contribution to end-of-life care, she states:

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I feel that the collaboration with all the members of the team, not just nursing, it's life enrichment, it's maintenance, housekeeping and dietary. I think there's a good relationship there and a willingness to talk which is important when it comes to end of life. It's not just the nursing care that's involved. Housekeeping I mean they can hear and notice a lot of stuff and a lot of housekeepers develop relationships with the residents and they should be involved in the whole thing because it's a family concept.

Throughout this data gathering and analysis, I found that this team approach is occurring often, and staff have their own rituals, traditions and ways of individualizing care that is entrenched in meaning for all involved.

Another manager KM talks about recognizing this empathetic individualized care for its existence and celebrating the staff for caring in the way that they do, she states:

Because you're giving them the support and you're validating. We hear you; we see you and that's huge and then we give the resident a better death because the energy from the staff would be better.

Chapter 5: Discussion

The Honourable Eileen E. Gillese writes in her Public Inquiry into the Safety and Security of Residents in the Long-Term Care Home System that "although the long-term care system is strained, it is not broken. The regulatory regimes that govern the system, together with those who work in it, provide a solid foundation" (Gillese, 2019, p.14). This is an important quote to consider and discuss in the finality of this research. LTC is not broken and the findings of this research clearly indicate that there are many ways in which we are thriving and consistently offering ethical care.

The ethics of care theoretical framework is the assumption that "every moral choice or ethical issue is conceived as inserted in a network of interpersonal relationships, nurtured by communication, since both illness and the patient experience can be considered as the products of a set of interconnections" (De Panfilis et al., 2019, p.2). End-of-life care is a lived experience for every involved staff member and an interesting place to start to explore the relationship between staff and resident, as a catalyst, to a system that works.

Through this research, I found that the qualities of a meaningful relationship between staff and resident at the end-of-life are fearlessness, meaningful time and vulnerability. When reviewing ethics of care research, specifically concerning the end-of-life, I quickly surmise that these qualities are often called by different names, being explored, questioned and reflected on. For the purpose of my research, I have come up with the above terms in order to truly reflect my data analysis. These qualities support one another and intertwine with, at times, nuance and other times, with jaw dropping logic.

Fearlessness

Open dialogue about death and dying is being able to look at someone and tell them the truth and be willing to discuss it in an honest and caring way. In order to combat the myth that LTC was where one went to die, staff often redirect resident questions about death in order to focus on living. LTC facilities often reject the notion of being recognized as "centers of excellence for end-of-life care, even though 1 of 3 residents died each year, […] they shared a concern that it would not be good marketing to clearly present the realities of dying and death in LTC facilities" (Cable-Williams & Wilson, 2016, p. 7). Ironically, taking time to dignify the resident's death and dying experience even within the confines of a demanding and task focused job is highly correlated to the overall culture of the LTC home (Cable-Williams & Wilson, 2016).

Data collected in this LTC home is full of passion, emotion and conviction that speaking openly and compassionately with a resident about their dying and death is life-affirming for both staff and resident. These discussions require courage yet selflessness and when openness and compassion are maintained, we can rest assure that this resident will die well. The more conversation and ways of acknowledging and honoring the resident's death, the more comfort other residents show in their own mortality (Banerjee & Rewegan, 2016). My data clearly identifies that within this quality of fearlessness there is a lived experience of internal confidence that tenses in the need to be humble, a necessary tension to be able to embrace the lived other experience and offer good care but also to deeply understand the autonomy of the resident. As De Panfilis et al. (2019) state, "the need to manage moral issues, such as respect for a broader meaning of autonomy, the central role of the patient's concept of dignity, the role of choice, the importance of

truth, the concept of quality of life, the value of emotions and the existential issue, is an integral part of the palliative care approach" (p.3). It has been highlighted that one of the most important aspects of providing quality end-of-life care is open communication. Though the topic is often secretive and avoided, it is vital in the end-of-life care trajectory to talk openly and honestly about death, this is one way to truly let go (Banerjee & Rewegan, 2016; Walsh et al., 2018).

