

Adult Palliative Care Providers and Their Interactions with Children of Palliative Patients:  
A Situational Analysis of Dominant Grief Discourse

by

Ian Scott  
BA, University of Winnipeg, 2008  
BSW, Lakehead University, 2013

A Thesis Submitted in Partial Fulfillment  
of the Requirements for the Degree of

MASTER OF SOCIAL WORK

in the School of Social Work

© Ian Scott, 2015  
University of Victoria

All rights reserved. This thesis may not be reproduced in whole or in part, by photocopy  
or other means, without the permission of the author.

**Supervisory Committee**

Adult Palliative Care Providers and Their Interactions with Children of Palliative Patients:  
A Situational Analysis of Dominant Grief Discourse

By

Ian Scott  
BA, University of Winnipeg, 2008  
BSW, Lakehead University, 2013

**Supervisory Committee**

Dr. Susan Strega, (School of Social Work)  
**Supervisor**

Dr. Kelli Stajduhar, (School of Nursing)  
**Outside Member**

## Abstract

### **Supervisory Committee**

Dr. Susan Strega, (School of Social Work)

#### **Supervisor**

Dr. Kelli Stajduhar, (School of Nursing)

#### **Outside Member**

Health care providers (HCPs) who work in adult palliative care occasionally encounter children who have a parent who is dying. This grounded theory (GT) study examines how adult palliative care providers respond to the needs of children who have a parent in palliative care. I use Adele Clarke's (2005) situational analysis method, a postmodern iteration of GT. Clarke's situational map acts as an analytical tool to identify and analyze different actors and elements in the situation of concern. Five semi-structured qualitative interviews were conducted with adult palliative care providers. Provisional theorizing resulted in three sub processes emerging from the data. First, adult palliative care providers must be cautious when identifying and responding to the needs of children who have a parent in palliative care, particularly because of the nefarious presence of dominant grief discourse (DGD). Second, these same adult palliative care providers, who are often distressed when supporting children who have a dying parent, benefit when they get comfortable with being uncomfortable. Third, adult palliative care providers tend to see themselves as part of a larger interdisciplinary team that informs their interactions with children who have a parent in palliative care. The entire analysis is imbued with a critical perspective of DGD, including its race, gender and class dimensions. This critique of DGD is informed by Foucauldian interpretations of discourse, power and subjectivity. Opportunities for resistance and social justice are explored. In accordance with my own research paradigm, I make a concerted effort to render my influence as a researcher visible throughout.

## Table of Contents

Supervisory Committee .....	ii
Abstract .....	iii
Table of Contents .....	iv
Acknowledgments.....	viii
Chapter 1: Introduction .....	1
Situating Myself in the Research .....	1
Objective of the Study .....	3
Summary of Chapters .....	5
Chapter 2: Literature Review .....	7
Purpose of the Literature Review .....	7
Justification for Literature Review .....	8
The Literature Review Process.....	15
Organization of the Literature Review .....	17
Needs Identified in the Literature .....	18
Roles and needs of HCPs.....	23
Roles and needs of parents.....	28
Communication: The most common need.....	29
Dominant Grief Discourse.....	31
Stage theories.....	33
Race, gender and class dimensions of dominant grief discourse.....	37
Race.....	38
Gender.....	39
Class.....	44
Resilience and dominant grief discourse.....	47
Childhood developmental stages, grief and dominant grief discourse.....	50
Normal and pathological grief and dominant grief discourse.....	54
Disciplining and Policing of Grief .....	61
Grief work.....	63
Resistance to the disciplining of grief.....	64
The Self and Meaning-Making in a Neoliberal Environment.....	65
Summary .....	67
Chapter 3: Methodology.....	68
The Field of Qualitative Research .....	68
Research Methodology - Grounded Theory .....	71
Rationale for using GT.....	73
Rationale for constructionist language.....	75
Different versions of GT.....	78
Situational Analyses and Maps .....	81
Research Design.....	84
Semi-structured interviews.....	86
Individual interviews.....	89

Finding participants. ....	91
Interview details. ....	92
The questions. ....	96
Dominant Grief Discourse.....	97
Data Analysis.....	101
Coding. ....	104
Evaluation and Assessment .....	109
Fit, workability, relevance and modifiability. ....	109
Evaluating for social justice.....	110
Evaluating for rigour, validity and accuracy.....	112
Potential Limitations of the Research.....	114
Ethical Considerations.....	115
Voice.....	115
Race, gender and class.....	117
Ethical research relationships. ....	119
Chapter 4: Findings and Data Analysis.....	122
The Situational Map.....	122
Identifying Needs .....	126
Needs related to resources.....	130
Needs related to family. ....	134
Needs related to childhood developmental stages.....	137
Needs related to normal and pathological grief.....	142
Uncomfortable Caring for HCPs.....	145
Uncomfortable caring and emotional reactions.....	149
Uncomfortable caring and HCP training. ....	151
Uncomfortable caring and HCPs' level of involvement.....	154
Uncomfortable caring and privilege, race, gender and class. ....	156
Uncomfortable caring and race. ....	159
Uncomfortable caring and gender and class. ....	163
Uncomfortable caring and judgment. ....	165
Uncomfortable caring and abusive situations.....	168
The Team Concept in Palliative Care .....	170
The team and the social worker role.....	173
The team and the divide in adult and pediatric palliative care.....	177
Chapter 5: Discussion, Recommendations and Conclusion.....	181
Thoughts on Theorizing .....	181
Identifying Needs With Caution.....	183
Getting Comfortable with Being Uncomfortable .....	185
Constructing the Concept of a Team .....	188
Evaluation and Assessment .....	190
Reflections on My Role in the Research Process.....	193
Further Implications for Practice and Policy.....	199
Recommendations for Future Research .....	200
Conclusion.....	201

Bibliography ..... 203  
Appendix A - Interview Screening Questions ..... 218  
Appendix B - Informed Consent Form ..... 219

**List of Figures**

Figure 1 – Messy Situational Map.....	122
Figure 2 - Relational Analysis Using Situational Map: Focus on Uncomfortable Caring	124

## Acknowledgments

Thank you to the participants who agreed to be interviewed for this study. Your insights and observations enriched the research and I am grateful for your generosity.

Thank you to my supervisor Dr. Susan Strega for providing me with excellent mentorship throughout the entire research process. From my early days in the program when you helped me explore potential topics right through to completion, your feedback was always useful, clear, encouraging, timely and balanced. I would also like to thank my committee member Dr. Kelli Stajduhar. I greatly appreciated your openness, encouragement and assistance as my thesis progressed. Thank you to Jaime Ready in the School of Social Work for your patient and wise guidance. Thank you to all of the other faculty and professionals who took the time to share their thoughts and advice with me, particularly in the early stages.

I was fortunate to receive a scholarship from the Social Sciences and Humanities Research Council (SSHRC) in the first year of my MSW program and I am grateful for the financial support.

To mom, dad, Krista and Megan, please know how thankful I am to be part of our amazing family. Thank you to the friends who supported me, expressed interest in my research and helped me out along the way. Thank you to Osha and Grayson for keeping me company.

My final thank you is reserved for Landon, who I love unreservedly. Thank you for your unwavering belief in my ability to complete this thesis. Your motivational pep-

talks were always well-timed, sincere and impactful. My thesis has taught me how many choices are involved in the research process, but I choose you every day.

## Chapter 1: Introduction

### Situating Myself in the Research

The most appropriate way to begin is by situating myself within the research. By making myself visible in the research from the outset, I hope to make it clear that I am implicated in and responsible for the decisions I have made throughout the process. This is a study of adult palliative care providers and how they respond to the needs of children who have a parent in palliative care and it is important to outline why I am researching this. This is not an attempt to situate myself once at the start so I can feel comfortable writing with an omniscient voice (Guba & Lincoln, 2005). In fact, I will try to elucidate my influence on the research at every turn.

Braun and Clarke (2006) encourage researchers to acknowledge the decisions, conscious and subconscious, that are made throughout the research process. I agree with the claim that a researcher should locate themselves within the research, because the researcher is not objective and is highly influenced by their own vantage point (Moosa-Mitha, 2005). Ladson-Billings (2000) states that a researcher's identity, beliefs and experiences affect not only what is researched, but how and why it is carried out.

I have come to realize that the point of locating myself within the research is not to reach a place of innocence, what Heron (2004) calls the "race to innocence" (p. 119). Regardless of the topic, my research will always be informed by my positionality. As an economically privileged White, able-body, heterosexual, cisgender male, becoming an "innocent" researcher is not my goal. This is a key consideration since research has long been founded on knowledge informed by the experiences and perspectives of White

men (Brown & Strega, 2005). Rather, my goal is to conduct research in a way that acknowledges the complexities, power relations, partialities and ambiguities involved with adult palliative care providers and their interactions with children. To this end, I adopt a social justice lens and will examine the race, gender and class dimensions of the area of inquiry.

How did I come to be studying adult palliative care providers and their interactions with children who have a parent in palliative care? The process of choosing a topic is not a neutral one, nor is any other part of the research process (Fine et al., 2003). Part of my interest in palliative care is related to my long-time curiosity in death and dying. I used to be afraid that I would die as a child, which is not an uncommon fear for children to experience (Griffiths, 2007). While I was trying to decide on a research topic, I had an opportunity to speak with Dr. Mike Harlos, the Medical Director of the Winnipeg Regional Health Authority Palliative Care Program. He described how the children who have a parent in palliative care often do not receive adequate psychosocial support from health care providers (HCPs hereafter) (personal communication, March 19, 2014). He pointed out that children who are part of the pediatric palliative world, either as a patient or a sibling of a dying child, generally receive significantly more support and attention. Adult palliative care providers have fewer opportunities to interact with children who have a dying parent. My research began to evolve into its current formulation following that conversation and Dr. Harlos' anecdotal observations were supported by my literature review. Shortly thereafter, I started working for a public benefit organization focusing on palliative care and bereavement support and this

professional experience helped me immensely because it intensified my personal connection with the subject.

Eventually, I decided that I would interview adult palliative care providers regarding their interactions with children who have a parent in palliative care. There is a tendency amongst social science researchers to focus their efforts on vulnerable or less-privileged populations, without ever turning the analytic lens on themselves or those in positions of privilege. By researching adult palliative care providers, I am researching “up”, or at least “sideways”, vis-à-vis my own positionality as a social worker.

It will become abundantly clear throughout this thesis that I reject objective, universal and foundational truth claims in favour of a postmodern and poststructural ontology. My critical perspective of dominant grief discourse (DGD hereafter) is influenced by Foucauldian interpretations of discourse, power and subjectivity. Methodologically, I used Clarke’s (2003, 2005) situational analysis, a postmodern iteration of grounded theory (GT hereafter). Rather than trying to inductively come to a theory that describes a basic core process within the data, I am concerned with analyzing the situation as a whole and making provisional theoretical observations.

### **Objective of the Study**

With the rejection of objective and universal truth claims, conducting research can feel tenuous and tricky because knowledge claims are situated and partial. However, it is imperative that we still make analytical commitments and acknowledge the material consequences involved in our research (Haraway, 1988). Research is key to understanding the world around us and can be used as a tool for social justice.

Therefore, the broader objectives of my study are to provide a critical analysis of DGD, highlight policy and practice implications and contribute to social justice. The purpose of the study is to provide insight into the interactions between adult palliative care providers and children who have a parent in palliative care.

There is already widespread agreement that children's grieving needs must be taken seriously (Auman, 2007; Jeffreys, 2005). However, many adult palliative care providers are uncomfortable talking to children about death and grief and may avoid these interactions altogether (Parkes, 1998). Many HCPs assume that it is better to say nothing than risk traumatizing the child, often believing that the child is too young or in need of protection (Librach & O'Brien, 2011). My research examines how the needs of bereaved children can be better fulfilled by HCPs. It does not replicate research that already identifies those needs, nor does it add to extant research that highlights the perspectives of families and children. Instead, it focuses on the viewpoints of adult palliative care providers and provides a critical analysis of DGD as it relates to the situation of inquiry.

Within DGD, there are many unexamined "truths" that I will try to unsettle in the following chapters. For example, there are several questionable assumptions related to children's grief and bereavement. Given that my research involves children who have a dying parent, it is not surprising that children's grief is a major factor in my analysis. Despite this, I appeal to the reader to keep in mind that we cannot assume that every child grieves in the same way, regardless of their age or the nature of their relationship with their parent. Nor can we assume that every child will grieve their parent's illness or

death, particularly if there is conflict or abuse in the relationship. This is just one example of how unexamined “truths” can be unsettled, questioned and problematized. It is equally important to remember that some of these “truths” may escape my scrutiny. Therefore, an ongoing critical perspective is essential in this research area and every social justice endeavour.

### **Summary of Chapters**

Chapter two is a review of literature related to the area of inquiry. Since GT researchers often abstain from doing literature reviews prior to data collection, I include a detailed justification explaining why I chose to conduct a literature review. I provide an overview of the needs literature, examining the needs of children with a parent in palliative care. The needs of adult palliative care providers and families are also addressed. The literature is then used to examine different elements of DGD, including stage theories of grief, the concept of resilience and childhood developmental stages. I probe the literature to illuminate how race, gender and class issues are treated within DGD. The concepts of “normal” grief and “pathological” grief are also subjected to closer examination. Existing literature is used to look at how grief is disciplined and policed and how people resist the disciplining of grief. I conclude with some reflections on self and meaning-making within a neoliberal environment.

Chapter three provides a comprehensive look at my chosen methodology. After a review of qualitative research and the evolution of GT, I provide a rationale for my methodological choices and use of constructionist language. The chapter then delves into Clarke’s (2005) postmodern version of GT and introduces the situational map, a key

analytical tool that I used for my data analysis. My attention then turns to my research design, including my recruitment techniques and some of the finer details involved in the interview process. I review my interview guide and how I used it to address different elements of DGD. This is followed by an explanation of my data analysis and coding. Evaluation and assessment criteria, ethical considerations and potential limitations of the research are also included.

Chapter four presents the findings and data analysis. I present the messy situational map, which was the primary analytical tool I used alongside memoing. This is followed by a relational analysis using the situational map, which demonstrates how I analyzed the relationships between different elements. The findings fall into three broad areas, namely “identifying needs”, “uncomfortable caring” and “the team concept”. These terms are defined and I examine different sub processes within each.

The capstone chapter makes some provisional theoretical observations based on the findings. The evaluation criteria from the methodology chapter are revisited and used to assess my work. I offer some further reflections on my role in the research process and I conclude with some implications and recommendations for practice, policy and future research.

## Chapter 2: Literature Review

### Purpose of the Literature Review

My literature review is intended to provide a critical analysis of recent and seminal works related to my research topic. I will use extant literature to situate my research on how adult palliative care providers respond to the needs of children who have a parent in palliative care. In essence, all literature reviews are designed to contextualize the research project by providing a critical summary of existing literature (Driscoll, 2013; Oudkerk & Ristić, 2012; Rozas & Klein, 2010). This involves closely analyzing arguments that are advanced in the literature and sites of disagreement. The importance of reading critically cannot be overstated. As I read, I analyzed the relevance, usefulness, strengths, weaknesses and purpose of each article, chapter or book. In this chapter, I will explain how specific works relate to my topic. The connection is not always obvious to you, the reader, so I must bear this responsibility in mind.

Although literature reviews are intended to evaluate existing research, I will subject my own review to an ongoing evaluation as I proceed. Oudkerk and Ristić (2012) propose a number of useful evaluative criteria, including the following questions: is the review comprehensive? Is it relevant? Does it provide a critical appraisal or merely summarize? Is it well-organized? I believe my literature review meets these expectations. I conducted an integrative literature review, which aims to use critical analysis to develop new insights.

## Justification for Literature Review

Deciding how and when to conduct a literature review is a hotly contested issue amongst GT researchers. In their groundbreaking publication *The Discovery of Grounded Theory* (1967), Glaser and Strauss advise researchers to initially ignore literature related to the area of study. Their main concern is that a preliminary review of existing literature would distract the researcher from exploring their own views. This would prevent the emergence of a new theory by enticing the researcher to follow pre-established theoretical frameworks. According to Glaser and Strauss, the data must be organized into categories that *emerge* from the data, rather than using categories found in extant literature. In their own words, ignoring the literature is a way “to assure that the emergence of categories will not be contaminated by concepts more suited to different areas” (p. 37).

It should be noted that Glaser and Strauss (1967) do not want to abolish literature reviews altogether. The debate hinges on the appropriate timing of a literature review. Glaser (2005) has maintained that the literature should only be examined when the analytical categories and emerging theory have taken shape. Strauss' position has shifted significantly and this is evident in his work with Juliet Corbin (1990, 1998). Strauss and Corbin see advantages and disadvantages to an ongoing literature review. It is advantageous because the literature can enhance theoretical sensitivity, stimulate questions, direct further sampling and be used as an additional source of data to help validate the findings. I used my literature review for these same purposes. Strauss and Corbin propose that “insights do not just occur haphazardly;

rather they happen to prepared minds during the interplay with the data” (1998, p. 47). However, Strauss and Corbin acknowledge that relying too heavily on the literature can stifle a researcher’s analytical creativity. Strauss’ decision to deviate from the purist position he originally shared with Glaser ultimately caused an ideological split between the two. In their work, Strauss and Corbin began to acknowledge the multiplicity of perspectives that must be accounted for in GT research. With this departure from traditional GT, the methodology began to evolve and laid the groundwork for constructionist GT, which I discuss in detail in the methodology chapter.

A number of scholars have added their voices to the literature review debate since GT was introduced. Hickey (1997) states that there are a number of disadvantages associated with a preliminary literature review in GT. He argues that a literature review may cause the researcher to make erroneous assumptions about the field of inquiry, particularly where there is a dearth of available research. In other words, if literature on a topic is sparse, then it might lead the researcher away from what is important. He calls on researchers to adopt a ‘not knowing’ stance so that new ideas can emerge from the data unencumbered by the literature. According to Hickey, GT is positioned to make its best contributions when there is a lack of extant research, because it can help generate new theory without relying on existing theoretical concepts found in the literature. However, as McGhee, Marland and Atkinson (2007) point out, “how can this paucity of knowledge be ascertained unless an initial review of literature is undertaken?” (p. 339-340). Furthermore, I fail to see how ignoring the literature in the beginning would prevent the researcher from making assumptions, being influenced by dominant

discourses or having personal bias. I will expand on this point in the following paragraphs.

Heath (2007) supports and extends Hickey's (1997) argument, focusing on how the GT researcher must minimize personal bias and be constantly vigilant to prevent the literature from distorting the emerging theory. Heath acknowledges that it is now widely accepted, while citing the notable exception of Glaser (1998, 2001), that researchers must be explicit about how their biases influence the research process. Therefore, this has caused researchers like Heath to seek out ways to minimize bias in their work. In this regard, delaying the literature review is presented as an effective strategy to reduce bias because it supposedly prevents researchers from being exposed to existing theoretical frameworks that could distort the emergent theory.

Although I agree that researchers must be reflexive about their influence on the research, I doubt that delaying the literature review can really minimize bias, as suggested by Glaser (2005), Heath (2007) and Hickey (1997). Most researchers agree that no one is a *tabula rasa*, or a blank slate (B. Davies, personal communication, April 1, 2014). Even as a relatively inexperienced Master's level researcher, I came to my research with some ideas about my topic and research area. Unless I somehow managed to pick a topic out of thin air that was wholly unfamiliar to me, having some preconceived assumptions was unavoidable (McCallin, 2006). It would be highly unusual and perhaps impossible to have absolutely no familiarity with existing literature on a topic. I would add that picking a topic out of thin air is also highly problematic for social justice reasons, because failing to describe my relationship to the topic as a researcher

is an exercise of power that would allow me to “hide behind the cloak of alleged neutrality” (Fine et al., 2003, p. 169). It was important to be clear about my relationship to the topic from the very beginning, which I shared in the introduction to this thesis. Although elucidating the relationship between researcher and topic is a critical step in the reflexive process that Heath claims to endorse, it is difficult to be reflexive if you are continually trying to position yourself as unbiased. Furthermore, selecting a topic involves an element of choice, which betrays the biases and personal interests of a researcher. Even if I had decided to avoid a preliminary literature review, I would not be immune to the role that bias plays at other stages in the research process. For instance, theoretical sampling requires me to collect data in a way that will help me best develop the emerging theory. I would argue that my perspective on “where to go with the data” would differ from other researchers facing the same choice, which suggests that bias persists throughout the research process.

Despite his seemingly ardent stance against early literature reviews, Glaser outlines what a researcher *should* read prior to collecting and analyzing data (1978, 1998, as cited in Heath, 2007). Andrew (2006) explains that a preliminary literature review is consistent with Glaser’s traditional GT, as long as the literature is not used as a source of concepts or core processes. According to Andrew, any preconceived ideas rooted in the literature will be “corrected” through the careful use of the constant comparative method, which I discuss in the methodology chapter. From this perspective, carefully comparing data and emerging ideas will challenge a researcher’s preconceptions.

In principle, I agree that the constant comparative method can help challenge preconceptions; this was one of the attributes that drew me to GT. However, I question whether it is feasible to follow Glaser's advice to avoid the substantive area of interest but instead read "in areas that appear unrelated to the area of investigation in order to challenge preconceptions" (as cited in Heath, 2007, p. 520). I find this directive to be untenable and impossible to follow. How can a researcher ensure that they are reading on the fringes of the substantive area? How can I know when literature is "too close" to the substantive area? Or alternatively, how will I know if my "unrelated" reading is completely irrelevant to the lives of research participants, resulting in a waste of time and energy? As Cutcliffe (2000) puts it, "just how much reading is 'extensive' and similarly 'too extensive'?" (p. 1480). Amidst all of all these decisions, bias would continue to play a significant role in determining what is appropriate to read, which is exactly what Glaser was trying to avoid. Fittingly, it appears that Glaser is attempting to turn literature reviews into an exact science, which corresponds with the objectivist leanings of traditional GT. In my view, it is simply not possible or desirable to follow Glaser's directions for pre-reading.

My decision to conduct a preliminary literature review is supported by a number of other GT researchers. Within qualitative research as a whole, literature reviews are considered an essential step to help focus and plan the study (Oudkerk & Ristić, 2012). I believe that this applies to GT as well, while recognizing that the research trajectory can change as the constant comparative method informs data collection and analysis. Dunne (2011) outlines the central arguments in favour of conducting early literature

reviews. For one, there are pragmatic reasons for conducting literature reviews, since researchers are often expected to produce a literature review to procure funding and ethics approval. This position is echoed by a number of other GT researchers, supporters and non-supporters of preliminary literature reviews alike (Martin, 2006; McGhee, Marland & Atkinson, 2007; Nathaniel, 2006; Thornberg, 2012). This applied to me as well, since my research required ethics approval before I could begin data collection. Other benefits to a literature review highlighted by Dunne include its role in helping to contextualize the topic, identify where more research is needed, justify a chosen research approach and assist the researcher in becoming aware of their own assumptions and location within the research. I believe my literature review accomplishes all of these things.

Thornberg (2012) concurs with Dunne (2011), adding that if the dictum to initially avoid literature in the substantive area is followed, it prevents researchers from conducting studies in their areas of expertise where they are already familiar with the literature. Furthermore, it would appear to prevent researchers from doing multiple studies in the same field, because a researcher cannot unlearn their previous research. Thornberg notes that even if a researcher is genuinely trying to follow Glaser's methodological advice, delaying the literature review might result in research that is perceived as lazy and atheoretical. Truthfully, the idea of delaying the literature review was somewhat appealing when I began this literature review. What novice researcher would not be at least intrigued by such a proposition? I do not think that delaying the literature review can be dismissed as "laziness", particularly because traditional GT

would still require extensive reading as the research progresses. However, Thornberg notes that delaying the literature review is still problematic because a supposedly emergent theory might already be established in existing literature. Additionally, May (1994, as cited in Hickey, 1997) argues that a literature review is necessary to avoid obvious and superficial findings. In other words, ignorance of the literature is not synonymous with analytical creativity.

Dunne (2011) and Thornberg (2012) also suggest that delaying the literature review is unnecessary because many researchers are able to reflect on extant theories without imposing them on the data. Although I do not think researchers can objectively weigh existing theories and completely prevent them from influencing their own data, I agree that ignoring the literature as you begin to research is an extreme measure. As I mentioned above, there are a number of potential benefits that can be derived from conducting a literature review and these benefits would be forfeited if the literature is ignored. In my view, it is incumbent on the researcher to be aware of and open about their influence on the research, while striving for rigour, validity and accuracy. These are concepts I discuss in more detail in the methodology chapter. From my perspective, it is not necessary or desirable for a researcher to take up a futile pursuit of objectivity.

McGhee, Marland and Atkinson (2007) suggest that the argument against early literature reviews is rooted in a postpositivist ontology. While postpositivist GT recognizes that it is impossible to fully “bracket” the researcher from outside influences, this approach still pursues objectivity. Within this paradigm, it makes sense to reject early literature reviews because they are considered an avoidable outside influence.

This does not coalesce with my own worldview, because I do not believe that complete objectivity is possible and I reject the concept of “bracketing” outright. McCallin (2006) points out that the debate over literature reviews is reflective of a larger internal struggle within GT being waged amongst postpositivist researchers like Glaser, Strauss and Corbin and postmodernists like Adele Clarke (2005) and Kathy Charmaz (2006).