Meaningful Time

When describing the role of caregiver, De Panfilis et al. (2019) state that we "can recognize patients' wishes and preferences, but equally important is their capacity for compassion as well as honesty, integrity and a sense of humility" (p.2). This research exposes an emotional side of care at the end-of-life that is begging to be expressed and validated by staff that give it.

We make every attempt to individualize residents' transition into LTC by gathering their social history and speaking with family members. However, there is still a way of doing things, a code of conduct to follow and a predictable life trajectory (Gawande, 2014). The task focused biomedical model of care does still exist, but it is being challenged by the very staff that are experiencing it. LTC is an institution like all institutions, where love and trust are not measurable; they are not depicted by a graph or in their own template with benchmarks or targets (Gawande, 2014). Love and trust are in the nook and crannies of the LTC home, in the touch, the laughter and the deep human care and connection (Gawande, 2014). Data gathered from this LTC home is drenched in ritual, connection, and tradition, etching out time from the mundane with an innate need to connect and to get to know one another. However, LTC remains an institution that

bows to data collection on safety, prevention of falls, weight fluctuations and medication changes (Gawande, 2014).

From my research, one can see that though the reality and concluding perception is that LTC is an institution, there are also real and meaningful relationships between staff and resident. I would argue, from the knowledge I have gained from my data analysis, that perhaps it is the protocol and policies doled out by management, based on an institutional model of care that is the biggest hurdle in creating meaningful time. The expectations put on frontline staff to just do their job as professionally as possible, complete their tasks, tick the ministry required boxes of documentation and to leave their emotions at the door is the biggest disservice to the residents and ourselves.

As we can see, this type of working environment shapes the staff member's understanding of their work and the end-of-life process (Sussman et al., 2017). If time to get to know a resident is not valued due to a task-focused framework, then end-of-life care becomes about the comfort of the body and less about the importance of their relationship with the resident (Sussman et al., 2017). This suppressed dialogue and unspoken expectations of how we are supporting a resident's death exists and is real and tangible. However, staff from all departments establish a relationship with a resident and get to know things about them, such as their "routines, their preferences for food and beverages, their facial expressions, what position they preferred for sleeping, and what comforted them" (McCleary et al., 2018, p.3). This relationship building through intimate care means that the death of a resident has an immediate and lasting effect on staff members (McCleary et al., 2018). This is particularly significant when it comes to the

organization of LTC that sends consistent messages for staff to remain on task, fill beds and follow legislated regulations (McCleary et al., 2018).

This research clearly emphasizes the parallels between a frontline staff members' tug of war between maintaining their confidence in the face of end-of-life care while at the same time remaining humble in order to heed the needs of those they are caring for. The lack of emotional nurturing within the bureaucracy that governs such care is something that deserves more understanding. Bourgault (2017) stresses it is not about struggling to infuse ethical care into political run institutions, but more about finally acknowledging that it is happening. Only out of a place of managerial transparency and emotional intelligence can we truly start to recognize that a strength-based approach to staff providing good care is possible within the confines of ministry requirements. The paradox is that we need the boundaries of bureaucratic expectations in order to know and feel how our empathy can work alongside of it. We need to start understanding the lived experience of the staff member by observing what caring truly looks like, outside of what we need it to look like, within the end-of-life caring interaction.

Staff and resident connections that are forged within the walls of LTC are real in their love, trust and mutual respect (Marcella & Kelley, 2015). They may not be long lasting, but the intimacy and consistency of the care creates a quick connection between two people that can end at any moment with the permanency of death (Marcella & Kelley, 2015). The emotional layers involved with the work and the long lives that end within the boundaries of care cannot be taken lightly and must be infused with just as much attention and care that is given to the residents in their dying days (Marcella & Kelley, 2015). This attention takes time, fostering autonomy in residents takes time. My

data collection circles around this concept of time throughout participants telling of their lived experiences. The time it takes to complete the tasks around end-of-life care is time away from a resident's interpersonal needs. My data argues that when the system flows and the hierarchal construct blurs, all in response to providing a good death, time is held and meaning is created.