In this atmosphere, Nathaniel (2006) suggests that the timing of the literature review is ultimately an epistemological one, based on our beliefs about how we acquire knowledge and how we come to know what we know. Do we acquire knowledge by delaying our engagement with the literature or do we use existing research as scaffolding for new discoveries? The answer to this question depends on the methodological approach that is chosen (Ekström, 2006). Therefore, I must turn to Adele Clarke (2005), whose situational analysis model guides my data collection and analysis. Clarke is adamant that a preliminary literature review should be conducted, because acquiring prior knowledge will prevent new research from regurgitating extant information. According to Clarke, researchers are not able to remove their influence on the research by avoiding literature that could potentially “contaminate” their views. Instead, she is proposing that “as researchers, we become more visible and accountable for, in and through our research” (p. 13). Therefore, I think a preliminary review of the literature that includes works on the substantive area is appropriate.

### **The Literature Review Process**

To conduct my literature review, I searched an array of library databases including *CINAHL with Full Text*, *Social Work Abstracts*, *Sociological Abstracts*,

*PsychINFO, ERIC, Web of Science, PubMed and Dissertations and Theses.* My primary search terms were health care/healthcare providers, palliative care, grief, bereavement, child\*, adolescen\*, race, gender and class. I used Boolean search strategies to bolster my results (e.g. “grief AND race OR gender OR class”). When I located pertinent articles, I also used the “Find Similar Results” tool available in most databases.

My search gravitated to two areas related to my topic. First, I zeroed in on articles that examined the relationships between HCPs and children with a parent in palliative care. I managed to locate a fair number of articles in this area, which I will discuss in the following sections. Simply reviewing the literature in this area helped me realize some of my own assumptions and contributed to a more nuanced approach when I began to interview HCPs for my data collection. For example, I realized that I had invested heavily in the idea that there is a clear distinction between the adult and pediatric palliative care worlds, which I discuss in the methodology chapter. I did not find literature that contradicted this distinction, yet I was reminded that the separation is not so steadfast that adult palliative care providers are oblivious to the needs of children that they encounter in their work. Every HCP participating in my research process came with their own experiences and perspectives on working with children who have a parent in palliative care. I found it useful to keep this in mind throughout the research process.

DGD is the other area where I focused my literature search. I sought research that analyzed dominant stage theories of grief and how these have been challenged and altered over time. I also read literature that addressed the race, gender and class

components of DGD. Most of the research I found gave little more than a cursory glance to issues of race, gender and class, but I analyze my findings in more detail later in this chapter. Additionally, I reviewed literature that discussed how DGD works to pathologize and discipline grief and how HCPs are implicated in this process. I will elaborate on these issues as I proceed.

Generally speaking, I found it difficult to find suitable materials. I consulted with four different librarians for guidance. One librarian suggested that it would be very challenging to find relevant resources (A. Osterreicher, personal communication, October 10, 2014). This is not necessarily a drawback, since a paucity of relevant materials seems to suggest that my research fills a gap in extant literature. Nevertheless, I found it necessary to go beyond social work literature to other health-related fields such as nursing in order to increase my results. This is why I use “health care provider” throughout my thesis, because many articles were not specifically about social workers who work in adult palliative care. Regardless, I still feel that I am capable of accomplishing the task of critically analyzing existing literature in order to situate my research. It is this task to which I now turn.

### **Organization of the Literature Review**

I begin by analyzing literature that identifies children’s needs in their interactions with adult palliative care providers. This section is expanded to include a discussion on the needs of HCPs and parents as well. I also use the literature to determine the roles that HCPs play in their interactions with children and parents. I then launch into a broad discussion about DGD, covering stage theories, issues of difference, resilience and

childhood developmental stages. This segues into a discussion on normal and pathological grief and how these topics are handled in the literature. This is followed by a critique of the ways that grief is disciplined and policed. I conclude with some observations about the concept of “self” and how social constructionist perspectives are currently influencing our collective understanding of grief.

### **Needs Identified in the Literature**

Since my topic was how HCPs respond to the needs of children with a parent in palliative care, I first sought out literature that examined what those needs are. In an exploratory study titled *Current Approaches to Helping Children Cope with a Parent’s Terminal Illness*, Christ and Christ (2006) conclude that witnessing the end stages of a parent’s terminal illness is a time of need for many children. They suggest that difficulties are exacerbated when the healthy parent is struggling with the ill parent’s diagnosis, which causes stress for their children. This argument appears to be rather obvious and straightforward. However, I am hesitant to use the term “healthy parent” in my research for a number of reasons, including the possibility that they might have physical ailments of their own, not to mention the emotional and psychological pain they might be experiencing regarding the palliative parent’s condition. While I understand the point Christ and Christ are trying to make, I must draw attention to their privileging of a traditional family model. This model is often understood to be “a middle-class family with a bread-winning father and a stay-at-home mother, married to each other and raising their biological children” (Lamb, 1999, as cited in Lamb, 2012, p. 102). I would argue that Whiteness is closely linked to the traditional family model as well.

Johnson and Loscocco (2015) point out the largely unquestioned connection between marriage and Whiteness, demonstrating that most research on marriage has been written through the lens of White, heterosexual, middle-class women.

The emphasis on the traditional family model appears repeatedly throughout the literature, as “non-traditional” families are poorly represented (*cf.* Draper & Hancock, 2011; Patterson & Ranganathan, 2010; Takei et al. 2014; Turner et al., 2007). As a result, the traditional family model becomes the standard by which all families are judged. This creates an assumption that children living within this traditional family structure are more likely to thrive and be “healthy” than children raised by a single parent, same-sex parents or non-biological parents. This assertion has been refuted in a number of research studies. For instance, Golombok et al. (2003) conducted an empirical study and concluded that lesbian-mother families and heterosexual-mother families had similar outcomes in respect to the quality of child-parent relationships and the social and emotional development of the child. Lamb (2012) concurs, stating that a review of the literature indicates that the most important factors in child development are the quality of child-adult relationships, the quality of relationships between the parents/guardians and other adults and the availability of economic, social and physical resources. The gender and number of parents in the family is not a determining factor in terms of the child’s overall health and development.

At the risk of being tangential, I want to examine various definitions of “health” because the term is so closely intertwined with what are perceived as children’s needs. The idea that children have certain needs that need to be met in order to be “healthy” is

often an unquestioned truth. Within the present discussion, “healthy” appears to be understood as a state that does not involve terminal illness or palliative care. In this sense, the definition is negatively oriented by demonstrating what is *not* healthy, rather than proactively demonstrating what it means to be considered “healthy”. This does not coalesce with the World Health Organization’s (WHO) definition of health, which defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (n.d., para. 1). The WHO definition actively defines what health is, rather than passively stating what it is not. However, the WHO definition does not address the privileging of the traditional family model that I highlighted in Christ and Christ’s (2006) work. Therefore, I turn to Foucault to demonstrate the precariousness of trying to define “healthy”.

In *The Birth of the Clinic* (1963/2003), Foucault expanded the meaning of the word “clinic”. In addition to the physical and institutional space, the clinic also encompasses the medicine and health care provided within the clinic and the system of thought that underpins health care practices. Rose (1999, as cited in Rysst, 2010) further developed this idea, using the term “healthism” to describe the way public objectives of good health and orderly conduct are intertwined with individual desire for health and well-being. The genesis of the term “healthism” is generally credited to Robert Crawford (1980, as cited in Rysst, 2010), who used the term to describe a general shift of health responsibility from the state to the individual. With individualized health responsibility and subtle disciplinary practices, human subjects learn to self-regulate and what it means to be “healthy” is bound within very strict parameters. This is an extension of

what Foucault calls governmentality, which I discuss later in this chapter. For example, Heyes (2007) demonstrates that “weight”, particularly as it relates to issues of eating, exercise and body size, has come to be equated with “health”. Within the dominant system of thought that Foucault referred to, public discourse has led many to simply accept that being “overweight” is unhealthy and irresponsible, because health in itself is now understood as an individual responsibility. As might be expected, my observations here do not bring me to a tidy definition of “healthy”. Rather, the task requires me to grapple with these tensions, rather than merely accepting established meanings of health.

Refocusing on the needs identified in the literature, MacPherson and Emeleus (2007a) performed an exploratory study to determine the psychosocial needs of children who have a parent with cancer in palliative care. They used a combination of interviews and focus groups with children and parents to compile a list of generic and individual needs. The two generic needs were a need for other people to understand the experience and a need for consistent relationships. The contextual needs were contact with the dying parent, preparation for the death, a way to sustain meaningful and private memories, continuity and normalcy, empathetic connections with others, quick and flexible responses when requesting assistance, support from other children and having some understanding of death. This appears to be a fairly lengthy list of needs that a child might face when a parent is receiving palliative care. I think it serves as a strong starting point, since the needs were largely identified by children themselves, although it is difficult to determine how the parents’ presence in the focus groups

swayed the results. Regardless, it relates well to my findings because I investigated how HCPs interact with children in similar situations and the participants cited many of these same needs.

In their own qualitative study, Patterson and Ranganathan (2010) also set out to identify the needs that arise when a parent has cancer, specifically focusing on adolescents and young adults. They point out that there is limited research into what adolescents actually need in these situations, since most studies tend to focus exclusively on the grief reactions of younger children. Patterson and Ranganathan argue that needs are usually only inferred in the literature, but they outline seven specific areas of need: support and understanding, help coping with feelings, opportunities to talk with people who have had a similar experience, information, permission to take a break and have fun, space and time to grieve and help with household responsibilities. Perhaps unsurprisingly, the two most commonly cited needs (support/understanding and help coping with feelings) were less likely to be satisfied. I suspect that it is much easier to identify unmet needs than it is to recognize needs that are fulfilled.

The needs bear resemblance to many of the needs that MacPherson and Emeleus (2007b) outline, with the exception of “help with household responsibilities”. Patterson and Ranganathan (2010) found that this need arises when the surviving parent, assuming there is one present, is unable to handle household responsibilities. This added responsibility reduces the time that adolescents can spend away from the family, either on their own or socializing with peers. Since females are typically

socialized to adopt the role of caregiver, it should come as no surprise that Patterson and Ranganathan found that this need was almost exclusively reported by female respondents. Here we see a clear example of how gendered expectations affect the needs that arise during a parent's illness and how these differences are supported by social discourses that encourage young women to step into a caregiving role. A broader discussion on gendered grief is included later in this chapter.

**Roles and needs of HCPs.** While identifying the unique needs of adolescents and young adults, Patterson and Ranganathan (2010) also demonstrate the unique role HCPs can play in addressing these needs. In particular, Patterson and Ranganathan found that adolescents needed a way to acquire honest information about their parent's illness without having to rely on their parents. HCPs can be a gateway for open and honest communication because young people are often encouraged to "stay strong" for their surviving parent by repressing their feelings (Devita-Raeburn, 2004, as cited in Patterson & Ranganathan, 2010). The need for accurate information and timely intervention by HCPs is supported by Beale, Sivesend and Bruera (2004). Parents often underestimate their child's need and desire for information, so HCPs are well-positioned to meet this need. Much like MacPherson and Emeleus (2007b), Patterson and Ranganathan provide an important contribution to the literature by identifying the needs of children. However, both studies gathered results by interviewing children and adolescents, whereas I collected data from interviews with HCPs.

Parkes (1998) notes that HCPs are in a privileged position, capable of acting as agents of change in people's lives. However, he adds that HCPs need information and

skills in order to fulfill their role. Here we see a direct correlation between roles and needs, because HCPs need certain tools to effectively assist children and families. In the context of assisting children with a parent in palliative care, MacPherson and Emeleus (2007b) note that it is relatively uncommon to encounter patient parental death, providing less opportunity to gain skills and develop capacity for helping children and families with their various needs. Furthermore, limited resources often lead to HCPs focusing their energy on supporting a primary caregiver, such as a surviving parent, rather than assisting the family as a whole (Hudson & Payne, 2011, as cited in Kühne et al., 2012). It is worth noting that these types of resource shortages were discussed by the research participants and seem to be understood as unfortunate yet inevitable realities. The need to do more with less has become its own unquestioned truth. This has major ramifications for social workers and other HCPs.

When having to make do with limited resources is widely seen as a fact of life, it leads to a proliferation of unwaged work within the social services. Baines (2004) offers a thoughtful critique on this phenomenon, noting that social programs and services have been drastically reduced since the first neoliberal federal budget in Canada in the mid-1980s. After conducting 83 in-depth interviews with social service workers from Alberta, British Columbia and Nova Scotia, Baines concluded that the roles of social service workers, social workers and other HCPs have been greatly deskilled and routinized, which has made it easier for agencies and organizations to replace waged labour with unpaid volunteers. This shift has occurred under the auspices of neoliberalism and its capitalist and managerialist accoutrements. In another Canadian

study, Handy and Srinivasan (2004) find that hospital-based volunteers in the Greater Toronto Area represent \$6.84 in value for every dollar spent, leading to remarkable monetary cost savings. I say “monetary” because there are other costs incurred that are not mentioned by Handy and Srinivasan, including the decline in workplace morale amongst workers who blame volunteers, rather than management or macro-level institutions, for threatening their job security. Aiming disdain and blame at volunteers is problematic, because it does not address the systemic changes that have brought about our reliance on unwaged labour. Therefore, adopting an anti-volunteer sentiment does nothing to destabilize the neoliberal policy environment that leads to social service cuts in the first place. I feel personally implicated in this particular issue within my own employment, because I am the only social worker and I oversee a large number of volunteers who offer companionship and bereavement support. Rather than having numerous social workers and other HCPs to work with and alongside volunteers, I occupy more of a managerial role because I do not have the time or institutional support to do the tasks currently performed by volunteers. Baines also notes that women and racial minorities are disproportionately affected by the spread of unwaged work, demonstrating the gendered and racialized consequences of this trend. It should be said that professional HCPs still have a role but cannot offer the same level of service as they once did, as they have been subjected to neoliberal ideals of cost-savings and standardization that reduce the need for professional expertise.

Turner et al. (2007) examine familial challenges that make it difficult for HCPs to fulfill their supportive role. For instance, HCPs can encounter parents, both ill and

healthy, that encourage a positive attitude in front of their children at all costs, no matter how unwell the ill parent might be. This makes it difficult for HCPs to fulfill their supportive role because they cannot communicate openly and honestly with family members, including children. One nurse that Turner et al. interviewed proposed that HCPs should not intervene in these cases, since *“what business do we really have in putting our beliefs on the kids or on the family unit as a whole?”* (p. 151, original emphasis).

Another related challenge highlighted by Turner et al. (2007) involves families that feel it is better to limit children’s access to information about their ill parent. Cipolletta and Oprandi (2014) conducted focus groups with 37 HCPs on what constitutes a good death and found that the majority of participants thought it was preferable to keep children away from the dying process. While there is substantial research that suggests children should be involved and kept informed (Worden, 2008), HCPs in Turner et al.’s study found it difficult to encourage this behaviour: *“if parents make a decision not to tell the children, how can you respond?”* (p. 151, original emphasis). Witnessing these family interactions, according to Turner et al., can cause emotional distress for HCPs. However, Turner et al. persuasively argue that HCPs must use self-care and collegial support in such a way that they can still be emotionally present for the ill parent and the family. Failing this, HCPs might avoid difficult interactions with the family, and parents may take this as justification to avoid sharing their own painful information with children. These are important challenges to be wary of, because they may have a significant impact on the professional conduct of HCPs.

The HCPs participating in Turner et al.'s (2007) study identified a number of their own needs, including attention to self-care, professional confidence, access to role models, educational opportunities and strategies for communicating more openly with children. The authors found that HCPs often feel ill-equipped to respond to the needs of children and families. They sought more opportunities to learn from others and struggled to find time to debrief difficult situations. The HCPs in Turner et al.'s study highlighted a number of obstacles preventing the fulfillment of these needs, including poor communication, burnout and the burden of caring, fear of making things worse, lack of training opportunities, unsupportive workplaces and time pressures.

There are a couple of notable trends in the Turner et al. (2007) study that deserve further attention. One is how HCPs downplay their ability to provide emotional support to children and families involved with palliative care. Although the tendency to minimize might reflect a lack of knowledge or confidence, Turner et al. suggest that downplaying their role might help HCPs justify their decision to avoid emotional connections with children and families altogether. A second trend is how many of the HCPs' needs are rooted in education and training. Cipolletta and Oprandi (2014), MacPherson and Emeleus (2007b) and Sweetland (2005) all conclude that HCPs often lack adequate training and are uninformed when it comes to interacting with children exposed to adult palliative care. Therefore, more education and training for HCPs seems to be a tangible need. However, when I compare the requests for more education to the first trend that sees HCPs downplaying their role with children and families, I am left wondering if they are somehow connected. Is it simply a matter of willingness amongst

HCPs to take on a supportive role, rather than a lack of education and training? This appeared to be a gap in the literature so I posed this question to participants. Their responses are included in the data analysis chapter.

**Roles and needs of parents.** Even as I focused my literature search on the interactions between HCPs and children, it was impossible to ignore the role that parents and guardians play in these interactions. Of course, the ill parent in palliative care cannot be ignored because adult palliative HCPs would otherwise not be interacting with their children. Perhaps less obvious is the role played by the surviving parent or guardian, assuming there is one. I already discussed the challenges involved in defining “healthy” earlier in this chapter, but suffice to say that much of the literature positions the other parent as a key mediator between HCPs and children. Christ and Christ (2006), MacPherson and Emeleus (2007b), Mahon (2009), Sweetland (2005) and Takei et al. (2014) all argue that the behaviour and reactions of the surviving parent have a significant impact on children’s ability to cope. This suggests that it is impossible and undesirable to ignore the considerable influence that parents have on children and vice versa. Parkes (1998) proposes that *“whenever a loss extends to affect the family it is the family, which includes the patient, that should be the unit of care”* (p. 134, original emphasis).

MacPherson and Emeleus (2007b) persuasively argue that since the reaction of the surviving parent is critical to how children respond to the illness of a dying parent, it makes sense to consider the parent’s needs. Specifically, how are the parent’s needs related to their children’s interactions with HCPs? Christ and Christ (2006) highlight a

number of needs the parents may have: guidance from HCPs upon request, open communication and empathetic listening from HCPs and assistance in preparing children for hospital visits to the ill parent. Christ and Christ also cite two studies (CDC, 1997; Wolfe et al., 2000) where consultation with a social worker provided effective and family-centred care when there were difficult interactions between children and their parents in palliative care. Sweetland (2005) adds to these needs in her autoethnography about her role as a palliative care nurse supporting an adolescent child of a dying patient. She notes that parents benefit from receiving timely and succinct written information that describe strategies for communicating with children.

Although the exact role that an HCP adopts when supporting a child with an ill parent varies depending on context, many sources that I reviewed position HCPs as a key resource to parents. Keeley (2000) suggests that HCPs should offer to be present when a parent informs a child about the diagnosis and encourage children to share their own ideas and questions. MacPherson and Emeleus (2007b) concur, adding that good coordination amongst different HCPs and the parents is critical. Turner et al. (2007) call on HCPs to offer parents information and professional support when interacting with children. The supportive role of HCPs in these scenarios appears to be quite clear within existing literature.

**Communication: The most common need.** As I reviewed literature focusing on the needs of children, parents and HCPs, I noticed that the importance of communication was a common thread throughout. The decision to avoid, deny or hide diagnoses and information from children and their families has often been made under

the presumed “best interest” of those involved. Fortunately this appears to be changing. However, it is erroneous to say that HCPs have recently been enlightened and only now understand the importance of communicating truthfully with families. In her pioneering book *On Death and Dying* (1969), Elizabeth Kübler-Ross herself said that “the question should not be ‘should we tell...?’ but rather ‘how do I share this with my patient?’” (p. 28). The impetus on communication has a long history, yet various challenges such as training, professional competence, personal hesitancy and lack of self-care can inhibit open and honest communication between HCPs, families and children.

In a descriptive article titled *Supporting Children’s Grief within an Adult and Pediatric Palliative Care Program*, Librach and O’Brien (2011) note that poor communication with parents and caregivers is often cited as a major challenge by children experiencing the death of a parent. Christ and Christ (2006) and Ayonrinde (2003) report similar results, advocating for more open communication between and amongst HCPs, parents and children. Sweetland (2005) points out that when HCPs communicate and share difficult information in a sensitive manner, it lays the groundwork for strong communication channels. These findings help dispel commonly held assumptions, such as the belief that children should not know about their parent’s illness and that it is better to say nothing to protect the child. Finding the right language can be tricky, as Brayne (2010) outlines all the misleading and unhelpful language that we use to avoid saying “death”, such as “gone to sleep” or “lost” (p. 108). Notably, Brayne also takes exception with the term “loved one”, which is problematic if the relationship with the dead person was abusive or lacking love. Nevertheless, good

communication is frequently cited as an indispensable part of healthy interactions between HCPs and children with a parent in palliative care.

### **Dominant Grief Discourse**

Before I can explain how DGD affects the situation of concern, I must first define the term “discourse”. In a thorough examination of the term, Mills (2004) illustrates that the definition of “discourse” is fluid and difficult to pin down. Given the postmodern and poststructural orientation of my research, I look to Michel Foucault for a working definition of the term. Foucault himself had multiple interpretations of the word, defining it “sometimes as the general domain of all statements, sometimes as an individualizable group of statements, and sometimes as a regulated practice that accounts for a number of statements” (1972, p. 80, as cited in Mills, 1997, p.6). Although Mills mentions that these definitions are often used interchangeably, it is the last one that is of particular interest to me. DGD is regulated, suggesting that there are rules and expectations that govern what is and can be said about grief and bereavement. These statements, utterances and texts determine what is acceptable and commonplace within DGD and what is considered aberrant.

Foote and Frank (1999) adopt a Foucauldian critique of DGD, arguing that it is a therapeutic discourse that produces particular kinds of “grievers”. I discuss Foucault and DGD in the methodology chapter, but the topic also deserves mention here. Grief therapy is used as a “technology of the self” (Foucault, 1988, as cited in Foote & Frank, 1999, p. 163). In essence, “grievers” are expected to discipline their own grieving practices so that they align with the circumscribed expectations of DGD. The “grievers”

also become objects of HCPs' expertise. None of this is accomplished through overt domination of "the griever", because power is used in more subtle ways to encourage people experiencing grief to discipline their own behaviour. In other words, the bereaved person is compelled, through their own self-discipline and the social and professional expectations of others, to grieve in a particular way.

In this context, it should come as no surprise that there are dominant ideas, perceptions and beliefs about grief. According to Foote and Frank (1999), the central lesson in DGD is that "'normal' grieving is short term and follows a linear trajectory from acute to moderate to a thing of the past" (p. 172). In an article on recent developments in grief and bereavement theory, Hall (2014) suggests that many common ideas about grief are no longer supported by the research. For example, he argues that grief is no longer seen as a predictable linear trajectory and that "grievers" are no longer expected to "work through" their grief. While the tide may be changing, I would argue that these ideas are still quite dominant. For instance, O'Rourke (2010) looks at the lingering effects of one of the landmark studies on grief, Lindemann's (1979) survey of survivors of the famous Coconut Grove fire. This study helped established the idea of "normal" grief reactions, differentiating it from delayed, exaggerated or absent grief. Far from being dismissed, contemporary research still draws heavily on these prescriptive terms to describe people who grieve in ways not considered "normal".

Over the next several pages, I will examine various components of DGD and their influence on the area of inquiry. I agree with Neimeyer, Klass and Dennis' (2014) assertion that grief is socially constructed, so it is worthwhile to examine the dominant

discourses that pervade personal and public life. I will take a closer look at the prevalence of stage theories and will follow this with an examination of the cultural dimensions of DGD as they relate to race, gender and class. I will then look at how “resilience” continues to play a large and often unquestioned role within grief research, particularly through the work of Bonnano, Papa and O’Neill (2002). I will also discuss how ideas about children’s developmental understandings of death have come to be accepted as self-evident truths.

**Stage theories.** An examination of DGD and its influence on interactions between HCPs and children immersed in the adult palliative care world requires some attention be paid to stage theories, which have pervaded DGD for decades. Kübler-Ross (1969) is generally credited for popularizing the stages of grief when she examined the anticipatory grief of dying people. She outlines five stages: denial, anger, bargaining, depression and acceptance. These came to be seen as the five stages of grief. For all intents and purposes, it has become quite popular to criticize and dismiss stage theories altogether (Calderwood, 2011; Corr, 2010; Hall, 2014). This dismissal is usually based on the argument that grief is not a linear process and stage models cannot capture the complex process that follows a death or loss. On a surface level, I certainly agree with the criticisms levelled at stage theories. However, I have two outstanding concerns with the widespread condemnation of stage theories found in the literature. First, I feel that critics often oversimplify Kübler-Ross’ work in a rush to dismiss it. Second, I am dubious that DGD has managed to move beyond stage theories, opting instead to repackage stage theories in new ways. Before I elaborate on these concerns, please note that I am

not immune to DGD and I have similar criticisms of stage theories. I think it is perfectly valid to question the supposed linearity and predictability of grief. Yet I think it is important to re-evaluate this area of DGD.

Given the dominance of stage theories over the last five decades, it is worth revisiting what Kübler-Ross (1969) had to say about the manifestation of grief. She did not say that one must complete the first stage (denial) before advancing to the second (anger) and so forth, although her work is often misrepresented in this way. Rather, she wrote that “these stages do not replace each other but can exist next to each other and overlap at times” (p. 263). Later in her career, Kübler-Ross published *On Grief and Grieving* (2005) to reiterate that the stages were not meant to simply compartmentalize difficult emotions and turn grieving into a knowable process. While reviewing the influence of Kübler-Ross and other prevalent grief researchers, O’Rourke (2010) suggests that the linear interpretation of the five stages has persisted because the public sees it as a way to control an inherently uncontrollable process. Although it is true that Kübler-Ross did outline some form of linearity (i.e. denial would never occur at the same time as bargaining in her model), her work has been oversimplified in recent decades. The criticism of stage theories can be so deafening that we ignore the monumental role that Kübler-Ross played in bringing death and dying into the public consciousness (F. Nelson, personal communication, September 19, 2014). Although there has been a shift away from stage theories in the field of grief research in recent years, this should not come at the expense of understanding what Kübler-Ross has

contributed to the field. Furthermore, I question whether the call to move away from stage theories has been heeded.

Although grief researchers appear resolute to find an alternative to stage theories, recent developments suggest that the stages are simply being repackaged as “phases”, “tasks” or “tracks”. This brings me to my second concern regarding the widespread criticism of stage theories, which is whether we can or should escape the influence of stage theories altogether. An examination of the literature shows that stage theories are alive and well in DGD, despite the criticism levelled at Kübler-Ross. Calderwood (2011) uses Prochaska and DiClemente’s (1983) stages of change model, alternatively referred to as the transtheoretical model (TTM) of behaviour change, to propose a new stage theory of grief. This one sees people move through the stages of precontemplation, contemplation, preparation, action and maintenance. Calderwood positions TTM as preferable to Kübler-Ross’ stages of grief for three main reasons. First, Calderwood argues that “precontemplation” is preferable to “denial” because the former denies the amount of grief work required to process the death, while the latter denies the death itself. Second, the “maintenance” stage is useful because it allows for a bereavement process that never truly ends, whereas Kübler-Ross’ (1969) “acceptance” is often seen as moving on from the grief, or decathexis. Third, Prochaska and DiClemente’s stages of change model is on a continuum, allowing people to oscillate between stages or identify with a combination of stages. I already argued that this continuum was present in Kübler-Ross’ work, yet Calderwood suggests that the continuum is more explicit in Prochaska and DiClemente’s model. Calderwood claims

that the stages of change model responds to the criticisms directed at Kübler-Ross' stage theory by accommodating unique bereavement experiences across the stages. However, it is clear that the profound influence of stage theories has not subsided when considering Calderwood's research.

There are other examples where stage theories have been repackaged into more palatable forms. Reeves (2005) uses an analogy of four circles to talk about how we advance from grieving and readjustment to finding energy that enhances our lives. Again, she is careful to add that the model is non-sequential and people can move in and out of different "circles". It is my contention that this sounds remarkably similar to other stage theories, with "circles" replacing "stages". Another popular model in contemporary DGD is Stroebe and Schut's (1999) Dual Process Model of grief, which sees the griever oscillating between feelings of loss and restoration. Again, the model allows for very different expressions of grief, but still uses two specific phases to describe the grief process. Even if the phases are non-sequential, they still resemble "stages" that a person who is grieving might find themselves in.

In the context of grieving children, Szymanowska (2014) and Christ and Christ (2006) discuss the HCP's role in helping children master a number of tasks. This task-based approach finds its origin in the works of J. William Worden, who famously outlined four tasks for bereaved children in *Children and Grief: When a Parent Dies* (1996). The four tasks are: accept the reality of the loss, experience the emotional aspects of the loss, adjust to the new environment without the deceased and reposition the deceased person within one's life while finding ways to memorialize them. Although

Worden places the “acceptance” task at the beginning rather than the end and notes that the tasks can be worked on concurrently or at different times throughout childhood, it still takes on the familiar form of a stage theory.

The persistence of stage theories is usually explained by describing their seductive nature. Dividing the grief process into clearly delineated and understandable categories renders a messy process into something much less intimidating. Robert Kastenbaum (1995, as cited in MacPherson & Emeleus, 2007a), another prominent researcher in the area of children’s grief, notes that these guidelines are attractive to HCPs because they provide a modicum of control. Despite their ongoing appeal, stage theories are widely seen as incapable of capturing the complexity, unpredictability and fluidity of postmodern interpretations of grief (Hall, 2014). As previously stated, my postmodern worldview means that I share these reservations about stage theories. Even still, I wonder if grief research can ever truly escape stage theories, or if this is even desirable. Corr (2010) argues that stage theories are not undesirable in themselves, but they can easily lead people astray if they are oversimplified or applied in a clumsy manner. Therefore, it is extremely important that HCPs are aware that rigidly applying stage theories can be harmful and hold themselves open to complexity and difference in grief experiences.

**Race, gender and class dimensions of dominant grief discourse.** Race, gender and class usually receive scant attention in literature related to grief and the relationships between adult palliative care providers and children. Rather than including explicit discussions on these important issues, DGD encourages researchers to use

umbrella terms like “multiculturalism” or “cross-cultural sensitivity” when addressing issues of difference (*cf.* Ayonrinde, 2003; Cipolletta & Oprandi, 2014). This approach means that race, gender and class are usually treated as separate issues. This is a major shortcoming in the literature because race, gender and class are interlocking issues that mediate everyday life. These issues help define who we are and what we believe (Harper, Lartigue & Doka, 2001). Although there has been an increase in the number of initiatives related to palliative patients and their children (Kühne et al., 2012), mine is unique because I am including an explicit analysis of race, gender and class.

**Race.** Although race, gender and class are intricately connected to each other, the literature often mentions them separately. For instance, research related to race may make no mention of gender or class. Despite this separate treatment, race, gender and class are often handled in similar ways within the research, treated as little more than identity markers that potentially carry statistical significance in quantitative research outcomes. Quite often, DGD on race is usually limited to a brief listing of the ethnicities of research participants. For example, Haine et al. (2006) conducted a research study on how positive parenting can act as a protective resource for children who are bereaved by the death of a parent. The extent of race-related discussions is limited to the percentage of participants who were Caucasian, Latino or Latina, African American, Native American and Asian/Pacific Islander. There is no accompanying discussion on what this meant and why it is important.

The way issues of difference are handled in the literature is usually dictated by prevailing assumptions within DGD. However, Ayonrinde (2003) demonstrates that the

importance of race and its role in therapeutic transactions like the ones in my study is a contested issue within DGD. At the very least, there is general agreement that awareness of cultural differences is important to some degree. However, Ayonrinde illustrates how some researchers consider race to be just one more influence that should be treated like any other variable. This approach aligns well with traditional GT methodology. Other researchers argue that a failure to adequately address issues of race can compromise therapeutic relationships, such as the ones between HCPs and children featured in my study. It should come as no surprise that I agree with this latter position, since I believe it is essential to name and analyze issues of race.

Ayonrinde (2003) also highlights the contrasting views on the need for HCPs to be aware of their own racial identity and how it impacts relationships. Whereas some researchers like me see this as an important consideration, others see it as irrelevant within therapeutic relationships. Ayonrinde is critical of HCPs who believe that all issues of difference will be easily averted if each individual is treated with respect, noting that this approach is fraught with problems. One such problem would be that it keeps the attention focused on the other person, preventing HCPs from reflecting on their own standpoint. Granted, it was important for me to treat HCPs with respect as I conducted interviews in my research. However, this approach alone is insufficient. I agree with Ayonrinde that researchers must be self-reflective of their own situatedness and analyze how this might affect their findings.

**Gender.** In a recent study, Penman et al. (2014) note that gender has received considerable attention in grief-related research. According to Penman et al., various

research studies have attempted to generate results that can be generalized by gender. However, the “gendering” of grief is clearly a site of disagreement within the literature. For instance, Stroebe, Stroebe and Schut (2001, as cited in Penman et al. 2014) found that men have poorer outcomes when experiencing grief. Alternatively, Chen et al. (1999, as cited in Penman et al., 2014) conclude that women are at a higher risk of traumatic grief, anxiety and depression. Lawrence et al. (2005, as cited in Penman et al., 2014) suggest that women and men experience grief similarly but cope in gender-specific ways.

In my reading, I saw similar attempts to make general statements about the relationship between gender and children’s grief. For example, Ens and Bond Jr. (2005) note that adolescent girls are more prone to death anxiety than their male counterparts. Furthermore, McClatchey et al. (2014) try to establish that female children are at a higher risk of developing complicated grief. These sweeping generalizations indicate how children’s grief is frequently portrayed within DGD. Another common argument within DGD is that boys and men do not acknowledge their grief and deny their feelings. Anderson (2010) suggests that this supposed “failure” to grieve creates difficult rifts in relationships. Doka and Martin (2002) challenge the assumption that men are ineffective grievers, noting that grief is more than just an emotional reaction, but is a multifaceted response to loss that also touches physical, spiritual and mental dimensions. Doka and Martin persuasively argue that the assumption that grief must be primarily expressed at an emotional level is marginalizing to anyone, male or female, who grieves in different ways. This serves as a major

challenge to DGD and its sweeping generalizations about gendered grief. I would add that the failure to question the gender binary at all is problematic as well.

The desire to make broad statements about the ways gender mediates grief expression seems to arise for three main reasons. One is the tendency for DGD and dominant discourses in general to compartmentalize people into understandable and predictable categories, much in the same way that we tend to organize grief into stages, as my earlier discussion explained. The categorization and compartmentalization of difference is problematic because it privileges White and Western ways of knowing, which tend to be less relational and nuanced than non-Western ontologies. For instance, Baskin (2011) and Hart (2009) have written about the significance of relatedness and interdependence within Indigenous ways of knowing and being. I want to be careful not to generalize Indigenous ontologies, because it would be hypocritical to compartmentalize Indigenous peoples in this way. Nevertheless, it is clear that compartmentalizing difference is not an innate human trait. The attempt to categorize also ignores the heterogeneity found within different groups (Sensoy, 2007). Children who might be grieving are not permitted to grieve on their own terms, but are forced into uncomfortable and ill-fitting gendered typologies. An analogy can be found in colonial discourse theory, which involves studying discursive materials that are produced within the context of imperialism. Here, the racialized “Other” is not permitted to exist on their own terms, but is negatively compared to the White colonial “Self” (Mills, 2004; Said, 1978). With this analogy, we can see how issues of difference like race and gender intersect. Despite the issues I have outlined, categorization and

compartmentalization are still prominent forces within DGD and its treatment of gender.

A second reason we see sweeping generalizations about DGD and gendered grief expressions is because research is often conducted within a positivist framework that tries to discover objective truths that can be generalized and replicated. However, it is impossible to make universal statements about grief patterns for even small segments of the population, let alone all females or all males. A third reason that these stereotypes appear in the literature is because it keeps all discussions about gender at a manageable and predictable level. DGD allows for discussion on how boys and girls might grieve differently, but does not encourage an exploration of alternative discourses that would deepen our collective understanding of the significant role that gender plays in HCP interactions. I will now turn to an article by Lowe (2011) to further clarify what I mean.

Lowe (2011) uses a feminist poststructural research design to interview 17 HCPs and analyze their exposure to gender and sexuality issues within their professional training. The responses indicate that the HCPs received minimal or no training on issues of difference. The dearth of training opportunities does not reduce the importance of gender and other issues of difference. In fact, Lowe outlines a number of ways that gender influences the health care field. First, health care usually places a higher value on knowledge perceived as masculine, although I have already noted the precariousness of making sweeping generalizations about what is masculine and what is feminine. Second, women regularly occupy lower status positions than men in health care fields. Third,

illness and grief are frequently associated with being weak and dependent, which are in turn negatively identified as stereotypically feminine characteristics. Finally, Lowe points to a shift away from women-centred initiatives in health care to the dominant model that is purportedly equal and non-gendered. This reflects the call in dominant discourse to appear neutral, a concept that Lowe says is used “to homogenise and therefore mask practices of power” (p. 185).

Clearly, Lowe (2011) demonstrates that gender is much more than a simple category, illustrating how it plays a much greater role in HCPs’ interactions. In her interviews, Lowe found that participants were unwilling or unable to engage in a discussion on gender. She identifies gender as a site of silence within health care education. She attributes this silence in large part to the unexamined privilege of HCPs, who do not work to disrupt dominant discourses or examine how power operates within the health care field. In a call for social justice, Lowe urges HCPs to make their own privilege visible by creating space for alternative discourses. These “discourses of vulnerability and susceptibility” (p. 188) would help end the silence by moving beyond simplistic accounts of gender roles currently found in the literature into a deeper discussion of privilege and oppression.

Adele Clarke (2003, 2005) calls on researchers to draw out these sites of silence in the data, which I expand on in the methodology chapter. Lowe’s (2011) work aligns with Clarke, as Lowe developed a map to explore the relationships and tensions within her data, much like I did. In order to integrate gender into my analysis and use my research for social justice, I examined how gender manifests itself in the interactions

between HCPs and children with a parent in palliative care. Furthermore, I reflected on my own privilege and how my gender impacted my research interviews. A review of the literature has convinced me that simply talking about how girls and boys grieve is misleading, insufficient and potentially harmful.

**Class.** Before examining how the concept of “class” is treated in the relevant literature, some description of the term is necessary. The meaning of “class” is hotly disputed with many competing definitions. Parker (2005) suggests that there has long been an assumption amongst people advocating for social justice that the definition of class is self-evident. However, there is nothing “self-evident” about class. One common definition is couched in Marxist terms, where class is understood as an “economic relation (of exploitation) between producers and nonproducers, working and nonworking classes” (Gibson-Graham, Resnick & Wolff, 2001, as cited in Parker, 2005, p. 17). Alternatively, class can be interpreted as a social hierarchy, including lower, middle and upper class categories. It is also sometimes defined simply as income level. Beck and Beck-Gernsheim (2002, as cited in Atkinson, 2007) refer to a Weberian definition of class that sees it as the “unity of shared life experiences mediated by the market and shaped by status” (p. 358). Furthermore, class can be perceived as “materially-organized collective solidarity, culture, identity, community and political action” (Beck, 1992, as cited in Atkinson, 2007, p. 358). Clearly, there are multiple ways to define class. Simply laying out an assortment of definitions in order to choose one is not the goal here. Rather, the complexities demonstrate that class is “an open question, something to be theorized rather than assumed” (Gibson-Graham, Resnick & Wolff, 2001, as cited in

Parker, 2005, p. 16). Therefore, I am not assuming that class is merely an economic relation or a rigid social hierarchy, but something to be grappled with. Some would argue that it is impossible to proceed without a concrete definition of class, but I would counter that strictly limiting yourself to one interpretation is more likely to constrain an analysis of class. As you will see in the next two paragraphs, class and the way it is treated by the literature impacts collective and individual circumstances and has material consequences for families and children who may be grieving.

Class-related issues tend to receive short shrift in the literature and dominant discourse. Much like race and gender, it usually receives little more than superficial treatment. In most cases, it is treated exclusively as a factor that either exacerbates or ameliorates the grieving process. Let us consider for a moment a study by Draper and Hancock (2011), who examine whether experiencing the death of a parent in childhood increases the risk of delinquency. The authors posit that social class is an important factor in bereavement and so-called “delinquency”, which is alternatively called “offending behaviour” (p. 287). They cite a study by Harwood, Miller and Lucca Irizarry (1995) that concludes “parents who are working-class tend to value obedience, conformity and authority more, whereas middle-class parents see greater value in initiative and self-direction” (p.287). These class values, they claim, affect a child’s bereavement experience. I am not disputing that parental values can influence a child’s bereavement experience, yet these sweeping statements about particular class values are problematic. When class values are categorized and presumed, it mitigates a deeper analysis of class and helps construct us as particular kinds of citizen-subjects, expected

to fulfill a role in accordance with our assigned social class. Following the above model, if I am poor then I can be expected to conform to acceptable methods of grieving. If I am middle-class, I supposedly have the ability to follow my own grieving process, as long as I use my initiative to complete the grief work that society still expects me to do. What we have here is essentially an intersection between a dominant discourse about social class values and a dominant discourse about grief. What is absent is a discussion about social justice which would include an analysis of social stratification and how certain expectations are imposed on particular groups. Draper and Hancock draw a connection between “class” and “delinquency”, while avoiding a larger conversation about equity and justice. Such a conversation would examine structural factors like poverty that lead to particular forms of parenting styles within lower-income families. To illustrate this, consider Shor’s (2000) work on how socioeconomic classification influences parents’ perceptions on what constitutes child maltreatment. He notes that low-income families are portrayed as “traditional” and “authoritarian”, while middle class families are characterized as “progressive and democratic” (p. 174). The favorable adjectives assigned to middle class families suggest a certain superiority, yet Shor notes that this low-class/middle-class dichotomy lacks context. In particular, parents in low-income families perceive authoritarian forms of parenting to be warranted in poorer neighbourhoods as a form of risk mitigation. Furthermore, what qualifies as “risk” varies across low and middle class neighbourhoods, resulting in different childrearing practices. Parton (1998) notes that even though “the notion of risk gives the impression of calculability and objectivity, it is inherently contingent and open to differing and

sometimes conflicting interpretations” (p. 102). Given the complications that arise when class values are homogenized, it is unwise to apply simplistic and class-based explanations for how we grieve.

There are other examples in the literature where class is mentioned only briefly and given minimal attention. Keeley (2000) determined that mothers with cancer were more likely to share information about their diagnosis with their children if they were from a lower socioeconomic class. Christ and Christ (2006) make a number of observations about the influence social class has on a child’s ability to cope with a sick parent. They state that higher class is a protective factor in grief and lower class is more commonly associated with psychological difficulties. Christ and Christ also mention that children who are from poorer families are more likely to provide direct care to an ailing parent and this changes the child’s grief experience. I am not disputing that these arrangements do not happen, because they certainly can. My concern is that this is usually the extent to which class issues are analyzed. Although social class is identified as a factor in grief, there is little discussion about what needs to be changed or challenged. Instead, DGD continues to place responsibility for grieving squarely on the individual. In my data analysis, I explore how socioeconomic class influences HCPs’ interactions with children who have a parent in palliative care.

**Resilience and dominant grief discourse.** Hall (2014) notes that the concept of resilience has emerged as a central component of DGD. In their article on resilience in grief, Bonanno, Papa and O’Neill (2002) question the assumption that the absence of outward grief expressions is cause for alarm. They argue that people are generally

capable of coping with loss and maintaining a sense of identity from pre- to post-loss. Their work has been influential in popularizing the idea of resilience in grief. The authors argue that grief counselling can even be damaging and disrupt a person's resiliency. Moreover, Bonanno et al. suggest that delayed or absent grief reactions are far less common than previously believed. The resilience discourse within DGD has spread quickly throughout grief research. Jordan and Neimeyer (2003) recommend that research on grief interventions focus only on high-risk mourners, to avoid disrupting resilience. Kühne et al. (2012) concur, calling on HCPs to only support people who are distressed and expect resilience from higher-functioning families.

I agree that resilience can act as a protective factor in grief, but I am hesitant to assume it is fully applicable to the experiences of children who have a parent in palliative care. Within DGD, the concept of resilience is often perceived to be a "natural" process, something that everyone will experience as long as they are not "high-risk". After reviewing the literature, I think the idea of resilience should be applied more cautiously. Beale et al. (2004) acknowledge that HCPs and parents commonly believe that children are naturally resilient and capable of adapting to loss on their own. This belief is bolstered when parents and HCPs fail to see subtle signs that a child might be struggling. While it might be true that many children are resilient, the assumption can leave children without the support they might need. While Patterson and Ranganathan (2010) admit that children can be quite resilient, the death of a parent can be incredibly stressful and can increase the risk an individual might encounter social exclusion or mental health difficulties. Draper and Hancock (2011) agree that resilience

can be compromised depending on the relationship a child has with the dying or deceased. The presumed “naturalness” of resilience is dubious even within the original work by Bonanno et al. (2002), because they outline the different processes that are required to build resilience, such as a person’s worldview, self-enhancement activities and ability to emotionally regulate. These are not purely natural processes. Instead, I would argue these are situated perspectives and skills that are acquired through interaction with ourselves, others and the world around us.

I am not opposed to the idea that people can be resilient. In fact, I would even describe myself that way, but it is difficult for me to know how much that self-description is influenced by societal messages that tell me to be resilient in the face of hardship. Similar to the aforementioned grief therapy, resilience discourse is another technology of self that is particularly relevant within a neoliberal framework that emphasizes individualization and self-dependency. If someone is struggling with their grief, resilience discourse encourages them to look inward at their own shortcomings and lack of perseverance. This inward gaze deflects attention from structural inequities that may contribute to a person’s struggles in the first place. When HCPs are solely focused on promoting resiliency amongst people who are grieving, their perceived expertise can deeply impact the ways individuals self-regulate their grieving behaviours (Rose, 1999). Therefore, I think it is wise to be careful about how resilience seeps into DGD.

O’Rourke (2010) offers some interesting observations about the resilience research done by Bonanno et al. (2002). She critiques the insistence that people are

resilient in the face of grief and notes that even George Bonanno himself may not be particularly resilient. She describes the autobiographical passages found in Bonanno's works and recounts how Bonanno thrived after his father died but felt compelled to begin performing a ritual for him many years later. Although this is not meant to reflect poorly on Bonanno, it does bring into question the prevalence of resilience and whether it should be applied as widely as it currently is.

**Childhood developmental stages, grief and dominant grief discourse. A**

dominant theme throughout the literature on children's grief is the different developmental stages of children and how these affect their reactions to loss. Patterson and Ranganathan (2010) point out that extant research has largely focused on children's expected grief reactions. A glance at the literature will show multiple examples of what adults supposedly should expect from children experiencing grief (Black, 1998; Christ & Christ, 2006; Corr, 2010; Himebauch, 2008; MacPherson & Emeleus, 2007b; Walsh, 2012). These grief reactions are usually divided into fairly strict age categories. For example, Himebauch (2008) claims that 0-2 year olds have no understanding of death, 2-6 years olds see death as temporary, 6-8 year olds see death as final but not universal, 8-12 year olds see it as final and universal and 12-18 year olds are able think about death in abstract terms. In this section, I will consider how these developmental understandings of grief impact DGD and how rigid age categories are misleading and problematic.

To an extent, using common developmental characteristics to study the manifestation of children's grief seems unavoidable. A child's dependency, cognitive

abilities and mastery of language are merely three of the areas that will evolve as they mature. Furthermore, parents and caregivers frequently request from HCPs a simple and easy-to-understand outline of how differently-aged children grieve. Once again, we see a deep desire to package information into a linear format, much like the dominant stage theories of grief that I previously discussed. Bugge et al. (2014) examine the dynamics between parents and children who are grieving and conclude that parents genuinely want to understand their children's needs and grief expressions. Therefore, it seems logical to provide information about how children grieve at different stages in childhood.

Although DGD is replete with references to how children tend to experience grief as they grow older, problems arise when these developmental conceptions of grief are applied too rigidly, much like stage theories of grief. It is widely-accepted throughout the literature that a "one-size fits all" approach to grief is ineffective (Kühne et al, 2012; Jordan & Neimeyer, 2003), which suggests that taking a similar stance in regards to children's development would be equally unwarranted. If Himebauch's (2008) age categories are used as a barometer, then we might assume that a 3 year old and a 6 year old will have the same understanding of death. How can we even assume that two 6 year olds will understand death in the same way? Corr (1998) explains that the central point undergirding developmental perspectives is that humans face more or less predictable tasks during their lifetime. However, these cannot always be applied uniformly or universally and they cannot be rigidly applied to chronological ages, as is usually the case within DGD.

Corr (2010) is particularly vocal about how developmental stage theories are used to interpret children's grief. He argues that these theories are often applied uncritically, ignoring the clear differences between individual children. A child experiencing multiple traumatic and violent deaths should not be expected to experience grief in the same way as a child of the same age that has a parent die relatively peacefully in a hospice or on a palliative care ward. There may be some similarities, but it is unwise to ignore the differences between these two vastly different experiences. Corr reminds us that "children are not like elevators that jump from one level of understanding loss and death to another in some mysterious, mechanical fashion" (p. 28). In effect, developmental age categories oversimplify children's grief.

The oversimplification of children's grief may come as no surprise, considering that it took a long time for grief research to even recognize that children experience any sort of grief (Brayne, 2010; Hall, 2014; Rowling, 2002). Contemporary literature certainly recognizes the existence of children's grief, but analysis is often limited to the aforementioned age categories. I would argue that it is possible to make some observations about general themes that can be seen in children's grief. Nevertheless, I think drawing strict age boundaries around children's grief expressions is unhelpful because it creates misleading assumptions for HCPs, parents and other adults. Therefore, it is appropriate to make some general statements about children's grief, as long as they are not rigidly applied. Worden (2008) manages to provide balanced observations in a piece that reflects on the lessons learned during his influential 1996 Harvard Child Bereavement Study, which interviewed children between the ages of 6

and 17. For instance, he points out that attachment is important and many children have continuing bonds with parents after they die. In addition, he explains that most children will participate in a funeral when given the opportunity. While these observations may seem like further generalizations about children's grief experiences, using words like "most" or "many" is less prescriptive and more suitable to the range of reactions children *may* have to grief and loss.

In *Deconstructing Development Psychology*, Burman (2007) describes how societal understandings of children's development are "not separate from issues of language and power, but turns out to be inextricably intertwined with them" (p.221). Burman adopts a Foucauldian view of power, one that is relational, demonstrating how discourses determine what can or cannot be spoken and what actions are acceptable and unacceptable. Applied to childhood grieving, child development discourse helps determine what is considered "acceptable" grieving by expecting differently-aged children to behave in very specific ways. Burman reminds us that childhood development discourse is not static and children can and do access alternative positions within it. However, Burman argues that childhood development discourse applies a deficit model to children that ignores the structural context that creates this supposed "deficit". In other words, a 6 year old's deficit may be their inability (according to the development stages model) to see death as final and an 8 year old's deficit is an inability to see death as universal, and so on. Many of these children are framed as incompetent grievers, while the unequal power relations do not permit alternative forms of grief expressions. This points to the major shortcoming of the childhood developmental

stages model, namely that it applies one model to all children. Furthermore, Burman points out that the discursive language in the childhood development discourse is also mediated by race, gender and class. In other words, dominant childhood development psychology is rooted in an ontological position that is White, Western and male. Burman (2012) is not calling for the outright rejection of childhood development psychology and suggests that such an approach is unlikely to succeed anyway. Rather, we have to find what she calls “cracks or fissures within this hegemonic discourse” (p. 433). Hopefully I have contributed to the effort here by disturbing the tidy categories by which childhood grief has come to be understood. At the very least, a more flexible and nuanced interpretation of childhood grief is essential. I will try to find more “cracks and fissures” in DGD as I move into a discussion on how grief is pathologized, normalized and disciplined.