Vulnerability

Data exploring the qualities that make a meaningful relationship between staff and resident poignantly addresses the hierarchal structure that exists within LTC. The professional hierarchal structure of LTC "begins with the PSWs at the bottom, and works up through the RPNs to the RNs, and then to managers […] the participants' perception is that the emotional burden of grief decreases the higher the staff member is on the professional hierarchy" (Marcella & Kelley, 2015, p.6). Data show that the constant emphasis of professional hierarchy diminishes frontline staff's ability to be vulnerable with the residents. Bourgault (2017) states "care provision is fragmented, and front-line workers experience a painful contradiction between the injunction to respect the rules imposed from above and the need to break these very rules in their one-on-one interactions" (p.206). In my data, there are several quotes expressing this fact, that staff do break the rules in order to be compassionate and empathetic. They view themselves as active caregivers in the dying and death experience and respect the sanctity and honour to care for a resident at such a significant time of their lives.

Training for staff is limited or nonexistent and it is important to note that the research shows a real lack of orientation to death and dying, almost as if there is a complete avoidance to the fact that we are taking care of residents while their life is

coming to an end and no one acknowledges or talks about this (Marcella & Kelley, 2015). My data sheds light on the fact that younger and inexperienced staff need mentoring. The positive relationship between experienced and inexperienced staff that can occur and the growth that can be exposed is vital to a system that needs to be grounded in emotional intelligence in order to be meaningful.

With this notion of a emotional intelligence focused education for staff, may I suggest here that a management supported in-service would be to have staff share their experiences of end of life care, using the quotes in these research transcripts. This would give a description of the emotional connection needed between staff and resident to foster a meaningful dying and death experience. The participants in my study were forthcoming and honest in their depictions. I know these personal experiences abound throughout the staff at this LTC home and I can be certain that an in service that focused on these personal experiences would touch many people and help them see the purpose and meaning that exist in their relationship with resident. Furthermore, it would allow them to recognize their own vulnerability, fearlessness and need for meaningful time and give them permission to take their own responsibility for these qualities.

My research aligns with research before it which emphasizes the past dying and death experiences of staff members, either personally or work-related, guides them in their end-of-life care. Staff in LTC depend wholly on their own life experiences to carry them through the loss of a resident (Marcella & Kelley, 2015). Staff are expected to move on quickly and continue to get their job done without the opportunity to express their sadness and process their loss (Marcella & Kelley, 2015). The ability to look inside oneself and identify how one's caregiving role influenced the dying and death experience

of the resident has a pivotal part in any grieving process for the staff member (Marcella & Kelley, 2015). The feeling of their role being validated and recognized in the resident's death is paramount in the acceptance of the resident's death (Marcella & Kelley, 2015).

Furthermore, the stronger the bonds between staff and resident, the less negative the grief response. The more meaningful the relationship, the more growth occurs for staff around the death and dying experience for a resident (Boerner et al., 2017; Marcella & Kelley, 2015; Sussman et al., 2017). There is a real risk for staff travelling alone throughout their grief, particularly when there is a considerable lack of support to assist in processing these emotions of grief. (Banerjee & Rewegan, 2016). The powerful relationship between staff and resident is exemplified at the time of dying. The residents' death must be honored and celebrated by all staff, including management, in order to ease the pain of grief for all and draw attention to an eternal truth which is that we all eventually die (Banerjee & Rewegan, 2016; McCleary et al., 2018).