**Normal and pathological grief and dominant grief discourse.** As previously mentioned, there are pervasive ideas within DGD regarding the “normal” length of time it should take for someone to grieve. In a study examining public attitudes towards normal and pathological grief, Penman et al. (2014) indicate that people still have clear expectations regarding the appropriate length of time to grieve, which usually ranges between a few months to two years. Foote and Frank (1999) argue that so-called normal grief reactions still exist, but more and more types of grief expressions are being pathologized. This is a formidable trend, even though Freud argued decades ago that grief should not be pathologized or interfered with (1984, as cited in Foote and Frank, 1999). Today, there are numerous forms of what could be understood as pathological

grief: complicated grief, unresolved grief, chronic grief, delayed grief, exaggerated grief, disenfranchised grief, prolonged grief, compounded grief and absent grief (Connor, 2009; Doka, 2002).

It quickly becomes evident when reading the literature that there are social norms governing the expression of grief. Brabant (2002) describes these as “the ‘shoulds’ and ‘should nots’ that govern any interaction” (p. 32). The norms act as guidelines for appropriate and socially-sanctioned ways of behaving, thinking and feeling. Therefore, grieving norms are culturally situated and influenced by a number of factors, including race, gender and class which I previously discussed. As grievers, a child or any person can conform to these norms or violate them. When a person violates grieving norms, their behaviour is disciplined, which may cause them to conform or offer more resistance. I will discuss the disciplining of grief in greater length later in this chapter. Suffice to say that if someone is grieving in a way that is generally perceived to be non-normative, their reaction is pathologized and subjected to discipline and correction.

There are researchers who have resisted pathologizing children’s grief. For example, Christ and Christ (2006) argue that child grief alone does not cause psychopathology, but could be exacerbated by adverse childhood experiences. In promoting their theory of resilience, Bonanno et al. (2002) have led the charge against the pathologizing of so-called “absent” grief, where grief is projected onto children (or adults) who may in fact be coping quite well. However, there is still a strong tendency to

pathologize and HCPs play a critical role in determining what is normal and what is not and this has significant ramifications for children, their families and my research.

The inclination to pathologize grief was evident in my literature review. Therese Rando (1993), another influential grief researcher, suggests that a significant proportion of people experience bereavement complications. She posits that a conservative estimate may be 6 million cases of complicated grief per year within the United States alone. Draper and Hancock (2011) propose that children who experience the death of a parent are far more likely to develop what they call “delinquent behaviour” (p. 303). Draper and Hancock call on HCPs to develop interventions that reduce children’s vulnerability to “delinquency”, which can have the effect of disciplining children’s behaviour when they are grieving so that they conform to socially acceptable norms. In an article on pathological grief written by Papa et al. (2013), the prevalence of pathological grief is taken as a self-evident truth and HCPs are encouraged to help people who are grieving develop “behavioral repertoires” which are intended to create “self-efficacy and a stable sense of self” (p. 920). The emphasis on encouraging appropriate behaviours so that individuals can self-regulate their grief is clearly a critical component of DGD. Papa et al. also outline the behaviours that most often characterize pathological grief: “disengagement, rumination, and avoidance” (p. 931). These behaviours capture everyone from those who are ruminating or perseverating on their loss to those who are avoiding and disengaging. As grievers, we are told that we should pay attention to our loss, but not too much if we wish to grieve in a “normal” way.

Although grieving norms and pathological grief are generally presented as self-evident truths, it is worth noting how conceptions of pathological grief can change and evolve. Consider the DGD position on continuing bonds with the deceased. Neimeyer et al. (2014) describe how in the early 20<sup>th</sup> century, there were elaborate mourning customs that were designed to sustain an attachment between the living and the dead. This changed with the emergence of Freud, as the goal of grief interventions evolved into helping the individual sever their bond with their dead family member, so they could “move on” (as cited in Neimeyer et al., 2014). Today, the emphasis on continuing meaningful bonds has re-emerged in DGD.

This treatment of continuing bonds demonstrates that what is normal and what is pathological is subject to change, as is dominant discourse in general. Crucially, these changes are not some sort of natural evolution, as it is often implied. The demarcation of normal or pathological is continually being negotiated through a complex array of power relations and discursive forces and it is transmitted and policed by those in positions of privilege, specifically HCPs. As the borders of normalcy and pathology are adapted or tweaked, the changes are often framed within DGD as “professional judgements” that are made in the “best interest of the public” and in accordance with “best practices”. This obfuscates how HCP privilege and race, gender and class help determine the relationship between normal and pathological. For instance, consider how White HCPs can dictate what is normal and what is not, because “the ideology of whiteness is characterized by its unmarked, universal ‘*normal*’ qualities” (Jeffery, 2005, p. 411, emphasis added). Jeffery (2005) defines whiteness as “a phenomenon of being

unmarked yet racially dominant” (p. 411). White HCPs are able to use this unmarked positionality to determine what normal grief is because whiteness is linked to notions of neutrality and altruism. Below, I expand on the ways HCPs police the differences between normal and pathological grief.

Given their privileged position, HCPs play a pivotal role in defining pathological grief. Lowe (2011) questions the willingness of HCPs to challenge dominant systems that maintain their professional privileges and the oppressive power relations that are rooted in race, gender and class hierarchies. Lowe argues that HCPs generally opt to use “discourses of control, authority, objectivity and non-investment” (p. 188), resulting in a failure to account for the ways HCPs are complicit in oppressive practices. These practices are ones that punish individuals and groups that deviate from the dominant White, male, able-bodied and middle-class norms. Lowe concludes that health care education tends to deny difference and ignore social justice issues. Here we see how HCPs are indoctrinated by DGD through their education and then this is used as a Foucauldian technology of power to regulate the grieving behaviours of the public.

Although my primary focus is how power and knowledge circulate within DGD to produce particular kinds of subjects, it is worth noting that DGD has far-reaching material effects beyond the regulation of individual grieving behaviours. My earlier discussion on resilience discourse provides a good example of these material effects. Specifically, the emphasis on personal resiliency within DGD can make it politically expedient to provide fewer material resources and supports because the “fault” for grief

is situated within the individual. This approach pathologizes grief and keeps the attention squarely on individuals and not on structural inequities.

One such way that ideas about pathology become ingrained is through the *Diagnostic and Statistical Manual (DSM) of Mental Disorders*, which is often considered an authority on psychiatric diagnosis (Hall, 2014). There was considerable debate regarding the inclusion of prolonged grief disorder (PGD) in the fifth edition of the DSM, published in 2013 by the American Psychiatric Association. The symptoms of PGD usually include sleep disruption, substance abuse, depression and various other complications. This is expected to lead to impairment of the bereaved, who are left “yearning, longing, and pining” (McClatchey et al., 2014, p.69). Ultimately, PGD was not included in the DSM-V but the guide suggested that Persistent Complex Bereavement Disorder (PCBD) is a condition that deserves closer attention in future research. When arguments over the inclusion of complicated grief reactions in the DSM arise, the supporting argument usually hinges on the severe and debilitating effects of grief and how including it will legitimize it as an illness and therefore garner more resources for treatment and intervention. To me, there are distinct problems with using a psychiatric manual to legitimize grief. First, all grief reactions are legitimate, whether or not they fall into dominant grieving norms. Second, the diagnosis can serve to pathologize and stigmatize the bereaved person. Third, the identification of pathology can be used to further discipline the person’s grief reactions and encourage the individual to regulate their behaviour to align with socially sanctioned expectations. In short, “diagnoses (are) cultural productions that create and sustain relations of power” (White, 1993, as cited in

Foote & Frank, 1999, p. 178). In the context of my research, there is a risk that HCPs who are indoctrinated with dominant ideas about pathological grief may diagnose people who are grieving to sustain their favorable position in those relations of power.

I have already discussed how certain discourses, including ones pertaining to grief, come to be viewed as self-evident truths. Foote and Frank (1999) explain that these truths are a form of power because they achieve this “self-evident” status. For example, the “truth” that bereavement counselling is considered necessary for people diagnosed with complicated grief is also a form of power because it can be used to influence or coerce grieving individuals to receive counselling and change their behaviour accordingly. As Foote and Frank point out, Foucault was preoccupied with what he called “the effects of power and the production of truth” (1988a, p. 118, as cited in Foote & Frank, 1999, p. 160). Foote and Frank propose that bereavement counselling is “an effect of power and a means of perpetuating power” (p. 160). In other words, the “self-evident” role of bereavement counselling in addressing pathological grief emerges from powerful discourses and it is then used to sanction and regulate behaviour, while persuading individuals to self-discipline as well. So it is not that HCPs always have the power “over” people who are grieving, because people are conditioned to discipline their own grieving behaviour. The desire for people to feel “normal” in grief is strong, which motivates people to monitor their own grieving behaviours (MacPherson & Emeleus 2007b). Nevertheless, HCPs are situated right in the middle of this process, helping to exert subtle and overt pressure to grieve in ways deemed to be non-pathological. If people resist the expectation to grieve “normally”, HCPs can

exercise their privilege in a number of ways. They can recommend medications, order hospitalization or even suggest that child protection services be brought in because the child is not able to grieve “normally” in their home environment. This discussion on discipline brings me to a more detailed discussion on the disciplining and policing of grief.

### **Disciplining and Policing of Grief**

Although it is not extensive, there is some research that has made important contributions to our understanding of how grief is disciplined. In some cases, researchers have not explicitly used the term “discipline” in a Foucauldian sense, but their writing still describes how grief reactions are regulated and controlled. For instance, Penman et al. (2014) look at public perceptions about normal and pathological grief and note that bereaved people are apt to internalize grieving norms because failure to comply can result in judgment and exclusion. This clearly demonstrates that people experiencing grief are aware of their susceptibility to discipline. Doka and Martin (2002) and Hall (2014) analyze the concept of disenfranchised grief, which is usually attributed to grief that occurs from a loss that is not or cannot be openly acknowledged. If disenfranchised grief is publicly displayed, it may also be disciplined and policed. Anecdotally, I recently encountered someone through my work in bereavement support services that has experienced multiple threats and deaths to his family while living overseas in a war-affected country. When he speaks about his experiences, he is calm, collected, smiles a lot and uses humour occasionally. When asked how he manages to cope, he said he quickly figured out that people will push you away if you are sad and

depressed, so he forces himself to be upbeat and personable (personal communication, October 20, 2014). Failure to do so could result in negative judgment from others. In this way, this individual begins to regulate and discipline their own grieving behaviour.

Although this conversation is not in the “literature” per se, GT methodology advises that everything should be treated as data.

There is some research that explicitly addresses the notion of disciplining grief. Neimeyer et al. (2014) are clear in their statement that “society polices bereavement” (p. 493). Neimeyer et al. argue that grief is policed in a number of ways, but most clearly in how the emotional aspects of grief are expressed and how continuing bonds with the deceased are managed. Foote and Frank (1999) are equally explicit about the way grief is disciplined. I find their critique to be particularly strong as they draw on Foucault’s concept of “governmentality”. Governmentality describes the ways individuals are disciplined and controlled by external and internal processes. There is a multitude of organized practices, institutions and discourses that help produce a particular kind of individual, or “griever” in this specific case. People who are grieving are not merely the targets of top-down power, but also act in self-disciplining ways. Foote and Frank argue that this is accomplished through therapeutic practices called normalization, medicalization, individualization and totalization. Normalization works to set up clear boundaries between normal and abnormal grief. Medicalization presents grief as an illness requiring a bereaved person to seek assistance and “recover”. Individualization speaks to how grief has been transformed into an intra-psychic process, rather than a social one, a view shared by Neimeyer et al. (2014). Totalization speaks to the

universalizing of pathological grief. As the definition of normal grief narrows, everyone “becomes a candidate for a therapeutic technology of the self” (Foote & Frank, p. 167).

**Grief work.** As grief is disciplined, it means that bereaved people are expected to adopt specific roles and complete certain tasks. I have already mentioned Worden’s (1996) task-based model for grieving children. The focus on tasks means that grief has come to be understood as something that necessitates work and labour. The concept of “grief work” is widespread in the literature and sets up clear expectations of what people are expected to accomplish while grieving, because it is their duty to society. O’Rourke (2010) writes that we are conditioned to plough ahead when we experience loss by throwing ourselves into our work, or “grief work”. If we carefully follow the socially acceptable path laid out for us, we should be able to pass through the “stages of grief” and return to “normal” functioning within a few months, a year at the most. Foote and Frank (1999) also identify grief work as a tool that is used to discipline people who are grieving. Although a bereaved person may be entitled to bereavement leave from their paying job, they still have obligations to accomplish grief work as efficiently as possible so they can return to their “real” work. Furthermore, dominant discourse requires bereaved people to outwardly express their grief. Failure to do so can be seen as a violation of grief work obligations, even if the individual prefers to process grief internally. The person may feel guilty or abnormal for not crying, since crying is often deemed to be the appropriate reaction.

MacPherson and Emeleus (2007b) found that children need to occasionally escape the stressful requirements of grief work tasks. This involves spending time away

from their dying parent and perhaps their siblings and peers. An escape might also involve some sort of physical activity or emotional release. I would argue that this “escape” can become part of the grief work that is expected of children. If children do not seek an escape, then perhaps their reaction will be deemed abnormal and in need of correction. The disciplining of grief requires the child to behave in very circumscribed ways.

**Resistance to the disciplining of grief.** Clearly, the disciplining and pathologizing of grief are formidable forces within DGD. Yet, Foucault was adamant about the opportunities for resistance within disciplinary discourses and governmentality. Foucault explains that “as soon as there is a power relation, there is a possibility of resistance” (Foucault, 1988a, p. 123, as cited in Foote & Frank, 1999, p. 172). Foote and Frank (1999) offer a number of possibilities for resistance within DGD. They describe how grief reactions can be reconstituted as form of resistance, rather than an expression of pathology. They posit that so-called “complicated mourning” can be one such form of resistance. To illustrate this, consider how “complicated grievers” use their bodies and emotional expressions to disrupt normal expectations. To actively and consciously resist involves trying to redefine “aberrant behaviours” as acceptable and normal.

White (1993, as cited in Foote and Frank, 1999) encourages people to use the dominant discourse to formulate their own personal grief narratives. Resistance requires a deliberate avoidance of the dominant discourse and a commitment to finding a new narrative. This narrative requires us to understand pathology as something that is

imposed externally, not something arising from the internal psyche of the bereaved individual. The dominant discourse can be further resisted by a refusal to discipline ourselves in a way that makes grief predictable and controllable. Accepting the chaotic elements of grief keeps us from assimilating our experiences into the dominant discourse. Foucault felt that his role was “to show people that they are much freer than they feel” (1988d, as cited in Foote & Frank, 1999, p. 184). It is possible to find different ways to grieve, ones that do not subject us to external discipline and cause us to carefully self-regulate our own grief. However, the ideas surrounding normal and pathological grief are very pervasive, as are the more subtle ways grief is disciplined and policed.

### **The Self and Meaning-Making in a Neoliberal Environment**

Although I have already written about self-disciplining and self-regulating behaviour, the concept of “self” deserves some more attention. Our “self” helps determine how we grieve and how we make meaning in our lives. Bonanno et al. (2002) note that “it is now widely accepted that the self is not a stable, unitary entity, but rather a multifaceted, flexible collection of experienced, anticipated and remembered selves” (p. 196). We do not have a singular or essential self within this postmodern perspective.

Neimeyer et al. (2014) incorporate this fluid sense of self into their social constructionist model of grief. They see grief as a situated activity that is constructed through an intricate interplay of personal and public narratives. These narratives help us construct meaning, personally and collectively. In this way, we develop a social identity

when we are grieving. Social construction involves the accumulation of individual and collective experiences, which form an established set of agreed understandings that become the way we see the world around us (Berger & Luckmann, 1971, as cited in Payne, 2006).

Neimeyer et al. (2014) have made an important contribution to grief research with their social constructionist account. They argue that even though everyone experiences grief, our grief experiences are “personally narrated, socially shared, and expressed in compliance with or contradiction to widely varying communal rules” (p. 486). Once again, we see how social grieving rules influence grief experiences and how there are possibilities to contest and resist those rules. HCPs are linchpins in this social construction of grief and can play a monumental role in either enforcing or resisting grieving rules and discourses. However, it is important to be particularly careful with this meaning-making discourse when working with children and families. It could be rather hazardous for an HCP to talk to a child with a dying parent about finding new meaning in grief. In the face of parental loss, talking about potential benefits and ways to find new meaning may seem rather callous and misguided.

Payne (2006) offers a useful perspective on the construction of self in the context of interdisciplinary teams. In particular, he looks at how palliative care social workers develop professional identities. He argues that professional identity is developed largely through interactions with interdisciplinary teams. From a social constructionist perspective, we can only construct identity and give meaning to our role

through relationships. The identity and role of social workers features prominently in my data analysis.

Neimeyer et al. (2014) note that despite the interactive meaning-making process involved in grief, public discourse still puts an incredibly strong emphasis on “radical individualism and contemporary capitalist consumer culture” (p. 493). Cipolletta and Oprandi (2014) discovered that HCPs are commonly pressured to find so-called “efficiencies” in their work resulting in a failure to treat dying patients and their families as actual people who need support and attention. Takei et al. (2014) identify a lack of resources, funding and organizational understanding as major obstacles for HCPs who want to provide support to these children. Turner et al. (2007) elucidate an array of similar systemic challenges, including time pressures due to staff shortages and limited access to specialist services. The strain is evident as resources are stretched thinner and HCPs are asked to do more with less.

### **Summary**

I began this literature review by discussing its general purpose and the steps involved. I have also justified why I conducted a review within GT, which is sometimes discouraged by proponents of the methodology. I have provided a review and critique of stage theories and their implications for my research. This was expanded into a broader discussion on various elements related to DGD. Although there are numerous research studies related to children’s grief, there is limited information on the interactions between HCPs and children who have a parent in palliative care. My research is intended to help fill this gap in the literature.

### **Chapter 3: Methodology**

Before I can discuss my research design, there are two important matters that I must attend to. First, I will briefly examine the field of qualitative research as a whole. Second, I will provide some general observations about GT, situating it within the broader field of qualitative research. I also discuss the various approaches within GT and where I situate myself on this continuum. It is worth noting that GT can be used in qualitative and quantitative research (Grounded Theory Institute, 2011). However, it is more frequently used in a qualitative manner, as I did in my research.

#### **The Field of Qualitative Research**

In the introduction to their comprehensive handbook on qualitative research, Denzin and Lincoln (2005) discuss the vast array of concepts, paradigms and methodologies associated with this form of inquiry. While addressing every aspect of qualitative research is outside the scope of my research, Denzin and Lincoln make some general statements that help illustrate what qualitative research entails. First, qualitative research uses an interpretive and naturalistic approach. This means that the researcher tries to interpret whatever is being studied within its natural environment, rather than trying to create a controlled environment to study an object or issue in isolation (Esterberg, 2002).

Second, Denzin and Lincoln note that “qualitative research is a situated activity that locates the observer in the world” (p. 3). The researcher is always a part of the environment where inquiry takes place, rather than occupying a distant and neutral position. Denzin and Lincoln refer to this as “the value-laden nature of inquiry” (p. 10).

This stands in stark contrast to quantitative studies that claim to measure causal relationships between variables without allowing the observer's values to influence the results. I consider these claims of objectivity to be highly suspect and I do not think it is possible to "scrub out" the researcher's influence.

Third, Denzin and Lincoln (2005) suggest that contemporary qualitative research includes a critique of postpositivism. To understand what this means, we must first analyze the historically significant role that positivism has played in the development of qualitative and quantitative research. As I discussed in the literature review, positivism forwards the idea that there are objective and foundational truths that can be rationally and systematically hypothesized, tested and replicated, allowing us to establish a "true" understanding of reality (Guba & Lincoln, 2005). Denzin and Lincoln argue that positivism dominated the field of qualitative research throughout the first half of the twentieth century and continues to have a major influence today. Postpositivism still strives for objectivity, but alters positivist claims by suggesting that reality can never be fully captured, yet it can be closely approximated through careful observation and testing (Patton, 2002).

The contemporary critique of postpositivism that Denzin and Lincoln (2005) refer to is fuelled by increasing acceptance of postmodern and poststructural approaches within qualitative research. These approaches highlight the socially constructed nature of reality, refuting the positivist claim of a stable and discoverable truth. Postmodernist researchers like me are concerned with the positivist tendency to advance a restricted notion of "truth", essentially silencing alternative voices and perspectives. Charmaz

(1990, 2008), who is credited with developing a social constructionist approach to GT, argues that this act of silencing is evident in the way qualitative research has long been marginalized by the dominant quantitative paradigm.

Although the marginal status of qualitative research has decreased as it continues to gain wider acceptance, conducting qualitative research from the margins allows for unique perspectives that would otherwise be inaccessible. Charmaz argues that “marginalized qualitative researchers can find another way of seeing, of gaining a deeper view” (2008, p. 15). This ability to see the world in a different and deeper way is shared by marginalized groups as well. In writing about racialized discourses, Ladson-Billings (2000) corroborates this “perspective advantage” (p. 262), because the view from the margins provides insight on marginal and dominant standpoints. Furthermore, Strega (2005) notes that “the ‘view from the bottom’ is fuller and often more accurate” (p. 224). I do not mean to suggest that the experiences of marginalized groups are somehow comparable to mine as a qualitative researcher, because I do not occupy a marginalized social location and I would argue that the stakes are much higher when discussing issues of oppression. Nevertheless, I believe the comparison helps demonstrate that qualitative research, when used within a postmodern paradigm that rejects positivism, creates opportunities for the researcher to explore different points of view and gather rich descriptions of people’s lives.

Finally, Denzin and Lincoln (2005) suggest that a qualitative researcher acts as a “*bricoleur*” (p. 4, original emphasis), someone who uses multiple strategies to piece together a representation of a complex situation. The point is that qualitative research

requires responsiveness and adaptability, rather than rigidity. This flexibility also means that there is no single methodology that exemplifies qualitative research. Therefore, it is not enough to simply describe a research project as qualitative, because such a description does not answer key methodological questions. I will now try to answer some of those questions by turning to a more specific discussion about my chosen methodology.

### **Research Methodology - Grounded Theory**

GT is a common qualitative methodology, yet there are a number of distinct versions (Gibbs, 2010d; Saldana, 2011). Therefore, it is important that I situate my own use of GT. Before doing so, there are some general observations I will make about GT. Introduced by Barney Glaser and Anselm Strauss (1967), GT emerged as a postpositivist response to the dominance of positivism and quantitative methodologies in sociology, in the hopes of setting up a series of systematic guidelines for generating useful theories “grounded” in the data (Dunne, 2011). Since its inception, GT has come to occupy a prominent place within the wider field of qualitative research, due to its popularity and widespread acceptance. There are many possible explanations for why GT became so popular. After Glaser and Strauss introduced GT, it garnered a cachet amongst qualitative researchers who were seeking a methodology that would be accepted in a positivist environment. Charmaz and Bryant (2007) suggest the GT’s popularity has only continued to grow over the last two decades as social constructionist and postmodern iterations of GT have gained a foothold. Alvesson and Skoldberg (2000, as cited in Olesen, 2007) propose that GT is seen as a feasible methodology and its accessibility

helped to popularize it. Unsurprisingly, the diversity of approaches has generated debate over what qualifies as GT and how it can be misapplied. Nevertheless, its continued growth suggests that the methodology is vibrant and very relevant in the contemporary research world.

When using GT, the researcher collects and analyzes data at the same time. This process of constantly comparing data and ideas is called the constant comparative method (Grounded Theory Institute, 2011). The purpose is to analyze and compare data to develop a new theoretical explanation about the topic being studied. In other words, GT does not rely on existing theoretical frameworks, but aims to identify the core and supplementary processes operating within a given social situation (Dunne, 2011; Gibbs, 2010d; Grounded Theory Institute, 2011; S. Strega, personal communication, February 24, 2014). Although interviews are commonly used for data collection within GT, the researcher can use multiple methods and data sources. Everything is considered data within GT (Glaser, 2012; Saldana, 2011; S. Strega, personal communication, February 24, 2014).

GT is usually described as an inductive methodology, but I believe it is better understood as an abductive approach. Induction implies that a GT researcher collects and analyzes data and uses this information to formulate a new theory. Missing from this process is recognition of the researcher's preconceptions and values. Dey (1993, as cited in Thornberg, 2012) argues that treating the researcher as a blank slate is ill-advised. Dey suggests that "it is better to make ideas and values explicit rather than leaving them implicit and pretending that they are not there" (p.246). Alternatively,

abduction involves creating a theory that explains a particular section of data better than other potential hypotheses (Douven, 2011, as cited in Thornberg, 2012). The concept of abduction was introduced by Charles S. Peirce (1992, as cited in Oliver, 2011), and it is a creative process requiring the researcher to use new data to modify and elaborate on existing ideas. Thornberg (2012) highlights three principles connected to abduction which I adopted throughout the thesis process: theoretical agnosticism, theoretical pluralism and theoretical playfulness. The first, developed by Henwood and Pidgeon (2003, as cited in Thornberg, 2012), requires researchers to be critical of existing theories and research. The second principle asks the researcher to entertain different possibilities and explanations (Dey, 1993, as cited in Thornberg, 2012). Finally, theoretical playfulness invites the researcher to innovate and be creative in their work (Charmaz, 2006). Kelle (1995, as cited in Thornberg, 2012) explains that abduction requires the researcher to use their previous knowledge, reject established “truths” and develop an open mind. Abduction never considers an emerging theory to be true or confirmed, but a site for further analysis. This coalesces with my own postmodern orientation, since abduction rejects the idea of “pure” and foundational truths that can be determined inductively. Abduction allows me to maintain my antifoundationalist beliefs and reject positivist claims of a discoverable and objective reality.

**Rationale for using GT.** On a purely topical level, GT appears well-suited for a study related to palliative care. Glaser and Strauss (1967) originally used the methodology to study illness and dying. Charmaz (1990) used GT to study chronic illness. For her University of Victoria Master of Social Work thesis, Wong (2007) used GT

to study the hope processes of care providers caring for cancer patients. There are many other examples of GT being used to research topics related to death and dying (*cf.* Charmaz, 1990; Charmaz, 2002; Glaser & Strauss, 1965; Strauss & Glaser, 1975). This is a notable trend, which suggests that GT might offer something unique to research related to palliative care. Charmaz provides some insight on this, suggesting that GT analyzes a variety of complex themes, which enables further exploration into how ill people, their care providers and other affected parties are impacted by palliative care. Of course, there are countless research studies on palliative care employing different methodologies (MacConville, 2009). Although it is promising to see GT used for studies in the same field where I focused my research, this alone does not provide a sufficient rationale. Just because it has been done before does not mean it was the only methodology I could have used for this particular topic.

Before deciding on GT, I seriously considered using a thematic analysis (TA) approach rooted in a constructionist paradigm. Perhaps explaining my decision to not use TA will help explain how GT was a good fit for my research. Virginia Braun and Victoria Clarke (2006) provide a concise overview of TA, describing it as a flexible method that can be used as a methodological approach to research if it is grounded within a clear paradigm. The goal of TA is to search for themes and patterns across a data set, which can provide insight, inform policy development and help the researcher make an argument in relation to the research question. Braun and Clarke point out that research claiming to be GT often fails to produce theory, resulting in what they call “grounded theory ‘lite’” (p. 81). In other words, GT must be geared towards theory

development, rather than simply coding the data for themes. Glaser (2012) agrees, arguing the entire realm of constructionist GT is more akin to general qualitative data analysis, producing merely descriptive accounts of research participant stories. Perhaps unsurprisingly, I would quibble with Glaser's sweeping dismissal of constructionist GT, but I do see these criticisms as a useful caution. It is important to conceptualize and analyze emergent processes in the data. Adele Clarke (2003) instructs GT researchers to focus on "provisional grounded theorizing rather than the development of substantive and formal theories as the ultimate goals" (p. 559, original emphasis). Constructionist and postmodern GT still try to generate useful theoretical ideas, much like traditional GT. The difference is that the former brings a more open-ended approach to research, recognizing that we can never fully capture the complexities that operate within the area of inquiry. This acknowledgement of complexity makes constructionist GT an appropriate methodology for my research project.

**Rationale for constructionist language.** A rationale for using constructionist GT also requires an explanation for why I am using the term "constructionist" rather than "constructivist". Although these terms are similar and often used interchangeably by postmodern GT researchers, this seems careless and hypocritical within a paradigm that advises us to pay attention to how "we word the world" (St. Pierre, 2000, p. 483). Steve Gentles (personal communication, October 14, 2014) points out that the terms "constructivism" and "constructionism" are used across a multitude of academic fields and different definitions and versions of the terms are not necessarily transferrable. I began this chapter by explaining why it is insufficient to simply describe research as

qualitative without elucidating the specific methodological approach that undergirds the work. By the same token, it is unhelpful to simply apply the label “constructivist” or “constructionist” to a methodology and hope that readers understand what you mean. In order to give this issue the attention it is due, I must first provide a brief summary of how the two terms evolved. Within general qualitative research methodology, Guba and Lincoln began alluding to constructivism as early as 1981 but it was still being referred to as “naturalistic inquiry”. In 1989, Guba and Lincoln refer to “constructivism” and “constructivist” for the first time (S. Gentles, personal communication, October 14, 2014). Charmaz (2004) was the first researcher to explicitly refer to her work as constructivist GT. Charmaz argues that data, including codes, categories and the resulting analysis emerge from a researcher’s interactions with the field and participants. In other words, “the researcher composes the story” (p. 271); they interpret the participant’s reality, but do not capture it.

Conversely, the concept of “constructionism” is usually credited to Berger and Luckmann’s *The Social Construction of Reality* (1966). Within the constructionist framework, there is a stronger emphasis on social interaction and the co-construction of data through shared experiences. Berger and Luckmann refer to how social constructionism stresses the “processes of being, knowing, meaning and experience, and the ways in which these are storied, within the social processes of self-making, relationship, culture and context” (Berger & Luckmann, 1966, as cited in Brown, 2008, p. 71).

With the background information I just outlined, I can now circle back to my initial concern, namely why I am using “constructionist” rather than “constructivist”. I agree with Brown and Scott (2006, as cited in Brown, 2008) that “constructivism runs the risk of perpetuating a conservative focus, as it relies on the individualized, internal processes of meaning-making within one person’s mind, suggesting the basis of the self as an autonomous subject” (p. 71). This emphasis on individual and internal processes is common in psychology and Charmaz (2006) claims her understanding of constructivism is influenced by psychological researchers like Vygotsky (1962). This influence could explain the prominence of “individualized and internal processes of meaning-making” in constructivist GT.

On the other hand, constructionism highlights the *social* processes of meaning-making that construct and create our shared experiences and interactions (Brown, 2008). While constructionism does not discount our thoughts and internal processes outright, it illustrates how they are socially constructed. Adele Clarke (2005) notes that social constructionism is not merely concerned with “the ephemeral or ideological or symbolic” (p. 7). Rather, social constructionism is concerned with the material world, which is itself constructed. In other words, we must account for the material world and its processes in our interpretations and analyses. Clarke calls this “a materialist constructionism” (p.7). From this vantage point, it becomes clear to me that constructionism is my preferred term, because constructivism tends to focus mainly on internal processes rather than social ones.

**Different versions of GT.** Graham Gibbs (2010a) notes that GT is by far the most common methodology within qualitative research. There is disagreement regarding exactly how common it is, since the multiple approaches to the methodology lead to disagreement over what actually constitutes GT and how often it is done properly (Braun & Clarke, 2006; Glaser, 2012). Following a similar trajectory to the one taken by the entire field of qualitative research which I previously discussed, GT has evolved from its positivist and postpositivist roots and increasingly takes on social constructionist and postmodern forms.

Kathy Charmaz (1990, 2006; Puddephatt & Charmaz, 2006) has helped take GT in a decidedly different direction with her social constructionist approach. She positions constructionist GT as a middle ground between positivism and postmodernism. Constructionist GT refutes the idea that data and theories are objectively determined and instead proposes that they are constructed through the researcher's interactions in the field (Thornberg, 2012). While still employing the constant comparative method, Charmaz's social constructionist approach recognizes the significant role a researcher plays in collecting and analyzing data and how the emergent theory helps construct just one interpretation of reality. This highlights the importance of locating myself within the research, because actions, values and standpoint impact the results. In Charmaz's words, "outcomes result from social interactions, negotiations and power" (1990, p. 1161). She draws a useful comparison to Foucault, who argues that discursive practices and power relations influence social conditions (1973, as cited in Charmaz, 1990). This approach to GT views "positivist givens as social constructions to question and alter"

(Charmaz, 2005, p. 509). For example, Charmaz (in Puddephatt & Charmaz, 2006) critiques the idea that there is always a single core process operating within the data. She notes that there may be many processes and trying to find only one can persuade the researcher to force the data into a singular process. She takes the critique even further, suggesting that the Glaserian model is particularly prone to forcing the data. She argues that since traditional GT does not sufficiently account for the researcher's standpoint, this purportedly objectivist form of GT allows researchers to ignore alternative perspectives and interpretations. Glaser (2012) would contest this claim, arguing that his version of GT accounts for the researcher's standpoint by including it as another variable to be analyzed in constant comparative analysis. I agree with Charmaz on this matter, who argues that the researcher's standpoint is more than just another variable that must be "neutralized" in the constant comparative method. Rather, our standpoint influences everything we see.

Following Charmaz (1990, 2005), different iterations of GT have become increasingly critical of positivist approaches to research. Although my use of GT is greatly influenced by Charmaz's constructionist innovations, my own theoretical orientation aligns most closely with the work of Adele Clarke (2003, 2005, 2009). Clarke and Charmaz agree on a number of issues, particularly the need for GT to shift away from positivist underpinnings towards constructionist epistemologies. Both researchers seek to "use grounded theory methods as flexible, heuristic strategies" (Charmaz, 2000, as cited in Clarke, 2003). Moreover, they tout the importance of GT's pragmatist and social interactionist roots in their respective works. To briefly explain, pragmatism is a

tradition that emerged out of the Chicago school of sociology, which emphasizes human agency and the influence that subjective meanings, language and relationships have on human action and social processes (Charmaz, 2005). As Charmaz notes, social interactionism grew out of the pragmatist tradition and reinforced the idea that human behaviour is influenced by our interpretations of social interactions. It is easy to see the influence these theories have had on constructionist GT, considering the emphasis on social processes, subjective meanings, interpretations and context. Charmaz is particularly vocal about the need for GT to stay close to its pragmatist roots. Clarke, on the other hand, recognizes the pragmatist origins of GT but also occupies herself with bringing GT around what she calls the “postmodern turn” (2003, p. 553). She is referring to the shift away from modernism and its emphasis on universality, rationality, stability and positivist science in favour of complexity, partiality, positionality and situatedness that characterize postmodernism. Clarke notes that constructionist GT has long had some postmodern elements, with its focus on partiality and situatedness, but she sees more potential in this regard. In particular, Clarke is concerned that many GT studies do not fully take the *situation* into account. In other words, Clarke wants GT researchers to make the *situation* a unit of analysis and give more serious consideration to geographical, temporal and other nonhuman aspects of the research (Mathar, 2008). According to Clarke, failing to take the situation into account “reeks of unacknowledged imperialism” (2005, p. 299). It is this emphasis on postmodernism that leads me to more closely align myself with Clarke, along with her useful strategies for using GT in a postmodern way. I will now describe her strategies and how I used them in more detail.

## Situational Analyses and Maps

Clarke (2003) forwards what she calls “situational analyses” (p.553), which are intended to supplement GT techniques and help researchers apply GT to complex social situations. Situational analyses still draw on longstanding GT coding practices and sampling techniques, but also enlarge the scope of GT in order to address the messiness and complexity that characterizes postmodernism (Mathar, 2008). Moving far beyond the modernist idea of a single basic social process that guides traditional GT, Clarke’s situational analyses build on Strauss’ social worlds/arenas/negotiations framework to offer fresh analytical strategies to grounded theorists. According to Clarke, these strategies can help address many of the challenges facing postmodern research. These challenges include the political nature of interpretation, the importance of self-reflexivity, issues of power in the research process and the fraught process of representation in the research, sometimes referred to as the “crisis of representation” (p.555). Situational analysis has become “a post-modern *method* in a tradition that is better at critiquing and saying how *not* to conduct research” (Alvesson & Sköldbberg, 2009, as cited in den Outer, Handley & Price, 2013, p. 1516, original emphasis).

To briefly summarize, Clarke outlines (2005) three kinds of analytic maps to be used in situational analyses. First, situational maps include all elements related to the research situation and ask the researcher to analyze the complex relationships between them, including human and nonhuman factors. Second, social worlds/arenas maps describe the collective actors involved in the research situation, in order to provide a mesolevel interpretation of what is happening. The postmodern approach means that

the boundaries and negotiations between these collective actors are unpredictable, and there are always possibilities for change. The term “mesolevel” traditionally refers to the group or community level and it is usually juxtaposed against “microlevel” (work with individuals) and “macrolevel” (system-wide) approaches (Hick, 2010). In this case, Clarke uses the term “mesolevel” as a postmodern analytical framework to explain how individuals are social beings that are continually creating discourses and being constituted by them. Through our actions, we become part of evolving social worlds and arenas, and social world/arena maps aim to illustrate this phenomenon. Third, positional maps describe the range of positions available on particular issues and examine what positions are taken and not taken by various actors in the research situation. It is possible for multiple positions to be taken, reflecting the complexity inherent in postmodern thought. Clarke uses the concept of mapping because she considers it to be a tool that disrupts normal ways of thinking and helps us see things in a different context. Maps are also helpful tools for doing relational analyses, which is important in the coding process that I will discuss later this chapter.

Situational analysis provided some useful tools for my own research project. Please note that I do not intend to oversimplify Clarke’s (2005) situational analysis model, since it is intended to be used for the exact opposite; that is, addressing the complexity and possibilities found in a given research situation. However, it is useful and necessary to describe exactly how Clarke influenced my work. Specifically, I focused my efforts by using the first analytic map listed above, the situational map. Clarke highlights situational maps as “excellent research design tools” (2009, p. 211). Since my research

focuses on the interactions between HCPs and children, my analysis benefited most from focusing on the complex relationships at play and a situational map helped me do that. A situational map helped me analyze nonhuman and discursive elements involved in the research situation, allowing me to move beyond an overly simplistic binary of HCP-child. Situational maps are the first step in a situational analysis and Clarke (2009) invites GT researchers to sample from her model as needed. In light of this, I did not feel that social worlds/arenas maps and positional maps could be incorporated within the scope of this thesis. Logistically, it would have been challenging to access different social environments to create a social world/arena map. It would also have been difficult to gather multiple points of view from various stakeholders such as children and family members, which would be necessary to create a positional map.

Situational maps, as the name suggests, operate on the postmodern assumption that “everything is situated” (Clarke, 2003, p. 571). They allow the GT researcher to look for common elements in a research situation and hold themselves open to complexities without having to force the data into a basic social process. The commitment to postmodern possibilities is clear, as Clarke calls on researchers to strive for provisional theories that reflect the complexities of postmodernism. In this formulation, theories maintain their theoretical nature, rather than becoming an “accepted” theory that acts more like a truth claim. The critique of this postmodern outlook appears rather straightforward: if you cannot say anything definitive, then how can you say anything of consequence? To counter this, I would argue that situational analyses do not foster an “anything goes” approach that is symptomatic of complete relativism (Denzin & Lincoln,

2005). Rather, situational analyses recognize the very real material consequences that emerge within a given research situation and how complex interactions cannot be easily explained away by a universally unifying theory. In this design, truths are only partial, always dependent on context and perspective. The situational map is a tool that aligns with my own theoretical orientation and improved my ability to use GT in a way that accommodated the possibilities and complexities of postmodern thought.

### **Research Design**

The constant comparative method is a way to facilitate the emergence of theoretical ideas (Gibbs, 2010b). As emergent theoretical ideas began to take shape in my interviews, this informed the sampling process. This is called theoretical sampling, where new data sources are selected in the hopes that they can help inform the emerging analysis (Clarke, 2003; Gibbs, 2010c). Clarke is emphatic that theoretical sampling has always been crucial to GT, and this has not changed with situational analyses. Although I describe my research design and data analysis methods separately, please keep in mind that the data collection and analysis began at the same time.

To collect data, I conducted five interviews with adult palliative care providers. Over the next few pages, I will explain my rationale for conducting interviews and the number of interviews I conducted. Before covering the specifics of what the interviews entailed, I have some reflections on the interview method itself. As Fontana and Frey (2005) demonstrate, interviewing is used extensively in diverse domains, including academics, marketing, politics and media. In this sense, we live in an “interview society” (Atkinson & Silverman, 1997, as cited in Fontana & Frey, 2005). However, interviews can

be used in very different ways. Within a positivist framework, interviewing is often considered to be a neutral tool that is used to objectively gather data. Fontana and Frey argue that all too often, researchers and the general population assume there is an inherent truth in interview responses that provide a fully accurate description of what is occurring. This belief in an inherent truth is positivist and problematic. I prefer to follow Fontana and Frey's advice to pay attention to the political potential of the interview. Just like other sources of data, interviews are filtered through the standpoints of the interviewer, participant(s) and other related elements. The interview is a collaborative and active process, because the interviewer and participant (and perhaps others, depending on the context) create a story through their interactions (Fontana & Frey, 2005). Therefore, I must pay attention to not only what each interview accomplished, but how it was created and conducted (Holstein & Gubrium, 1995, as cited in Fontana & Frey, 2005). One way I did this was by refusing to "write myself out" of the interview, so that my influence and standpoint are clear. Ultimately, I was the one transcribing the interviews and doing the analysis, so I could not pretend to occupy a neutral role or attempt to position myself as merely a friend of the participant. Additionally, I had to pay close attention to those voices that were absent in the interviews, namely children and their family members who are receiving palliative care. Atkinson and Silverman (1997, as cited in Fontana & Frey, 2005) warn researchers like myself to avoid privileging specific ways of seeing the world, including those of privileged interview respondents. Although the voices of HCPs will feature prominently in my research, I could not afford to ignore other voices that are not explicitly present in the data. Therefore, my data

analysis frequently refers to children and families and their role in interactions with HCPs, even though I only interviewed HCPs.

Charmaz (2005) raises some concerns about the use of interviews in GT as well. She is concerned that relying on interviews can deflect attention away from context, suggesting that there is often too much emphasis placed on the present rather than past experiences. It is a thoughtful critique, as she suggests that interview data is generally collected at one point in time in one particular context. While conducting multiple interviews with the same participants was outside the scope of my thesis, Charmaz's critique is still worth paying attention to. As Fontana and Frey (2005) persuasively argue, the interview can be a tool for social justice if the interviewer gives up claims of neutrality and chooses to make their values and standpoint visible. This is what I tried to do, and it is what I consider to be the only ethical option.

**Semi-structured interviews.** I chose to conduct the interviews using a semi-structured model, which allowed for a more open exploration of ideas and opinions so the participant could take the discussion in different directions (Esterberg, 2002). I have included the questions for an interview guide in this chapter, but I did not follow it rigidly. The interview guide was useful when the conversation became too tangential, but I think the analysis benefitted from allowing the interview to go in unpredictable and insightful directions. An overly structured interview guide may have prevented participants from discussing critical pieces of information. This could have been detrimental, because it is important to look for "what the participants anguish the most over" (Keddy et al., 1996, as cited in Rutman et al., 2002, p. 150).

This position on semi-structured interviews differs somewhat from other GT research, which often uses more structured interviews. Many researchers, using GT and other methodologies, argue that structured interviews encourage consistency and rigour (S. Strega, personal communication, April 15, 2014). Rigour refers to the idea that research is high quality and thorough, which suggests that the findings can be trusted. It is closely tied to the idea of validity and I deconstruct and define both of these terms later in this chapter. Suffice to say that I am sceptical of the claim that structured interviews are more rigorous than semi-structured ones. My scepticism is partly due to the different meanings and interpretations participants can bring to an interview, even a highly structured one. From my own postmodern perspective, I would argue that it is very likely that the participants would have assigned different interpretations to the same question since each person and question is differently situated. Furthermore, structured interviews can give too much control to the interviewer, since the interviewer crafts each question and the participant may not be given sufficient clarification during a structured interview. Therefore, I question the belief that structured interviews allow for more rigour and consistency than semi-structured interviews.

I believe that semi-structured interviews were more appropriate for my research than unstructured interviews. Unstructured interviews allow for a more open-ended and free-flowing conversation (Esterberg, 2002; Fontana & Frey, 2005). At the time I conducted the interviews, I was relatively unfamiliar with the field of palliative care, so it would have been more difficult to conduct completely unstructured interviews because

I had finite background information on the topic. Moreover, I feel that the coding and analysis was made easier with some semblance of a structure, because the interview guide made it easier to track codes and topics that arose in multiple interviews. I also recorded the interviews with the consent of participants, which automatically made the interview feel less spontaneous than a purely unstructured model.

Scheurich (1997, as cited in Fontana & Frey, 2005) convincingly argues that conducting interviews involves more than learning a few simple steps. I agree with his assertion that interviewing is “persistently slippery, unstable, and ambiguous from person to person, from situation to situation, from time to time” (p. 707). However, Fontana and Frey (2005) provide an idea about what postmodern interviewing can look like. One example is polyphonic interviewing, which encourages the researcher to maintain the multiple perspectives of different respondents, rather than collapsing the responses into one singular analysis. I tried to maintain this complexity in my analysis, noting occasions where certain participants held viewpoints that were not necessarily shared by others. This polyphonic approach coalesces nicely with the emphasis on complexity that is promoted by Clarke (2003, 2005). In concrete terms, this means keeping segments of interview transcripts separate, rather than blurring the responses into one.

Esterberg (2002) states that the semi-structured interview process “resembles a dance” (p. 87), since the participant responses influence and shape the questions that follow. To me, this seems very appropriate, since the theoretical sampling in GT follows a similar dance-like process. As data is collected, it shapes the following questions that

we ask of the data. Given the results of my research, I feel confident that semi-structured interviews were the appropriate choice.

**Individual interviews.** It is important to provide my rationale for conducting five individual interviews, rather than focus groups. Undoubtedly, there can be benefits to group interviews. For example, the interviewer can sample a larger population at a low cost, it can make marginalized populations more comfortable with a dominantly-situated interviewer and it allows the interviewer to observe interactions between participants (Berg, 2004; S. Strega, personal communication, March 17, 2014). However, I feel that individual interviews were appropriate for my research.

Some critics would argue that only conducting five interviews must have prevented me from achieving theoretical saturation. Achieving saturation means no new information can be derived from the data (Morse, 1995, as cited in Charmaz, 2005). However, Charmaz (2005) decries the troublesome trend amongst GT researchers who automatically claim to have reached theoretical saturation. She argues that such claims are often made in the absence of adequate empirical material, so that GT researchers can justify small samples like mine. She argues that claims of saturation based on small sample sizes generally cheapen the overall credibility of GT. With this in mind, I am not making a claim that I have achieved saturation with only five interviews. In constructionist GT, the aim is to use interviews to explore the data and emerging theoretical ideas, not achieve saturation. Charmaz states that the overarching question is "*what stands as adequate research?*" (p. 528, original emphasis). Charmaz also encourages GT researchers to go beyond saturation and aim for interpretive sufficiency,

a criterion advanced by Christians (2000, as cited in Charmaz, 2005) and Denzin (1989, as cited in Charmaz, 2005). Interpretive sufficiency asks if the analysis reflects the complexity and multiple interpretations found in the data. To be sure, I tried to derive as much information from the data as possible and interpreted it in different ways. I believe that the five individual interviews were adequate for my purposes and allowed me to assess the ways adult palliative care providers respond to the needs of children. In a study that ultimately involved sixty in-depth interviews, Guest, Bunce and Johnson (2006) suggest that basic elements and themes were captured within the first six interviews. This does not imply that saturation or interpretive sufficiency can be achieved after six interviews, but it does provide a basis for strong qualitative research.

There are two more reasons I chose to do individual interviews rather than focus groups. First, I question the commonly cited argument that focus groups effectively reduce power imbalances that are present in individual interviews (Berg, 2004). Even as a focus group moderator, I believe that the interviewer still exercises considerable power as the discussion progresses and the results are analyzed. Furthermore, the HCPs I interviewed are established professionals within the world of palliative care, so I was not studying an explicitly marginalized group of people who might have been more comfortable within a focus group. Having said that, I had to be vigilant regarding the ways my own privileged social location could have impacted individual interview responses. I simply feel that this vigilance is a must regardless of method; issues of gender, race and class do not evaporate within a focus group, simply because there are potentially more participants from a marginalized group. Specifically on the issue of

gender, Oakley (1981, as cited in Fontana & Frey, 2005) notes that interviewing has traditionally taken place in a masculine paradigm that downplays what are often viewed as more feminine traits, such as emotionality and sensitivity. While this strict gender dichotomy is problematic in itself, I would agree with the general idea that “gender filters knowledge” (Denzin, 1989a, as cited in Fontana & Frey, 2005, p. 710) and this impacts the interview process. I would extend this argument to race and class as well. Fontana and Frey cite a positivist study (Singer & Presser, 1989) that suggests age, gender and interviewing experience have minimal impact on interview responses. I disagree, because this argument seems to imply that there is little need for the interviewer to situate themselves and be reflexive about the ways they influence the interview. As previously mentioned, issues of power and difference need to be brought out into the open, not “hid(den) behind the cloak of neutrality” (Fine et al., 2003, p. 169).

My final reason for selecting individual interviews over focus groups is related to issues of confidentiality and sensitivity. In a focus group, issues of confidentiality are complicated and some people may not want to participate in a group discussion about a sensitive topic. As my topic relates to sensitive issues around death and grieving children, I felt that individual interviews were more appropriate than focus groups. More details on how I managed consent and confidentiality is included later in this chapter.

**Finding participants.** I identified participants by using key informants to reach potential participants (Biernacki & Waldorf, 1981, as cited in Esterberg, 2002). For

example, a professional contact who does palliative care research helped me identify some prospective participants. Interviewing a representative sample of a particular population was not the goal; the aim was to collect data to help inform the emerging theoretical ideas (Puddephatt & Charmaz, 2006). Please see Appendix A for a list of the screening questions I posed to potential participants prior to conducting the interviews.

There were some basic characteristics that I was looking for in research participants. I found participants who work as HCPs in adult palliative care and have opportunities to interact with children in their work. HCPs who work in the pediatric palliative world were not considered, because the focus of my study was contained within adult palliative care. Previous experience working in pediatric palliative care might provide very different insights on how to interact with children, so I delimited the sample to HCPs who only have palliative care experience with adults. I also restricted my sample size to palliative care providers with a minimum of one year experience. Ultimately, I interviewed five HCPs, including two social workers and three nurses. They all live and work in Winnipeg and all of them have more than twenty years of experience. Since the palliative care community in Winnipeg is fairly tight-knit, further demographic information is omitted to protect their identities.