Being with a resident at the end of their life is a humbling experience that allows for growth and acceptance around death and when this is shared among staff, it can be a powerful tool of end-of-life education for all staff (Kaasalainen et al., 2017). An understanding and appreciation for team roles throughout the home needs to be a focus of future research in order to fully grasp a system of subtle commands that exist on a fundamental level (Leclerc et al., 2015). Not only does the resident benefit from such a resident-focused approach to care but so do other staff by listening and empowering each other via the care of the resident (Clemins et al., 2016). A helpful and supportive method of process around death and dying would be opportunities to meet with other staff and share experiences (Marcella & Kelly, 2015). The importance of validation and

recognition from all levels of the professional hierarchy for their care of and closeness with the resident assists in coping and closure for the staff member (Marcella & Kelley, 2015).

I can see many opportunities for future scholars to expand on my research. Implementing the research led in-service, using these specific lived experiences of staff as the foundation of a home wide education and collecting the before and after perceptions of staff would contribute to this exploration. A staff education that seeks to alter the narrative of professional boundaries and focuses on creating and celebrating emotional relationships with residents could begin to change the culture of LTC.

Even though it is rare to have a resident be cognizant and verbal at end of life, it does happen and to gather the lived experience of resident at the end of life in relation to the staff caring for them would be so telling to the power of this research. Throughout this project, I became fascinated by the lack of conversation around dying and death between staff and residents. There is substantial research on this phenomenon and it makes me curious on the power of creating honest dialogue through life enrichment programming around dying and death. We know that residents can be comforted by discussing residents who have passed and sharing their memories, this lets them know that they will be remembered too. Future research could look at implementing dying and death quality of life programming to remove the stigma and allow residents a safe, supported and open space to work out their fears.

It is clear from this research that there exists an emotionally driven mutual relationship between staff and resident at the end-of-life that is initiated by the staff member and validated by a resident. The vulnerability of a resident in their last days of

life is a feeling that is shared by staff members. The vulnerable resident is entrusting themselves unto the staff member. The months or years prior, this relationship was defined by a service agreement born of a system that gives the power to the caregiver and the resident is meant to be the submissive unknowing receiver (Bourgault, 2017). However, through this research we see that when fearlessness, meaningful time and vulnerability are celebrated and understood to be fundamental to good care then the power shifts and a resident is able to be the one caring for the staff member. In the resident's lived experience of dying, we are able to uncover parts of ourselves and learn what it means to care.

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Appendix A: Letter of Invitation

Title of study: The lived experience of a staff member's care within an interdisciplinary team at the end of life in Long Term Care.

Principal Investigator: Colleen Whyte PhD, Department of Leisure Studies, Brock University

Principal Student Investigator: Leyla Attis, Master's student, Brock University

Faculty Supervisors: Trent Newmeyer, Associate Professor and Colleen Whyte, Associate Professor

I, Leyla Attis, Master's student, from the Department of Leisure Studies, Brock University, invite you to participate in a research project entitled, A staff member's interdisciplinary lived experience with end of life care in Long Term Care.

The purpose of this research project is to explore your experience in your professional role in supporting your peers and ultimately, the dying and death experience of a resident, at end of life care. Should you choose to participate, you will be asked to, have a sit-down recorded interview of six exploratory open-ended questions with myself, Leyla Attis. The expected duration of this initial interview will be from 30 - 60 minutes.

This research should benefit the dying and death experience of residents in the Golden Plough Lodge. My expectation is that by learning about your experience with end of life care, I will be able to initiate significant change in the interdisciplinary approach to end of life care. This would include all departments and values input from every interaction with the resident across all professions.

This is a single cite project and will only be requesting information from staff who work at the Golden Plough Lodge and have had firsthand experience with interacting with a resident through the dying and death experience.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905-688-5550 ext 3035, reb@brocku.ca)

If you have any questions, please feel free to contact me.

Thank you,

Leyla Attis

Appendix B: Consent Form

Faculty Supervisor: Trent Newmeyer, PhD, Associate Professor
Brock University
Department of Sociology
Brock University
9056885550 ext.5114

You are invited to participate in a study that involves research. The purpose of this study is to explore your lived experience as a professional within an interdisciplinary team at the end of life care for a resident.