**Interview details.** The interviews ranged from one and a half to two hours in length. I conducted the interviews in spaces that were confidential and comfortable for the participants. One participant expressed a desire to be interviewed in her own home and I interviewed her there. Another participant opted to be interviewed in her office. Both of these settings were convenient and familiar for the participants. For the other

three participants, I booked study rooms in local health centres that were easily accessible to them.

I did not incur significant costs, but I provided food and small gift certificates to the participants. I think that this was important given the participants' sacrifice of valuable time, but I was not in a position to offer more substantial remuneration. Furthermore, all of the participants expressed a desire to participate and contribute to this area of research, perhaps because the findings could inform the ways they interact with children in practice settings. The overall time period for conducting interviews was a month and a half. I offered to share the interview transcripts and research findings with the participants. Three out of the five participants selected to receive the finished transcripts, four out of five chose to receive the results. I think this was an important step since I was analyzing their responses in my thesis, but I did not expect more time commitment on their part. Morse (1998, as cited in Charmaz, 2005) discourages the practice of involving participants, arguing that it requires the researcher to keep the analysis at an accessible level. She also raises the point that the views of participants who get more involved might be overstated in the final write-up. First of all, I think it is imperative that the analysis remain at an accessible level, particularly for HCPs who might benefit from it. Second, I think the ethical choice is for participants to have the opportunity to stay connected to the research project. It does not mean they have editorial control, but there would be no research at all if it were not for the participants (Tracy, 2010).

Since I have professed a desire to make myself visible in the research, the actual process of transcribing the interviews deserves some consideration. Bucholtz (2000) describes transcription as a political act involving interpretive and representative decisions. According to Bucholtz, objective and neutral transcription is impossible. When the subjective and creative nature of transcription is taken into account, “the researcher strives not for an unattainable self-effacement but for vigilant self-awareness” (p. 1461). Extant literature generally describes two major forms of transcription, naturalized and denaturalized. These are usually understood to be at opposite ends of a spectrum and researchers use a combination of both, usually without reflection (Davidson, 2009). As I was researching transcription before conducting my interviews, I came across some disagreement about the definitions of naturalized and denaturalized transcription. Bucholtz describes naturalized transcription as a style that prioritizes the written form and *removes* idiosyncrasies, stutters and pauses found in oral language. To Bucholtz, denaturalized transcription is an approach that cleaves closely to the features of oral language and can be difficult to read for people unfamiliar with this form of transcription. Oliver, Serovich and Mason (2005) take the opposite stance, suggesting that naturalized transcription is greatly detailed and *maintains* idiosyncrasies such as “um” and “er” and denaturalized transcription corrects the grammar and standardizes the written version. Using the latter definitions, Oliver et al. (2005) propose that denaturalized transcription (with grammar corrected and stutters removed) is well-suited to GT. Denaturalism and GT are compatible because GT is interested in perceptions, meanings and interview content that helps inform the theorizing process.

The language used in the interview helps construct these meanings and perceptions, but it is not a mirror of the “real” world. GT research is less interested in the mechanics of speech and rejects the idea that including every vocalization will preserve an objective and empirical reality. For these reasons, I used Oliver et al.’s version of denaturalized transcription. I still attempted a verbatim transcription, but decided to leave out accents and involuntary vocalizations. This decision also made the transcripts more accessible to the participants who chose to receive them.

I created a consent form (see Appendix B) to go over key issues with each participant before beginning the interview. The consent form outlines the purpose of the study, how the data could be used and how identifying information is protected. On this last point, I continue to keep the transcripts on a password protected computer inside my workspace, which is locked when I am not present. The transcripts are backed up on a USB stick, which is kept in a locked container inside my workplace. The consent form also covers issues related to mandatory disclosure and other requirements outlined by the Health Research Ethics Board (HREB). I used the consent form to ask for permission to record the interviews, to which all the participants agreed. While the consent form is an important tool, Bhattacharya (2007) and Warin (2011) propose a more fluid approach to handling consent. From this perspective, consent is an ongoing process that must be continually renegotiated. At the beginning of each interview, I explained to the participants that they could choose to withdraw their consent or end the interview early. None of the participants chose to do so, but respecting this decision is part of creating an ethical research relationship with the participants.

**The questions.** My interview guide is found below. I have included them here because the following section on DGD analyzes several of the questions. This is not a comprehensive list of questions because each interview required different follow-up questions to explore a variety of themes (Esterberg, 2002). I followed Patton's (2002) advice to not actually use the word "probe" during the interviews, because it can sound like you are investigating something illegal or "proctological" (p. 372). The questions evolved as a result of the constant comparative method. I tried to design open-ended questions rather than leading ones, to prevent the interviews from following predetermined routes. In each interview, the HCP was positioned as the expert, given their experience in the field. Each interview began with a period of casual conversation to build rapport, explain the focus of the research and get to know each other better. This was a natural occurrence, rather than an artificial attempt to ingratiate myself towards participants. Trying to build rapport simply for the sake of "improved" data would have been unethical in my view, and I was not capable of "faking it" anyway. Following the interviews, I immediately rewrote my notes, transcribed the data and memoed my thoughts, not allowing too much time to lapse or details to be forgotten.

Interview Guide:

1. Why do you work in palliative care? What attracted you to this work?
2. Can you give me an idea of what your typical workday looks like? (Examples of follow-up questions: Can you tell me about your work environment? What are your responsibilities at work? Do you work alone? Do you work as part of a team? Do you have a daily routine?)
3. When you encounter a child who has a parent receiving palliative care, what is this like for you? (Examples of follow-up questions: Do you have a specific example of an interaction you've had? What happened? Where were you? Who

else was there? How were you involved? Are there other factors that influenced the interaction?)

4. Do you have conversations with these children as part of your interactions? What sorts of things do you say? How does the conversation usually unfold? (Examples of follow-up questions: Can you give a specific example? Do you feel comfortable in these conversations with children? What makes you feel comfortable/uncomfortable? Why do you say what you do in these conversations?)

5. What sorts of reactions have you witnessed in your encounters with children? (Examples of follow-up questions: How have children responded emotionally? Physically? Was there anything that surprised you in their reactions?)

6. Can you describe what these encounters with children are like for you emotionally? (Examples of follow-up questions: Can you tell me a little more about what that felt like? Do you have physical reactions before, during or following these encounters?)

7. How did your professional understanding of child's grief develop?

8. As a health care provider (HCP), what do you think are the needs of a child with a parent in palliative care? (Examples of follow-up questions: How do you think these things come to be seen as needs? Can you tell me a little bit more about it?)

9. How do you think HCPs working in adult palliative care can respond to those needs? (Examples of follow-up questions: How do you currently respond to those needs? What can those HCPs do differently? What can HCPs do that they were not doing before? What are some possibilities for your practice? Is it possible to do nothing? What can other people do to help respond the needs of these children? Who else is involved?)

10. Do you see a difference in the way children's grief is handled in the pediatric and adult palliative care worlds? What are your thoughts on this division?

### **Dominant Grief Discourse**

I want to revisit the dominant discourse around grief and loss that I introduced in the literature review, because it played a significant role in my analysis and interview questions. Foote and Frank (1999) turn to Foucault to examine the dominant discourse

of grief. For Foucault, everything is impacted by power relations, including grief. DGD is created through a complex collection of institutions, ideas, rules, practices and processes, and this shapes our collective understanding of grief. From this, certain “truths” about grief come to be accepted as common knowledge. These truths are produced by and are effects of the power relations that permeate society. It is critical to note that Foucault is not referring to power that is possessed by certain people and elements of society, but as something circulated, albeit unevenly and unpredictably. In Foucault’s analysis, one of the key ways that power works is by persuading individuals to regulate their own behaviour by using technologies of the self. This is all part of what Foucault calls *governmentality* – the power relations, technologies of self and institutional and social practices that govern the conduct of society and each and every individual.

So what does Foucault’s governmentality have to do with the dominant discourse of grief? According to Foote and Frank (1999), grief is yet another site of disciplinary power that governs individual behaviour. This is accomplished by pathologizing grief and turning the grieving subject into an abnormal subject, as discussed in the literature review chapter. The grieving subject is expected to experience their grief within very strict guidelines or they should seek medical assistance. Not all expressions of grief are understood as pathological, but the range of so-called “normal” expressions of grief is rather narrow. Furthermore, HCPs play a pivotal role in disciplining expressions of grief that do not adhere to what is generally seen as “normal”. Regardless of whether grief is perceived as “normal” or “pathological”, DGD locates grief within the individual, no

matter what external factors may have caused it. Foote and Frank outline how everyone is at risk for grief and each person is expected to do specific grief “work” to resolve their grief. Although individuals are expected to self-discipline, they do not act alone. Power is relational and it impacts the relationships that people have with HCPs, family members and society as a whole. Foote and Frank argue that these processes are all workings of power, which often operate in subtle and insidious ways.

Clarke (2005, 2009) refers to Foucault’s work on discourse as a key root of situational analysis. Indeed, the complex web of factors that influence DGD is similar to the array of factors that make up Clarke’s situational map. This suggests Clarke’s situational map is well-suited to my analysis, because it incorporates numerous issues at once. According to Clarke, Foucault helped destabilize the idea of an all-knowing subject and challenged the social sciences to account for the discourses and social practices that constitute our subjectivities. Clarke illustrates how this refocusing on situatedness and discursive practices is central to situational analysis, making DGD especially pertinent to my research.

Allow me to describe how this Foucauldian analysis of DGD impacted my questions. In the context of my research, HCPs are often positioned as the “all-knowing” professionals that instruct other individuals to behave according to socially sanctioned expressions of grief. By asking how their professional understanding of a child’s grief developed in question #7, I tried to take up this matter in my research. By understanding how an HCP’s understanding of child’s grief develops, it might provide useful insight into how HCPs adopt or resist DGD. It is possible that HCPs are

indoctrinated into DGD and then use their privileged position as a “knower” to alternately guide, encourage, coerce and discipline people so that they adopt “acceptable” grieving behaviours. It should be said that DGD is transmitted in several ways, not simply through HCPs. For instance, technologies of self, power relations and institutional, social and cultural practices are all ways that DGD is disseminated. However, my analysis was directly focused on the role of HCPs within this wider context.

Foote and Frank (1999) describe how truth claims often make certain arrangements appear self-evident, as if that is the only way of doing things. GT is well-suited to investigate how these self-evident “truths” are established, because GT has the tools to examine how processes evolve into institutionalized practices (Charmaz, 2005). As I reflected on self-evident truths, I wondered why or if there is a division between the adult and pediatric palliative worlds to begin with. This question was posed to each participant and their responses are taken up in the data analysis chapter.

Another element of the DGD that appears self-evident is the inevitable need to do *something*. Foote and Frank describe this as the totalization of grief, where everyone is required to engage in grieving processes. It seems unfathomable to do nothing as a HCP when a child is grieving. Perhaps it is even unethical. However, I was able to excavate this part of DGD by asking each participant if it is ever possible to do nothing when a child has a parent receiving palliative care, which is a follow-up question to #9. Their responses are discussed in the data analysis chapter.

Foucault (1984, as cited in Foote and Frank, 1999) maintains that there is always a possibility of resistance within power relations. This applies to grief as well. Foote and

Frank (1999) argue that the subject can resist the technologies of self, by disrupting normal expectations for grief and rejecting externally imposed diagnoses. I asked the participants to describe any surprising reactions they have witnessed from children to create space for a discussion on the different reactions children might have and how these can disrupt usual expectations. For example, it is possible that a child might not feel grief, particularly if the dying parent has been abusive. If the HCP does not know about the abuse, the absence of grief could be interpreted as an unhealthy and abnormal development within the DGD. If a child is then expected to grieve in a particular way that is deemed “appropriate” within DGD, it could cause further trauma. As a corollary, I asked participants to reflect on situations where they witnessed abuse or suspected it was occurring and their responses are included in my analysis.

Since the goal of my research is to examine how HCPs respond to the needs of children with a parent in palliative care, I asked participants how we come to think of certain things as needs. Although the needs of grieving children are often perceived as self-evident within the dominant paradigm, this question was able to open up a deeper level of analysis. In fact, the identification of needs was an important process occurring in the data and is taken up in my data analysis.

### **Data Analysis**

Charmaz (2005) states that “no analysis is neutral” (p. 510). Having established this, I want to lay out how I used Clarke’s (2003) situational map in more detail. I will then explain how I coded the data. When making situational maps, Clarke highlights four key pieces of information to keep in mind. First, the maps are intended to “open up” the

data, allowing the researcher to find new points of entry and inquiry. This was an attractive feature to me, because my limited exposure to the palliative care field meant that situational maps could assist me in finding ways to analyze the data. It is crucial to remember that the map is a dynamic process used as an analytical tool, not a static product reflecting a final analysis. Second, a situational map can be created with coded data gathered from traditional GT techniques or even partially with uncoded data that the researcher has “carefully read and somewhat ‘digested’” (p. 560). This is intended to facilitate the analysis process, so that the researcher is unafraid to play with different emerging ideas throughout the data collection phase. I used both coded and uncoded data in creating my map, which allowed me to get familiar with the data and include elements that were not readily apparent but still significant in the situation of concern. Third, Clarke implores researchers to use memoing to record their thoughts, ideas and observations. I memoed regularly through the entire research process. This is part of what Thornberg (2012) calls “constant reflexivity” (p. 254). The memoing process allowed me to document my ideas about the data and it helped situate me as the researcher, providing a record of my thoughts and how they affected my decisions regarding the research (Gibbs, 2010b). Fourth, researchers must investigate the sites of silence in the data. This requires alertness and sensitivity to things that do not initially appear in the data and I highlight some sites of silence in my analysis.

There are usually two major steps involved in making situational maps, although each has particular tasks associated with them. The first was to create a messy version of the situational map, which means “*lay(ing) out as best one can all the human and*

*nonhuman elements in the situation of concern of the research broadly conceived*"

(Clarke, 2003, p.561, original emphasis). These elements were determined by the responses of the participants and my own observations. To determine what nonhuman elements should be included, I followed Clarke's suggestion by asking "*what nonhuman things really 'matter' in this situation of concern?*" (p. 563, original emphasis). These include institutions, discourses, controversial issues, concepts and paradigms. When an issue had questionable relevance, I followed Clarke's advice to include it rather than pre-emptively excluding it. The map allowed me to make provisional analytic comments and further the analytic process. Following Clarke's suggestion, I used a big piece of paper to lay out my situational map. The final version of my messy situational map can be found in the data analysis chapter.

The second step usually involves creating an ordered version of the map. This happens in a similar fashion to the creation of categories in traditional GT. I played around with making an ordered map and looked at different categories in Clarke's (2005) works, including individual and collective human elements, nonhuman elements, implicated/silent actors, discursive constructions and political, economic, sociocultural, temporal and spatial elements. I did not find this process to be very helpful to my analysis. Clarke acknowledges this possibility, recognizing that "some people may not even want to do the ordered working version. That's fine. It isn't necessary" (p. 89).

Once the map was created, I looked at the connections between different elements and memoed my answers. Specifically, I followed Clarke's (2005) advice by circling one element and drawing lines to every other element on the map, one line at a

time. I then reflected and wrote a memo about the relationship between the circled element and every other element, before moving on and circling another element on the map. This process often seemed mundane, but occasionally triggered a breakthrough in the analysis. Clarke indicates that memos should initially be tentative, allowing new questions and ideas to enter the fold. This helped guide theoretical sampling, because memos helped me formulate new questions to ask participants. Clarke suggests that if questions created during memoing remain unanswered and interesting, then the researcher should give them closer attention. I did this by asking new questions that emerged in earlier interviews. For example, I asked about the concept of moral distress, the palliative care team's reliance on the social worker and whether anyone ever gets "dropped" or forgotten about, which are all ideas that emerged during memoing. The relational analysis of the situational map helped me explore the complexities of the research situation and determine what findings should be highlighted in the data analysis chapter. Clarke agrees with Glaser (1978, as cited in Clarke, 2003) that it is important to give sufficient time to reflection and memoing, because rushing to discuss emerging ideas can narrow our lens of inquiry. Charmaz (in Puddephatt & Charmaz, 2006) notes that emergence is a major strength of GT and qualitative research in general. Therefore, I made a concerted effort to memo and allow this process to take place.

**Coding.** Using situational maps for analysis still required the interview data to be coded. Once the data was coded, relevant concepts and categories were integrated into the situational map. Although mapping is unconventional, Strauss and Corbin (1990),

Clarke (2005) and Charmaz (2006) advocate for the flexible use of GT techniques. More clarification is necessary to explain how I actually did the coding, because “coding gives a researcher analytic scaffolding on which to build” (Charmaz, 2005, p. 517). Coding involved labelling pieces of data in a way that helped me summarize what I was seeing in the data so I could begin making analytic observations (Charmaz, 2006). The word “analytic” is emphasized here to distinguish GT from other qualitative research intended to accurately represent and capture a truth or essence as described by research participants, such as phenomenology or case studies. While GT is sometimes criticized for “fracturing data” or misrepresenting participants’ stories, the goal of GT is to produce a unique and emergent analytic understanding of a social phenomenon (Clarke, 2005).

Before I can explain how I analyzed the codes, I must first discuss how I determine what was a code and what was not, which is a puzzling question considering the dictum that “everything is data in GT”. However, the researcher plays an active role in constructing codes by choosing the words to describe them. Charmaz reminds us that “our codes arise from the languages, meanings and perspectives through which we learn about the empirical world, including those of our participants’ language as well as our own” (2006, p. 47). Although I try to express my data analysis with words, some data simply escapes language (St. Pierre, 2002).

Charmaz (2006) offers some helpful advice for creating codes, which I tried to follow. Her suggestions include remaining open to different interpretations, keeping codes short and simple, moving quickly through the data to help spark creative thinking

and coding for actions that appear in the data. This last piece of advice, coding with words that reflect actions, is considered a way to begin detecting processes and actions as described by the participants. As Charmaz explains, this helps *ground* the coding in the language used by participants, preventing the researcher from making premature analytic leaps. As I formulated my initial codes, I used gerunds (e.g. 'describing' instead of 'description', 'stating' instead of 'statement') because this helped create a stronger sense of action (Glaser, 1978, as cited in Charmaz, 2006). Examples from my research include "uncomfortable caring", "relying on the social worker", "using tentative language" and "respecting kids' space".

Clarke (2009) is clear that coding for action is important, but not sufficient when creating a situational map because it does not always account for nonhuman elements that are part of the situation of inquiry. Therefore, I tried to code for nonhuman objects that are also part of the research situation, such as institutions, discourses, media and cultural objects. Some examples of this were hospitals, home-based care, written materials, needs-based discourse and health care resources. Furthermore, I used *in vivo* codes when appropriate, which are codes that are taken directly from key words uttered by the participants. This does not mean I captured the essence of the participants' stories, but it helped me keep codes precise and preserve actions that were present in the data. Two examples from my analysis are "planting some seeds" and "being is more important than doing".

To complement *in vivo* codes, I also coded with sensitizing concepts, which are codes and categories that the researcher applies to the data. These concepts can give

the researcher “a general sense of reference” (Blumer, 1969, as cited in Patton, 2002). Strauss and Corbin (1990) warn GT researchers to avoid overusing sensitizing concepts, because they carry commonly held meanings that can hurt the theorizing process. As a safeguard, Strauss and Corbin encourage researchers to be very precise with their definitions of sensitizing concepts. A good example of a sensitizing concept is childhood developmental stages, which appeared as a code in my data and was carefully defined and discussed in my literature review. In my view, sensitizing concepts are another component of the creative analytical process.

As the data is being coded, Glaser and Strauss (1967) recommend that we continually ask “what is this data a study of?” Vivaldi, Charmaz (2006) adds that we must follow up this first query by asking “from whose point of view?” (p. 47). Indeed, I did my best to be open to different interpretations of the data, but coding remains a highly subjective process. As McKee, Delaney and Brownlee (2002) suggest, “we are socialized into ‘ways of looking’ which render some things visible, others invisible” (p. 496). That being said, Charmaz’s coding advice helped me advance my analytical work.

Now that I have discussed how codes were recognized and established, allow me to explain how I analyzed the codes. I began with open coding in an attempt to determine what was happening in the data (Grounded Theory Institute, 2011). I coded the interviews line by line. As more data was collected, the open codes were revised and reanalyzed to improve fit (Charmaz, 2006; S. Strega, personal communication, February 24, 2014). I used the human, nonhuman and discursive elements that emerged and applied them to the situational map. With a provisional map in place, I began drawing

connections between different elements, as described above. This process of relating map elements worked in the same way as axial coding in traditional GT, which entails looking at how different coding categories relate to each other. Through this process, different processes began to emerge. As the constant comparative method proceeded, I continued to analyze connections and relationships on the situational map. The task of looking for further connections acted similarly to the selective coding process in traditional GT. Clarke (2003) notes this relational mapping “help(s) the analyst to decide which stories to tell” (p. 569). As I became increasingly familiar with the situational map, it helped me decide what parts of my analysis should be featured in my write-up. It is important to acknowledge my role in this decision-making process (Braun & Clarke, 2006).

It is of critical importance to remember that I created and interpreted the codes, categories and the situational map. This could not be done in a neutral manner. In fact, Charmaz (2005) argues that GT coding practices help us see the assumptions we bring to the research. This provides more reason to situate myself within the research, so that my role is transparent. “Bias” has long been a dirty word in both quantitative and qualitative research, but it is no longer tenable to claim objectivity as a researcher. Patton (2002) suggests that the acrimonious debate surrounding the concepts of “objectivity” and “subjectivity” is futile and it would be better to find a different way to evaluate the trustworthiness of research. In the evaluation and assessment section that follows, I attempt to move beyond the subjectivity-objectivity binary to a more insightful discussion about rigour, validity and accuracy.

## Evaluation and Assessment

Charmaz (2005) is adamant that GT researchers must include a precise explanation of how their research meets evaluative criteria, but they seldom do. Every step of the research process requires evaluation (S. Strega, personal communication, February 16, 2014). This includes the selection of the topic/methodology/methods, the reasons for undertaking the research and the gap it fills in the literature. I have already discussed these decisions throughout my introduction, literature review and methodology. Glaser and Strauss (1967) point to four criteria for assessing GT research that will help me evaluate my analysis: fit, workability, relevance and modifiability. The analysis must fit the situation being researched; provide an explanation of the area of concern; address the processes that emerge from the data; and adapt to changes that occur over time. These criteria are useful for my purposes as well, as discussed below.

There are two more evaluative measures that I applied to my research, and each are covered separately in this section. The first examines the potential for the research to contribute to social justice. Second, are the research findings valid? This latter criterion requires a closer examination of what validity looks like when it is operationalized. I use the space below to introduce the standards I used to evaluate my research. The discussion and recommendations chapter provides an actual evaluation of my research.

**Fit, workability, relevance and modifiability.** Glaser and Strauss (1967) begin by asking if the research “fits”. This includes the appropriateness of the methodology, the gap in the literature that is being addressed and other considerations (S. Strega,

personal communication, February 16, 2014). I have already discussed many of the issues related to “fit”, with respect to the connection I have to the topic and the rationale for using GT. In addition, are the emergent ideas suited to the adult palliative care world being analyzed? Second, are the results workable and useful? Fine et al. (2003) ask the critical question, for whom do we conduct research? For whom is it useful? If my research is intended to improve the ability of HCPs to respond to the needs of children with a parent in palliative care, does my analysis accomplish this? How is this accomplished? Can the HCPs make use of the findings? Will the generated knowledge contribute to social justice by improving HCPs’ ability to respond to the needs of children with a parent in palliative care? Have I managed to challenge dominant grief discourses and disrupt the status quo? This last question hearkens back to my discussion about Foucault. There are a number of ways of evaluating workability and this is a central part of research evaluation. Third, is the research relevant? Does it address the relationship between HCPs and children affected by loss? Is the research credible, and from whose perspective? Do HCPs “see” themselves in the data? Fourth, can the emergent theoretical ideas be modified? This is important within a postmodern paradigm, so the analysis can evolve in an increasingly complex, fragmented and heterogeneous context.

**Evaluating for social justice.** Charmaz (2005) argues that one of the major advantages of GT is that it provides tools that can be used to study social justice issues. To illustrate her point, Charmaz points to how GT researchers analyze processes that occur in participants’ worlds and this emphasis on process allows GT researchers to

analyze issues that carry social justice implications. For example, grounded theorists can analyze the relationships between human actors and institutional structures, as I did with my situational map. Charmaz contends that this analysis can uncover implicit processes that have major social justice ramifications for human actors.

I believe that my research must be assessed for its contribution to social justice. As I conducted my research, I tried to be attuned to the ways DGD manifests itself and what the negative consequences are as they relate to issues of race, gender and class. I explore my findings related to race, gender and class in the data analysis chapter.

To further assess my research for its contribution to social justice, Charmaz (2005) highlights three more areas of interest that help bring a social justice focus to the research process: resources, hierarchies and policies/practices. First, what social, political, personal and economic resources are present in the area of concern? What meanings are given to these resources? Who needs them, and why? Who can access these resources? How are they distributed? As Charmaz demonstrates, information and power are crucial resources, so I investigated the role of these resources in my analysis. In doing this, I adopted the Foucauldian view of power that I mentioned earlier, where power is circulatory and relational, rather than a possessed resource.

Second, what hierarchies affect the area of concern? How did they come about? Who benefits and/or suffers from the hierarchies? Where am I, as the researcher, situated in hierarchal formations? When investigating hierarchies, Charmaz asks “how are the hierarchies related to power and oppression? How, if at all, do definitions of race, class, gender, and age cluster in specific hierarchies and/or at particular hierarchal

levels?" (2005, p. 513-514). Social justice research must incorporate an analysis of gender, race and class. The data provided some insight into the participants' views of these terms and how these perceptions influence the research topic. Charmaz states that "researchers must define how, when, and to what extent participants *construct* and *enact* power, privilege and inequality" (p. 512, original emphasis). I would add that researchers must ask those same questions of themselves. How visible is my role in the construction of data? How do I construct and enact power, privilege and inequality?

The third area that can help create a social justice focus involves an examination of the social policies and practices that affect the research area. Whose interests are protected and ignored? Are the policies and practices contested or potential sites for resistance? What are the consequences for the actors involved? As I talked with participants, I asked them questions about resources, hierarchies and policies/practices and I included this information in my analysis.

**Evaluating for rigour, validity and accuracy.** As research paradigms become increasingly complex and diverse after the postmodern turn, the meanings of rigour, validity and accuracy are often unclear. Charmaz (2005) argues that GT researchers must clearly outline their evaluative standards, because failing to do so makes it easy for critics to dismiss the study outright. With this in mind, if I wish to evaluate my research on the basis of rigour, validity and accuracy, I must first define these terms.

Beginning with rigour, Guba and Lincoln (2005) describe two forms that can be used. The first comes from the positivist paradigm and I alluded to it in my discussion on interview formats. In this approach, the researcher tries to systematically apply research

methods in such a way that certain truths can be drawn from the data. I reject this positivist approach on the basis of its objectivist leanings, since I perceive “truth” to be a partial and unstable concept. Instead, I prefer the second interpretation of rigour, which is rather interpretive in its own right. In this view, the researcher analyzes the data to advance a plausible interpretation of reality. This definition of rigour still requires that careful attention be paid to method, but it does not make objective and universal truth claims.

My working definition of validity strays from the positivist idea of objective truth as well. It is essential to prevent my evaluation strategies from falling prey to a limited notion of validity. Lather (1993) writes that issues of validity demand our attention and the concept must be reimagined in a way that does not reinscribe positivist and foundational “truth”. Guba and Lincoln (2005) offer several alternative ways of defining validity. For example, can the research be used for resistance or transgression? Can it help construct a deeper and more complex understanding of the research area? Richardson (1994, 1997, as cited in Guba & Lincoln, 2005) calls this *crystalline* validity. Using a crystal as a metaphor, Richardson asks researchers to examine the multidimensional and fractious elements involved in the research. Like a crystal, a research situation can have countless angles, shapes and patterns. This approach draws on postmodern sensibilities and helps the researcher transgress the traditional understanding of “objective” validity. It is important to note that transgression is not solely a concern for the researcher. Are the findings informative to research participants and galvanize them to take action towards social change? This is what Lather (1991, as

cited in Kincheloe & McLaren, 2005) calls “catalytic validity” (p.324). This form of validity helps disrupts the status quo definition of validity and opens up space for social justice efforts. According to Guba and Lincoln (2005), validity can also be measured in how we create ethical research relationships. In other words, validity has ethical and moral dimensions. Validity involves collecting data and analyzing research in an ethical and non-exploitative way.

Finally, my definition of “accuracy” relies on the same postmodern assumptions that influence my perception of rigour and validity. Accuracy is an important concept, but it is not synonymous with the notion of an objective, neutral and foundational truth. To be accurate, my analysis must be rooted in empirical data and should resonate with the HCPs. This is sometimes referred to as internal validity, which means there is enough data to support the analysis, the findings are coherent with the experiences of HCPs and the roles of the researcher and participants are made clear (Merriam, 2002; S. Strega, personal communication, February 16, 2014). This last point is particularly important, because my analysis always originates from my own standpoint. My influence as a researcher does not compromise the accuracy of my analysis, but it informs and qualifies it.

### **Potential Limitations of the Research**

Some might argue that my postmodernist subjective and interpretive approach to GT represents a limitation because it does not try to establish an objective and universal truth (*cf.* Glaser, 2012). This argument hinges on a modernist paradigm, suggesting that particular and fluid conceptions of truth are inferior to universal ones. I

would argue this is not a limitation, because a constructionist approach to GT recognizes that knowledge is situated and influenced by context and power relations.

A second potential limitation concerns the number of sources I used to collect data. My literature review, memoing and interviews represent three sources of data. I believe that doing much more than this would go beyond what is usually involved in thesis research. However, I have already discussed Charmaz's (2005) concerns about research that relies heavily on interview data, because interviews tend to prioritize the present over the past. Furthermore, Clarke (2003) is quite clear that researchers must do their best to acquire data and information from a wide array of sources. In an effort to address this potential limitation, I continued to read and research the topic as I conducted interviews and collected data. This flexibility towards data collection strengthened the internal validity of my research and is a hallmark of theoretical sampling in GT.

### **Ethical Considerations**

**Voice.** There are a number of ethical issues that have to be considered as well. First, it is essential to reflect on the "voice" that is most prevalent in the research. Fine et al. (2003) discuss this in terms of representation, noting the difficult and contentious work of representing people. While there is no easy solution to the oft-mentioned crisis of representation, it is important that the voices of the participants can be heard in the data (Denzin & Lincoln, 2005). It is equally important to write in my own voice, rather than making myself invisible. Each interview is a mutually constructed product, or a "negotiated accomplishment" (Fontana & Frey, 2005, p. 717). I do not believe a

researcher can ever erase themselves from the process. As I analyzed the findings, I made sure to include the voices of participants and tried to make my influence evident. Notably, the voices of the children and families are not included. There are pragmatic and ethical reasons for this, because it can be difficult to recruit children for research in this area. I consider this to be another potential limitation to the study, but not one that obstructs other benefits to the research, such as its usefulness to HCPs.

Keeping with the issue of voice, there is another ethical issue that I had to account for. Namely, I had to “voice alternative perspectives even when this departs from dominantly valued notions of professionalism” (Morley & Macfarlane, 2010, p. 53). In this context, I undertook a critical examination of the biomedical model, which is rooted in the positivist and modernist paradigm. This paradigm stands in contrast to my own, so I tried to ensure that my analysis does not reify my own paradigm as self-evident truth either. I paid careful attention to language throughout the research process because the language we use helps shape meanings. Dybicz (2010) argues that dominant modern discourses require social workers to adopt a “techno-rational consciousness” (p. 42). I explicitly reject this, opting instead to follow the postmodern discourse that requires each social worker to adopt a critical consciousness that “views each (person) as creating his or her own world and views human action as springing from the social construction process” (p. 43). This is particularly important as I strive to resist DGD that is rooted in the aforementioned “dominantly valued notions of professionalism”. In the literature review chapter, I discussed how DGD affects the way many people come to understand grief. Specifically, grief is often perceived as a linear

and time-bound process that must be expressed in very specific ways in order to be considered “normal”. Social workers like myself play a significant role in defining what is normal and what is pathological. To adopt a critical consciousness and promote alternative perspectives, I try to stay aware of the influence of DGD on my actions and find ways to endorse the critical consciousness rooted in social constructionism that Dybicz refers to.

**Race, gender and class.** Addressing the crisis of representation also required me to account for issues of gender, race and class. All three of these interlocking issues were key factors on the situational map. Olesen (2007) outlines the three major criticisms of GT that have emerged in feminist qualitative research: positivist elements, a lack of reflexivity and a limited analysis of ethical issues. I have already spoken in detail about positivism and reflexivity and I am addressing ethical issues in this section. Olesen is clear that these criticisms are largely directed at traditional GT rather than postmodern and constructionist formulations of the methodology. However, these critiques are important reminders because “lurking around the corners are countervailing conservative forces that seek to disrupt any agenda of social justice that may form on such tricky ground” (Smith, 2005, p. 85, as cited in Denzin, 2007). Denzin’s (2007) work on the politics of interpretation also gave me an idea of how to analyze gender, race and class at each stage of my research. He encourages grounded theorists to look beyond seemingly neat and tidy interconnections and processes in the data and

see the chaos and disorder that permeates the data. This is “intended to illuminate the arbitrary and unjust, the unfair practices that operate in daily life” (p. 459).

Green et al. (2007) suggest that every researcher treats diversity either as a primary, complementary, peripheral or absent concern. While a discussion on peripheral and absent diversity are not necessary for my purposes, Green et al. suggest that diversity is treated as a *primary* concern when gender, race and class are at the centre of the situation of concern. For example, studies on how race operates in the workplace, how women feel about palliative care or how class differences affect access to palliative care would position diversity as a primary concern within Green et al.’s framework. According to Green et al., my research treats diversity as a *complementary* concern, because it does not drive the research but serves to enhance it. I have trouble with this classification system for two reasons. First, it seems quite rigid and simplistic. It seems entirely possible to me that a study could have “gender”, “race” or “class” in its title or research question, but might only analyze these issues on a superficial level, meaning that it would more likely treat diversity as a peripheral rather than primary concern. Second, I do not think considerations and analysis of gender, race and class matters simply “complement” my research. As the interviews evolved and theoretical sampling informed my questions, I asked each participant to discuss how issues of race, gender and class impacted their interactions with children who have a parent in palliative care. Although this did not always lead to in-depth responses, it generated some meaningful discussion on these interlocking issues.

A critical question arises, however, as Green et al. (2007) ask “if scrutinizing the data does not elicit these issues, to what extent can the researcher force diversity questions on the data?” (p. 479). In response, I refer back to Clarke’s (2003) situational map that calls on researchers to illuminate sites of silence in the data. Even if no participants had uttered the actual words, this does not reduce the power implicated in matters of gender, race and class. Marginalization, domination and subordination are usually rooted in gender, race and class, so addressing these issues is of paramount concern (Razack, 1998, as cited in Strega, 2005). This is especially true for research like mine that aims to contribute to social justice. As my analysis and discussion demonstrates, I was able to garner some observations on race, gender and class.

**Ethical research relationships.** Creating and managing ethical research relationships deserves more attention. Wolcott (1999, as cited in Warin, 2011) asks a provocative question: “is it ever ethical to probe into other people’s lives?” (p. 806). It is certainly a fine balance between the potential benefits of research and the risks posed to the privacy of participants and other related parties. In my view, ethical research relationships require the researcher to “own up to their own involvement” (Etherington, 2007, as cited in Warin, 2011, p. 813). Warin argues that using reflexivity is deeply connected to what she calls “ethically mindful research” (p. 806). This ethical mindfulness involves being sensitive to how we influence and are influenced by participants. It involves an interplay between our self as researcher and the other as participant, what Fine (1994) calls “working the hyphens” (p.70). Reflexivity is not merely a private activity, because it is also important to share information about myself.

Oakley (1981, as cited in Fontana & Frey, 2005) states that there is “no intimacy without reciprocity” (p. 711). Since I was asking participants to share information with me, I had to be willing to reciprocate. This practice does not skew the results, as a positivist researcher might argue, but it helps build a relationship between participants and the interviewer. Sharing personal information does not do away with issues of gender, race and class, but it certainly does not ignore these issues altogether. In light of this, I explained my interest in the research to the participants and told them about my academic and professional background. Sharing this kind of personal information is critical for building relationships and rapport (Esterberg, 2002).

Another part of creating ethical relationships involves paying attention to the emotional aspects of research. Although it is not always easy to talk about sensitive topics like palliative care, grief and death, numbing myself to these issues could have prevented me from understanding their influence on the research. I made sure the participants knew that the interviews were intended for research and that further support options were available if needed. Although none of the participants expressed a need for further support, I was aware that retelling certain stories evoked emotional reactions in some participants. This awareness is part of what Harding (1993, as cited in Warin, 2011) calls “strong objectivity” (p. 810), meaning that reflexivity actually allows the researcher to get more distance from the research process. It is easy to see how the distinction between research and counselling can be blurred, given that attentive listening and disclosures are common in both (Mitchell & Radford, 1996). Therefore, I believe it would have been unethical to deflect all disclosures and emotional

expressions from participants. I found that the ethical approach was to be clear about my role as a researcher while treating participants as human beings rather than mere data sources.

During the research process, it was helpful to allow for silences and moments of reflection when sensitive topics arose. As mentioned, Clarke (2003) urges researchers to “articulate what we see as the *sites of silence* in our data” (p. 561, original emphasis). I tried to accomplish this “without putting words in the mouths of our participants” (Clarke, 2003, p. 561). By paying careful attention to reflexivity and sites of silence, I was better situated to create ethical research relationships.

## Chapter 4: Findings and Data Analysis

### The Situational Map

Before proceeding to review and analyze the data that I collected in my interviews with HCPs, I want to include a version of my messy situational map, which I explained in the methodology chapter. I made six different “messy” maps over the course of my data collection and I am including the most recent one (Figure 1). Although a computer-based map may not have the same import as a handwritten version, this will demonstrate a major instrument involved in this research. It is important to keep in mind that Clarke (2005) calls for situational maps to be used as analytical tools that help the researcher engage with the data. In other words, the map is meant to stimulate thinking and is not a final analytical product. I will discuss my findings in detail throughout this chapter, but an examination of my map will give an idea of some of the major elements that emerged during the research process. The meaning and context of some of these terms will become clearer throughout this chapter.



**Figure 1 – Messy Situational Map**

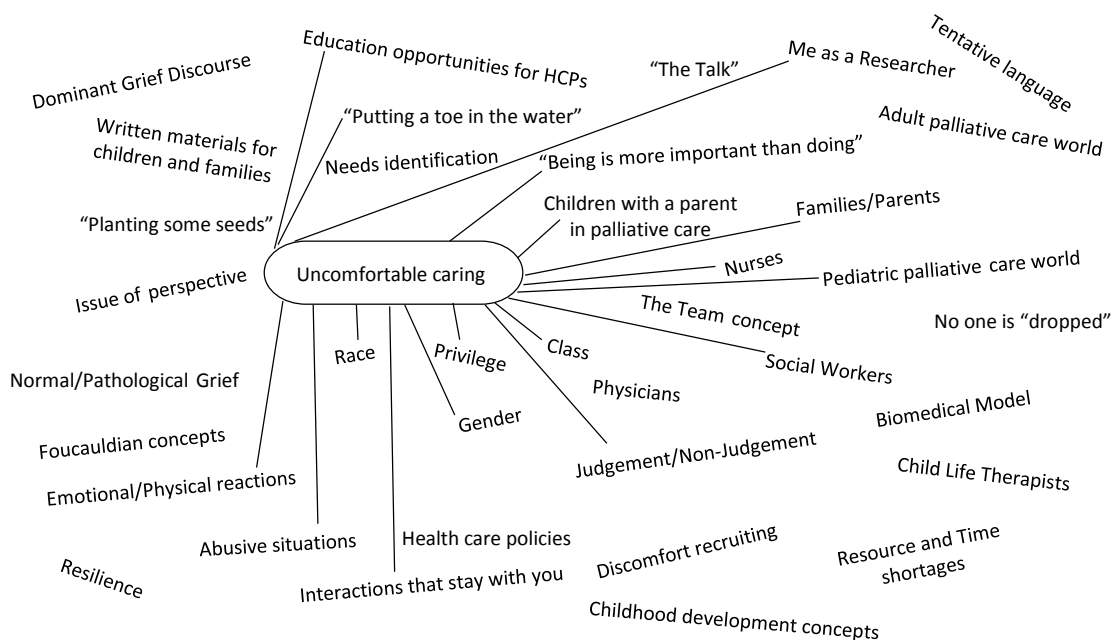
When looking at this map for the first time, it may appear jumbled and confusing. Remember that this version of the map is meant to be messy so that the researcher can get a broader view of the situation being analyzed. As I immersed myself in the data between interviews, the concepts and connections on the map began to make more sense to me. I tinkered with different versions of the situational map by adding some items and removing others, depending on their relevance. This process of collapsing and expanding the situational map aligns with Clarke's (2005) methodological instructions.

Many of the items on my map are more conceptual or discursive, rather than explicit actors or institutions that are present in the situation of concern. This is not a cause for alarm, because these are the concepts that emerged in the mapping process and I have included the actors and institutions that appeared relevant. For example, I include "judgement/non-judgment", "normal/pathological grief" and "tentative language". Perhaps these are not human or nonhuman "actors" in the traditional sense, but all three play significant roles in the data. Clarke (2005) advocates for flexible application of these tools, so it made sense to me to include these elements on the map alongside human and institutional elements.

I used coded and uncoded data to create the map, particularly in the early stages. This is a practice I mentioned in the methodology chapter. For instance, I used coded data by applying in vivo codes a number of times in the situational map, including "planting some seeds", "putting a toe in the water" and "being is more important than doing". I also created the map using data that was not coded. For example, "Me as a

Researcher” appears on the map, but this was not a piece of coded data. Rather, it was added after reflecting on my role in the research and my role in creating the map.

It is not necessary for me to review every item or connection on the map. This is not a “how-to” guide to situational analysis; Clarke (2005) provides enough instruction in that regard. Moreover, the remainder of this chapter will highlight and analyze three map elements that are key processes within the data – needs identification, uncomfortable caring and the team concept in palliative care. However, I provide a brief example of how I did my relational analysis with the situational map below.



**Figure 2 - Relational Analysis Using Situational Map: Focus on Uncomfortable Caring**

To do my relational analysis, I considered the relationship between each item and every other item on the map. As I worked with the data, I related different items on the map and wrote several memos as the analysis progressed. Uncomfortable caring,

the focus of the relational analysis in the map above, is a key process involved in HCPs' interactions with children who have a parent in palliative care. I define "uncomfortable caring" and examine how it relates to other elements on the map later in this chapter, so I will not do that here. However, I want to point out that one could potentially see a relationship between "uncomfortable caring" and other items on the map. For example, consider "childhood development concepts". One could argue that childhood development concepts can make certain HCPs uncomfortable when caring for children who have a parent in palliative care. However, I did not find that to be the case in the data and it did not emerge as a pertinent relationship as the analysis progressed. Many of the connections that I included in my memos were ultimately excluded from the analysis, because they were irrelevant, mundane or spurious. To provide a cogent analysis, I could not have a relational map that connected each item to all of the others. Therefore, I think it is important to recognize the subjectivity involved in mapping and relating the items. Another researcher working with the same data set would not create the exact same map, although there would undoubtedly be some similarities. This indicates the importance of recognizing my role as a researcher and my influence on the entire process.

The subjectivity involved in the process brings me to a final note about how situational maps are created. As previously mentioned, Clarke (2005) urges researchers to broaden their scope and include as much of possible within the situation. However, my poststructural orientation leads me to believe that it is impossible to identify every relevant element within a situational map. It is impossible to capture everything

because there are significant constraints and underlying structures that determine what is thinkable and knowable in a given situation, what Foucault called “conditions of possibility” (1966, as cited in Gutting, 2005). Under the conditions of possibility, Foucault argues that “individuals operate in a conceptual environment that determines and limits them in ways of which they cannot be aware” (as cited in Gutting, 2005, p. 33). Foucault calls this the “marginalization of the subject”, where he is more interested in what makes certain thoughts and ideas possible, rather than simply providing a history of those ideas. Therefore, I am left wondering what is unthinkable and unknowable within the conceptual environment that I am researching. What is outside the bounds of my situational map? Despite my efforts to follow Clarke’s (2005) instructions to highlight sites of silence, I am still working under specific conditions of possibility. If my goal was to make an objective truth claim about the present situation, this would be a significant limitation. Instead, I think it contextualizes my findings and highlights the tentative status of emerging theoretical ideas.

### **Identifying Needs**

Given that the purpose of the study was to examine how adult palliative care providers respond to the needs of children who have a parent in palliative care, it is insightful to reflect on how the participants discussed these needs. When asked about the needs of a child with a parent in palliative care, there were a number of needs that featured prominently in the data. Participants identified a need for openness, which includes involving children when their parent is ill, answering their questions and interpreting important information for children. There is a need for support while their

parent is sick and after they die. At the same time, multiple participants identified a need to respect children's personal space when providing support. When interacting with children, HCPs cited a need to be creative and the importance of speaking in accessible and literal language without resorting to euphemisms. The data suggests that children need opportunities to play and be with other children in similar situations. These identified needs nicely align with the needs identified by Patterson and Ranganathan (2010) who researched children's needs when a parent has cancer, as discussed in the literature review. Participants also noted that children are often in need of protection, but were quick to clarify what children need protection from. Specifically, children need protection from unsafe situations, but should not be "protected" from being involved with their dying parent.

*It's not protecting them from the death – I think that's a mistake. You can't protect them from the death, it's going to happen. You have to go with the family when talking about death, but definitely I think when you are talking about the death, the concept and topic of death has to be included. I would say in the palliative care program we do include the children (P1: 16).*

It bears repeating a point made in the literature review about the danger of using "protection" in a pejorative sense, because families with fewer economic resources may be inclined to "protect" more often because of a perceived level of risk for their children (Shor, 2000). However, the participant here is referring specifically to how families either facilitate or prevent the involvement of children when a family member is ill. The above quote also points to the role HCPs play in discussing death with the family and the educational aspect of those discussions. Participants identified education as an indispensable need for children and families, which coalesces well with

the aforementioned need for openness, because both require a willingness to ask and answer questions and interpret information. Although families play a pivotal role in meeting the information needs of children, HCPs also see a role for themselves in providing resource materials and modelling appropriate communication and language.

The primary medium that HCPs use to provide this education is “The Talk”, a phenomenon that arose in earlier interviews and was explored in later interviews as part of theoretical sampling. It initially emerged as a discussion that helps families adjust to a palliative diagnosis, particularly when HCPs feel that families do not understand the specifics of their situation. As I sought to clarify its meaning further, one participant explained “The Talk” in this way:

*I'm familiar with that idea. And I think those conversations are ongoing and they happen all the time without always knowing it's "a conversation" (P3: 32).*

The participant described “The Talk” as being on a continuum, not a single identifiable moment where an HCP sits and talks with the adults and children. As the interviews proceeded, there were more comments about how to engage in difficult discussions with children in an effort to meet their needs and provide them with the information that they desire. HCPs used a variety of techniques to make “The Talk” an educational tool for children and families. For example, one HCP described using a “safe word” that children can say when they want the conversation to end. Other HCPs explained that they use tentative language when asking and answering questions with children:

*I'm always a bit tentative, or try to be, so (I say) "sometimes people might feel like this" or "sometimes people understand things differently" or "you know, down the road you might find this is what's happening"... "Do you ever, have you*

*ever..."; that curiosity and that tentativeness opens up a lot more doors than the "so what do you feel?" kind of comment. (P4: 22).*

"The Talk" demonstrates the importance of communication, a crucial need that is supported by the literature. HCPs found that "The Talk" unfolds differently based on circumstances and it is intended to provide children and families with accurate information. Although some participants were far more comfortable with participating in "The Talk" than others, it was unanimously positioned as a positive and useful tool for HCPs. However, HCPs should be careful when engaging in "The Talk" because some families will not be receptive to these difficult conversations. One participant stated that conversations with children are rare so it is hard to remember what to say in these situations, which was also a finding in MacPherson and Emeleus' (2007b) research on children with ill parents. This discomfort will be explored in greater depth later in this data analysis chapter.

Participants described how children with a parent in palliative care can be given information in subtle ways. Two participants used the term "planting some seeds" to describe how they view their role as an educator when interacting with children and their families:

*I really would want to be encouraging kids to be kids. Helping them know there is nothing wrong with crying, nothing wrong with being sad. Nothing wrong with being angry. As long as you don't hurt someone else, damage something or yourself. You know that kind of thing. So planting some seeds like that. (P2: 27)*

*Sometimes it's helpful to put those words out there. And they might not come back right away, but a little bit later in the conversation or in a day or so, they might come back. I think it's sort of planting that seed that they are ok, and other people feel like this. (P4: 23)*

“Planting some seeds” works as a metaphor to acknowledge how it can be difficult for HCPs to know if the conversation is having an effect on children. In an effort to meet the education and information needs of children with a parent in palliative care, “planting some seeds” represents how HCPs try to introduce ideas to children in a gentle way by using tentative language.

**Needs related to resources.** Having the proper resources was another major need identified by the participants. In some circumstances, participants pointed to the need for specific child-friendly resources that would benefit children with a parent in palliative care. There was an emphasis on using literature and web-based resources to meet the educational needs of children. One participant wondered aloud if there are appropriate materials for kids:

*Are there pamphlets for the kids that are non-threatening? ...Some of the stuff we have is all adult-oriented, but they might be curious, they might want to go to a website for kids only. (P5: 18)*

It was glaringly obvious to participants that there are insufficient child-friendly resources. Without the proper staffing and infrastructure resources, it is extremely difficult for adult palliative care providers to find time to visit with children and respond to their questions and concerns. One social worker felt that simply providing child-friendly resources is not enough and there is a need for HCPs to adopt an active role when sharing those resources with children and families:

*What's needed is not only that information, but somebody to interpret that information. To have someone sit down with families to talk about “what is this stuff?” How does it apply to me, or what makes sense, or this is what happens when we read this book together, or what the message is in the book, does it give the message that I want to give... In some cases some of the nurses are able to do some of that, but I think more often they are saying "oh, we've given them what*

*they need". I think they know it's not totally what they need. But sometimes it is all that they need, but sometimes it isn't. (P2: 47)*

Although participants acknowledged the need for meaningful interaction with children and families, the stark reality of time constraints and staffing shortages is abundantly clear. Although the needs of children with parents in palliative care were relatively easy for participants to identify, the discussion repeatedly came back to the challenge of finding the time to meet those needs. When asked what would make HCPs more willing to become involved in supporting those children, one participant replied:

*Well, support for health care workers I guess. Things have changed drastically in palliative care, they are more acute than ever. But staffing hasn't increased that much. (P3: 11)*

A social worker who tried to follow up with families and children after a death found similar time-related obstacles:

*Part of the challenge of that job is the time limitations. It was difficult to be following those kids when there were 3 new people a week coming through. (P4: 19)*

As the conversation shifted to staffing and time resources, there was a tangible shift in the way needs were being described by participants. Whereas the other needs were clearly focused on the children, such as openness, support, accessibility and respect for personal space, staffing and time resources are needs that affect children indirectly. The indirect nature of these needs does not diminish their impact on children, but meeting these needs would also have a more obvious and direct impact on HCPs and improve their ability to do their work. An increase in staffing and time resources would also benefit the health care system as a whole.