As a participant, you will be asked to sit down with myself, Leyla Attis, and answer six open ended questions that will serve to guide your communication about your experience of supporting your peers and the resident at the end of their life. Participation in this research will take approximately 30-60 minutes of your time.

Possible benefits of participation include enhancing the interdisciplinary approach to end of life care, better supporting staff in their grief process and giving the resident the best dying and death experience possible. There also may be risks associated with opening up about a sensitive topic like the resident dying and death experience, peer support and being validated for your role. The content of the interview could lead you to experience deep emotions or bring up your own memories. Our non-denominational Chaplain will be available to assist you in working through this experience.

The information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, with your permission, anonymous quotations may be used. Shortly, after the interview has been completed, I will send you a copy of the transcript to give you an

opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. It must be noted that not only am I the researcher, but I am also the Resident and Family Services Manager at the Golden Plough Lodge, where you work and where this study is taking place. I ask that I be considered the researcher of this study for the duration of our interview. Though my knowledge and experience working in a manager role at the Golden Plough Lodge has fostered my interest in this topic, it will not play an active role in the interview process, data collection or interpretation. My role will be solely researcher throughout our time together.

Data collected during this study will be stored in a locked cupboard in researcher's office. The data will be stored for seven years at which point it will be destroyed. Access to this data will be restricted to the researcher, Leyla Attis.

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without penalty.

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available from the researcher, Leyla Attis who can be reached at la08zs@brocku.ca.

If you have any questions about this study or require further information, please contact Leyla Attis, Trent Newmeyer and Colleen Whyte using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [insert file #]. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905)688-5550 Ext. 3035, reb@brocku.ca

Thank you for your assistance in this project. Please keep a copy of this form for your records.

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____ Signature: _____

Date: _____

Appendix C: Interview Questions

1) Can you describe your role within this organization when it comes to resident's care at end of life?

    a. In your professional role, do you feel that your daily interactions with residents have importance when that resident is at the end of their life?

        i. If yes, please share with me what about your interactions, while you are doing your work, could enhance the resident's dying and death experience?

        ii. If no, do you feel there is a part of your job that could be improved in order for you to be able to contribute to a resident's end of life experience?

        iii. Can you take a few moments to describe your feelings around end of life care?

2) Can you describe an experience caring for a resident at end of life?

    a. If yes, what about your prior interactions with this resident enabled you to have this experience?

        i. Did other factors play a role for you in having this experience?

        ii. Can you take a few moments to describe your feelings around this experience?

3) What do you wish you could be doing differently in order to improve the care of residents at end of life?

    a. Can you think of any ways that your knowledge of the resident could make their dying and death experience better?

    b. Do you think there could be a change, within your professional role, that would allow you the ability to share more knowledge about the resident to make their dying and death experience better?

4) How would you describe the team approach as it pertains to end-of-life care?

    a. What are we doing well? Where could we improve?

        i. How do you feel about the way we communicate between departments at the end of life? Are you communicated with? How do you know if a resident has died?

        ii. Are you asked for your knowledge about the resident? Do you feel supported by your peers when it comes to the end of a resident's life?

5) What organizational changes would be necessary in order for us to have a better team approach to end-of-life care?

    a. With these changes, how do you think the resident's dying and death experience would be better?
    b. How would interdisciplinary support be better?

        i. What does being validated and/or acknowledged in your role by other departments look like and feel like for you?

6) Can you describe your idea of a good death? Can you describe your idea of a bad death?

Appendix D: Recruitment Poster

Leyla is looking for a participant from different departments to sit down with me for a 30-60 minute interview to share with me your experience working within an interdisciplinary team at the end of life. This is part of a research project for Brock University.

Seeking Participants to talk about end of life care

Are you interested? Please contact Leyla at 2493534539 or email at la08zs@brocku.ca

Participation in this research project is strictly voluntary. This project has absolutely no affiliation with the Golden Plough Lodge or Northumberland County. Furthermore, participating or not participating in this study has no influence on your job performance or status.