The participants conveyed that there are multiple services providers working together to meet the needs of children and that they do not feel isolated in their work. However, the staffing resources are simply insufficient to create the desired space to interact with children and respond to their needs. HCPs do what they can with the time provided, but would like more time to interact amongst themselves and consult with each other in difficult situations. When asked what kind of resources would make it easier to support children with a parent in palliative care, a social worker responded this way:

*I think that more of a team approach where the social worker and the nurse could engage in a conversation. But that's not going to happen within our health care system, because that nurse has five patients and some of them are really heavy and some of them not so much. People die unexpectedly and there are family issues to deal with. So unless it's a really quiet day and you have someone who is quite committed to participating in that, I'm hesitant to say it will happen. But in the best of all possible worlds that would be an ideal model. (P4: 30)*

The comment “that’s not going to happen within our health care system” is a telling one. The notion of a cash-strapped and resource-deficient health care system appears to be an unquestioned truth and this also arose in my literature review. Participants found it difficult to talk about interacting with children who have a parent in palliative care without qualifying their responses with references to the time constraints and staffing challenges they experience while working within this system. I find it curious that resource shortages seemingly become a fact of life within a neoliberal system that stresses efficiencies and cost-savings. The impact of the neoliberal economic system is an unarticulated site of silence in the data and I am highlighting this silence. I cited a study by Baines (2004) in the literature review which documented the

cuts to social programs and services in Canada over the last three decades. Participants did not explicitly cite these service cuts and resource challenges as an excuse or reason to not interact with children, but the impact is unmistakable. This is a stark reminder of the broad material consequences of DGD, which I also mentioned in the literature review when discussing the resilience discourse. If grief is solely considered to be an individual responsibility and experiencing difficulties simply suggests a lack of resilience, then it is easier to justify cutting services because the health care system is not expected to provide resources or support for people who are grieving.

Some participants were acutely aware about the trickle-down effect that staffing shortages have on children and families, particularly those who do not have strong advocates. When there are limited staff resources and there is someone strongly advocating for their family member, people without advocates are often silenced:

*The other piece of it is who's advocating for you outside of the health care team? Sometimes people have a really strong advocate who will be able to push boundaries and get what they need, be forceful enough so they can get what they want for their family member. And people have said I don't really care about the other 500 people, I only care about my person and I get that. But in a social justice realm I do care about the other 500 people. So sometimes you have someone who has a really strong advocacy system and sometimes you have people who have nobody. Sometimes we're able to advocate for them, but sometimes not. (P4: 31)*

Despite the heavy emphasis on resource shortages, some participant comments describe a physical environment that was adequate in many respects, including the physical infrastructure accessible to children and their families:

*We have a great unit where there is a TV room and things for young kids to do and teenagers to hang out or whatever. A solarium and a quiet room... Their children would stay the night and watch movies through the night. Just kind of make the most of the time. (P3: 14)*

When asked about policies that were either helpful or a hindrance in their effort to support children with a parent in palliative care, participants struggled to identify harmful policies. Again, there was silence on the neoliberal economic policies that create staffing shortages and resource depletion. Several participants acknowledged the positive aspect of having unlimited visiting hours for families with a patient on palliative care. One participant also noted that there are policies in place and resources available to bring family members from Northern communities to larger urban areas to be with someone receiving palliative care.

Despite these positive aspects, the data clearly suggests that there is a need for more resources, which would benefit children directly and indirectly. Participants unanimously stated that more educational and staffing resources would benefit children. These resources would help HCPs provide timely and age-appropriate support to children who have a parent in palliative care.

As I conducted the interviews, I noted that several other needs-related areas emerged in the data. Although these were not always instances where participants were explicitly describing the needs of children, they do provide insight into how children and their needs are constructed in participant responses. In specific, there were several references to family, child development and normalcy, all of which deserve separate attention here, particularly because these topics were discussed in the literature review chapter.

**Needs related to family.** In many respects, it was difficult for participants to discuss children's needs in isolation from the family unit. The participants perceived the

family to be the unit of care, and addressing the needs of the family is also seen as addressing the needs of the children. This echoes what I found in the literature as well. As a result, parents are often the mediators when HCPs try to respond to the needs of children. One social worker explained:

*My contact with kids was through the parents, so I may not be talking to the kids directly myself, but I would be talking to the parents about talking to the kids... And we would often have conversations about what have they talked about? How have they talked about it? What is going on with him, what kind of behavior is he showing... have you noticed anything, have you talked with people in the school, what do they say, all those kind of conversations went on. (P2: 7)*

In order to meet the needs of children, HCPs have to communicate effectively with the parents, guardians or caregivers that have key relationships in a child's life. According to participants, communication is most likely to take place with adult caregivers, which suggests that positive relationships with the adults can help children cope when a parent is ill and receiving palliative care. The same social worker used the metaphor of "guardrails" to describe the pivotal role that parents play:

*Your kids are going down a road, and they come to a curve in the road, and they accelerate into that curve, they don't slow down into that curve. So we have guardrails up on the highway to protect, to keep people on the road. That's what your goal is as parents. You're there to keep them on the road. And somehow you have to be close enough to the road. And you have to be strong enough. And you have to be firm. And you have to be tall enough to see that there is a road that they are going down. And have that perspective. (P2: 16)*

As HCPs, the participants explained that often their role is to work with the family in meeting the needs of children, not to do it independently from the family. If they are present when a parent or adult family member is communicating with a child, they want to make sure they are on the same page as the family and fostering an attitude of openness. When encouraging families to involve children in important

conversations, there was also an acknowledgment that there has to be an element of choice for the children involved. In other words, fostering an attitude of openness is akin to encouraging children to become involved and informed about their parent's health and family situation, but erring on the side of caution and not making their involvement mandatory.

These interactions with parents and other family members can be quite difficult for HCPs. One social worker described an occasion where she was trying to work with a parent to support a child and ended up in a difficult position between the mother and child:

*(She) wanted me to talk to her child to find out, because this kid was pretty reserved, what was going on. And I had said to her that you need to be mindful that whatever she says to me I'm not going to run and tell you, because otherwise she's not going to say anything. I have to be able to explain to her that what she says I will respect... And then afterwards she wanted to know and I wouldn't tell her and she was furious! (P4: 13)*

The participant explained that this negative reaction with the mother had ramifications for her social work practice, describing how it made it more difficult for her to engage with children who need support:

*I think what wasn't helpful was that then I was even more vigilant and it made it more, perhaps less easy to engage in those kinds of conversations. Because there's always that...even though you document, there's always that fallback. (P4: 14)*

Granted, the same participant was conscious that these types of interactions were exceptions, stating that most interactions with parents and guardians are quite positive and the families are generally quite open to HCPs becoming involved with their children:

*Most often, when kids were involved with the dying parent, those parents wanted whatever they could get for those kids. They were not reticent, they wanted whatever was available for their kid. (P4: 16)*

It is clear that responding to the needs of children with a parent in palliative care involves a partnership between HCPs and the family. However, HCPs must be cautious about how much responsibility they assume and be careful about overburdening the family. When asked if the family is partly responsible for meeting the needs of children with a parent in palliative care, one participant replied:

*They would be central to it. But if you're already having...that's a hard question. Because for me, say if I knew my husband died and my kids were younger, even now, I'd be having a hard time managing my own grief, plus theirs... So I think they have a huge role to play in it, but I don't even know if they know what they need. (P5: 21)*

In this response, the participant sees a role for the family in supporting children, but imagines what such a situation would be like for her personally. She concludes by questioning whether families themselves know what they need. Since I did not interview family members for my research, it is difficult to know if family members would agree with such a statement. However, it is clear that HCPs' relationships with families is important for meeting the needs of children, but also unpredictable and dependent on each individual family.

**Needs related to childhood developmental stages.** When discussing childhood grief, participants described common reactions that adults might see in children. This opened up a discussion on childhood developmental stages, a concept analyzed at length in the literature review chapter. Participants were vaguely familiar with the

various age categories and the “typical” grief reactions that corresponded to each age group, but saw the developmental stages as a guide and not a perfect predictive tool:

*I think they are very general. I mean a kid whose 6 or 8 who has never had to deal with illness in their whole world isn't going to be at the same place as someone who has. (P3: 20)*

*You can have some rough ideas about stuff like that. I think it helpful to think about approximating ages and stages and things, but don't bet your life on it. (P2: 12)*

To some participants, childhood developmental stages are reminiscent of stage theories of grief, an understandable connection since each age category outlines how a child is expected to grieve at that stage. One participant said she preferred to talk about children’s grief as a process, rather than a series of stages, because there is a strong likelihood that children will regress or experience things multiple times. This fits nicely with the critiques of stage theories that I discussed in the literature review. Another participant agreed, using a metaphor to show how the concept of stages can be misleading:

*Some people will really think about it as an elevator - you get to the second floor and this is what you see, you get to the fourth floor and this is what you see and it's very predictable. Versus you look out... over trees out there, and you'd see different trees, that are probably similar ages but they look different, they've matured differently. They have different kinds of foliage, different heights, and different ways of looking. Leaning different, affected by the wind, whatever. I think kids are like that too. (P2: 12)*

This comment blends well with the work of Corr (2010) that I mentioned in the literature review, as he also dismissed the elevator analogy. On a practical note, one social worker pointed out that the childhood developmental stages are not much use to HCPs because they rarely see children beyond their current age. They have to respond

to the needs of those children in the present moment, but cannot get bogged down in trying to assess if the child is grieving “appropriately” according to the development categories. Even if HCPs were able to interact with children at different points in their life, it does not seem wise to rely on the stages.

Despite this hesitant stance towards developmental concepts, participants made several remarks about what HCPs can expect to see from kids who are grieving. The participants did not say these reactions or characteristics were universal, but suggested that they were common and perhaps even expected. As HCPs responding to the needs of children with parents in palliative care, participants discussed the need to accommodate these reactions and characteristics for the child’s sake. For example, several participants described children as egocentric and discussed the impact of this when a parent is in palliative care:

*The one that really stands out for me that is really important about kids... is this sense of egocentricity, where kids feel the world revolves around them. And when something happens in the world they have a tendency to point to themselves. (P2: 13)*

*And kids can be very egocentric, right? The other moms are doing this with their kid or that with their kid, why aren't you? A little bit of blame on the parent who is dying. I think that's just a developmental stage and the age. (P3: 5)*

*I think there is some degree of that. But I think, I mean they are egocentric, they do think the world revolves around them. But they also are able to see the other pieces. (P4: 38)*

In these comments we can see a tentative approach to the concept of egocentricity, where there is reluctance to paint all children with the same brush. Although the last comment appears to suggest that all children are egocentric, the participant is careful to point out that kids can see beyond themselves and are capable

of compassion, generosity and empathy. While the participants identified egocentricity as a need that should be accommodated by HCPs, they did not see it as a central concern or something that affects every situation.

Without explicitly referring to childhood developmental stages, participants referred to some other “typical” grief reactions that HCPs might expect from children. Some participants talked about the likelihood of kids reverting in their maturation process, such as toilet-trained children having bedwetting issues. There were comments about children being worried that they could “catch” the illness that their parent has. Multiple participants talked about the tendency of young children to “check in and check out”, referring to a need to engage for shorter time periods, interspersed with play and distractions. I see the merit in this, but I am still concerned that a child who does not “check out” might be seen as an abnormal or someone who is not doing their “grief work”, a point I raised in the literature review. There were remarks about the unique needs of teenagers, including a need to be with peers, to be able to access information without adult assistance and to be involved in their parent’s care. Evidently, participants still relied on developmental grief categories to inform their practice, although they described how these were only to be used as a guide and not unequivocal truth. As I discussed in the literature review, HCPs must use caution when considering such stages and avoid oversimplification. The participants in my study appeared to use the categories as no more than guidelines to understand how children might react when a parent is receiving palliative care and what needs might emerge in such a context. A

social worker described the balancing act required when using developmental categories:

*They do it in their own way. There is no prescription, there is nothing that says "ok you are going to do this, you're going to feel this and you're going to feel this". Maybe not. And even two kids in the same family react differently even if they are a similar age. (P4: 25)*

When discussing developmental stages, the social workers seemed to have encountered a challenge that was not shared by the nurses. When supporting a family, the social worker participants would occasionally be asked by a parent or caregiver if their child's behaviour was attributable to grief or if it was simply part of their development and maturation. Social workers likely encountered this issue more often than nurses due to the nature of their interactions with families, which often involve more follow-up and psychosocial support. In addressing the concern with families, the social workers in my study would explain that there is no clear answer to the question of whether behaviour is grief-related or development-related:

*Time and time again that particular issue was front and centre... What's going on here, is this normal teenage rebellion or is this somebody who is really bummed out because of what is going on? Or is it a combination of both? Probably 9 times out of 10 it's a combination of both. And what are you going to do about it anyway? It's going to be a similar kind of response in terms of trying to understand. (P2: 15-16)*

*That would be part of the conversation with the parent. My sense is that it's really hard to pick out "teenagerism" from grief because part of their developmental task is to be withdrawing and becoming a person in their own right. So that distance is normative, but is it heightened by the fact that their parent is dying or is it just what it would be? And there's often an element of it being a bit more exaggerated because of the impending death. (P4: 16)*

This concern shared by parents and caregivers appears to suggest a need, or perhaps a desire, to understand the cause of their children's behaviours. The comment

“what are you going to do about it anyway?” is a useful reminder that the distinction between grief and development is nebulous and a matter of perspective. It is not particularly valuable for the purposes of supporting children. This reminder appears to apply to childhood developmental stages on a broader level as well, because whether or not a child’s grief fits within their corresponding age category, HCPs must still respond to that individual child as needed. While developmental categories are often presented as an indicator of “normal” behaviour, the participants in my research suggest they should be used cautiously and sparingly.

**Needs related to normal and pathological grief.** Since childhood developmental stages imply that particular grief reactions are normal while others are not, I also asked participants to share their feelings about the terms “normal grief” and “pathological grief”. The participants often made reference to ideas of normalcy before I asked them directly about the distinction between normal and pathological. One participant discussed how the biggest concern for teenagers can be a desire to feel and appear normal and the most important way to support a child with a parent in palliative care is to normalize the situation, which was echoed by other participants as well:

*You will heal from this, but it's not like it happens overnight everybody has their own way of dealing with it. And normalizing those kind of things is really important. And I think that's what I mean by normalizing. Having some sort of understanding that grief is a unique situation but recognizing that there are also qualities to it that are understandable, because other people have gone that way. It is normal to have poor concentration, it is normal to be upset years afterwards, it is normal when you hear that song on the radio and it freaks you out, or you're in the shopping line and all of a sudden it strikes you... Those are all kind of normal occurrences, which if you didn't have exposure to other people thinking or feeling those ways you would think that there is something wrong with you. So that idea of normal helps to recognize that those things exist. (P2: 20)*

As the importance of normalcy became apparent, I asked how this might be distinguished from pathological grief. The participant responses varied on this point.

One participant corrected me on my language:

*We don't call it pathological anymore, because I think abnormal and pathological implies more negative outcome, but we do call it complicated grief, because complicated has the potential to be uncomplicated, or to help deal with the complexities down the road. (P2: 21)*

“Pathological” appears to have a pejorative connotation, whereas complicated is much more palatable. One participant used the term “pathological” before being asked to explain her point, but then backed away from using the term:

*Even having used the term pathological, I struggle with that, because to me that denotes something, it's so medical. Which is part of what I struggle with, because I come from a medical model, to be mindful not to use lots of those terms. (P4: 21)*

This tension is intriguing, leading me to wonder if there is a distinguishable difference between “pathological” and “complicated”. Even though we may have replaced the former with the latter, they are generally used to describe the same sorts of grieving behaviours. Still, I am inclined to think that there is more to this than semantics, because language helps us construct meanings and subjectivities, which fits within my poststructural worldview. I concede that “complicated” can seem less medical and prescriptive than “pathological”. However, I do not see a significant change in the way such grieving behaviours are treated. Whether it is called pathological or complicated grief, participants said they were able to identify it when someone is really struggling to get through the day, stuck on feelings of anger and guilt, or harming

themselves or others. In this way, complicated grief still has the ability to pathologize people who are grieving, which is why I continue to use “pathological” for my purposes.

There was significant concern amongst the social workers that I spoke to that Prolonged Grief Disorder (PGD) was considered for inclusion in the DSM-V, as discussed in the literature review. One social worker questioned how this created false ideals of normalcy, suggesting that grief is bound to have major ramifications on someone’s life and the notion of normalcy is difficult to pin down. Another participant said they had not seen a distinction between normal and pathological grief in children and would only notice a difference if it was drastic:

*Unless something was really obvious and hitting me in the face, like somebody’s not going to school, they’ve stopped eating, they completely change their behaviour... they’ve taken off and they’ve moved to Vancouver, like those would be clues to me that something is going on. But I normally wouldn’t pick up any distinctions, I don’t think. (P5: 15)*

Participants grappled with the dilemma of wanting to help normalize a difficult situation for children and their families without imposing strict boundaries of normal behaviour. Participants felt this was best accomplished by using the same tentative and accessible language and open ended questions used in “The Talk”, which I described previously. This opposition to imposing strict boundaries fits in nicely with some of the general needs identified by the research participants in terms of being open and accessible and providing support and education where needed. There appears to be a tension between wanting to help normalize certain behaviours while not pathologizing others, while still classifying some behaviours as “complicated grief”.

At times, participants were explicit in identifying the needs of children with a parent in palliative care and occasionally the perceived needs could be interpreted through comments on family, childhood developmental stages and the notions of normal, pathological and complicated grief. When asked how effective HCPs are in responding to the needs of children with a parent in palliative care, an experienced social worker stated: "I think there is more awareness about the needs of children. I'd like to think that anyway" (P2: 28). However, heightened awareness does not necessarily indicate that the needs are being met. Another participant said "I just think there needs to be more out there for kids" (P5: 19), but then said it is possible that she is projecting her own needs as an HCP. One of these professed needs is more education and training on children's grief, which causes a great deal of discomfort for HCPs, an issue I tackle in the next section. Although this was not a comparative study of how much HCPs understanding of children's needs have changed over the years, the findings suggest that HCPs are able to identify several possible needs that these children could have.

### **Uncomfortable Caring for HCPs**

As the participants reflected on interactions with children who have a parent in palliative care, they expressed a notable degree of discomfort. Whether it involves speaking to children directly, speaking to their parents or even contemplating what a child might be thinking and feeling, adult palliative care providers often feel uncomfortable around a child with a parent in palliative care. Although participants were adept at identifying the needs of these children, the prospect of addressing these

needs was scary for some. When asked what possible reactions make her the most uncomfortable, one nurse replied:

*I think when kids show me when they're really, really sad I feel really uncomfortable because I can't do anything to make it better. And I think that's because as a mom and a nurse, and maybe who I am, I'm not sure because sometimes the other roles you have impact who you are in the moment right? There's been a few times when some of the younger children have started to cry... oh god, I just feel sick, just because I can't make it better, and it's natural for them to feel sad and you want to let them be sad. I just feel so bad for them, your heart just breaks. (P5: 8)*

As the above excerpt indicates, some HCPs are uncomfortable when children express strong emotions. Her own identity as a mom and a nurse informs her reaction as well, as she described feeling ill-equipped to make things better. Even asking children specific questions is a daunting task in some circumstances:

*Asking people "what do you need?" That's sometimes a really scary question because that's like walking into the lion's den. "So what can I do for you, what do you need?" Well, you might get a laundry list, and what are you going to do with it if you can't do anything? (P4: 40).*

These first two comments demonstrate how the fear of not being able to do anything for a child is a major contributor to the discomfort felt by HCPs. As I will demonstrate in this section of the data analysis chapter, there are a number of other factors that contribute to this general feeling of discomfort. There are different ways that adult palliative care providers attempt to cope with this discomfort and these strategies are present in the data. I have adopted the term “uncomfortable caring” to describe this general discomfort that adult palliative care providers feel towards children who have a parent in palliative care. I use the term “caring” rather than “care” because I use gerunds for coding purposes, as explained in the methodology chapter.

On a basic level, the discomfort largely stems from not knowing how to interact with children (or perhaps not wanting to, which is something I address later in this chapter). Not knowing what to say, how to say it and when to say it are all common concerns. It appears that many HCPs do not feel like they are competent when a child is potentially struggling. It does not seem like children's grief is forgotten about, but it is sometimes ignored or avoided. Whether it was breaking the news to a child about their parent's illness or death or responding to unexpected questions, the data suggests that interacting with kids is harder than it sounds:

*At times I've done it. It sounds like it's easy - it's not. You know you're walking in and there are kids around and there is a part of you that's like "god..." (P1: 17)*

Some participants explained to me that they had consciously decided to become adult palliative care providers rather than work in pediatrics because they feel uncomfortable when a child is suffering. This discomfort extends to seeing children grieving the illness or death of someone close to them. The participants all expressed a fondness for children and there was no disdain for them. Yet, there was no desire to work with children on a regular basis:

*I find kids fun, they are lively when you're with them in their homes. I find them incredibly interesting that they are so spontaneous and they're fun to play with. Not dealing with the sadness and their pain and that stuff. I prefer not to. I certainly will, I would never not do it, but it would never be my choice or what I would do for my line of work. (P1: 33)*

The discomfort appears to apply to younger and older children alike, yet interacting with older children presents its own challenges. Participants said they were often unsure about how to approach teenagers, particularly because they are undergoing a major maturation process physically and emotionally, although this can

occur at different speeds. Uncomfortable caring also extends to interactions with parents about their children, because adult palliative care providers are not always at ease talking to a parent or caregiver about a child's behaviour. In some circumstances, participants expressed that they were worried of having a confrontation with parents or caregivers, which makes them reluctant to engage in a conversation about the children. Although HCPs recognized a need to work with parents and caregivers, one nurse described why this is not an easy task:

*Talking to children for me isn't necessarily the easiest thing to do, so going back and having further conversation about what happened, just...I'm not sure how to react to it or what suggestions or...if they (the parent/caregiver) want to talk about it, I'm always open to having conversation. I can just nod and say "do you want us to get somebody to help them?" But trying to delve into what's going on, I wouldn't feel comfortable. (P5: 10-11)*

As the participants were sharing the uncomfortable feelings involved with supporting these children, they made sure to include what they do feel comfortable with. As adult palliative care providers, many were comfortable with the clinical components of care, including symptom and pain management of the dying parent. They feel competent in their ability to help the parent receiving palliative care feel comfortable. Yet this type of comfort care tends to be patient-focused and symptom-focused, which does not encompass the discomfort that HCPs can feel when addressing children and families. It is also worth noting that uncomfortable caring is not something that is felt solely by the adult palliative care providers, but can be felt by children and families as well.

*I think for kids, it's scary for them, to have so many people come into their lives. We're kind of descending on them as a team. (P2: 9)*

Even though adult palliative care providers may recognize that their discomfort is shared by children and families, this does not necessarily calm their own nerves when faced with the prospect of interacting with children. One reason for this is the various emotional reactions that HCPs might experience, both personally and from the children they encounter.

**Uncomfortable caring and emotional reactions.** I asked participants to describe the emotional reactions that they have witnessed in children with a parent in palliative care and anger, guilt, rejection and fear were common responses. Participants stated that sometimes there was no visible reaction at all. There are exceptions, as a social worker described how some children experience a sense of relief when a parent dies:

*Kids might feel relief that "I don't have to go to the hospital anymore, I don't need to not go into things at school. I can actually be a kid." But then there's the guilt that goes along with that. So lots of talking about how sometimes this is what you might feel like and that's ok. (P4: 21)*

The same social worker also noted a compassionate reaction that she witnessed from a young girl:

*Some really huge acts of compassion and inner strength. We had a little girl whose mom was dying and she was just little teeny, like 5 or something. And she climbed up on the bed and lay there as her mother died. And stroked her mother's face and sobbed. That's when you need a bucket of Kleenex. (P4: 24)*

Clearly, children experience a wide range of emotions when they have a parent receiving palliative care. I have already mentioned how participants feel uncomfortable when they feel there is nothing they can do when a child is upset. They expressed feeling uncomfortable around a child who is struggling. Yet, some participants also said that there are no emotional reactions that shock or surprise them:

*Nothing stands out that surprised me. Maybe I've just been around too long that not a lot surprises me. (P5: 8)*

It is interesting to consider that many HCPs express some level of discomfort around grieving children, yet this is not due to being surprised by their reaction. In fact, it would seem that they are entirely unsurprised that they feel uncomfortable. Even if a child's reaction is expected, it still does not seem to erase the discomfort that HCPs feel. Nor does it prevent them from having their own personal reactions, as some participants described feeling anxious, getting a rash or becoming frustrated when confronted with children who are struggling. In fairness, participants were also able to identify encounters with children that made them feel good, usually when the child was coping or communicating well with their family. In circumstances where a child is struggling, witnessing their emotional reactions can lead to emotional reactions for the HCPs themselves. This contributes to their overall feeling of discomfort, requiring strategies for managing their emotions.

Self-care emerged as a key strategy for coping with uncomfortable caring. Participants were cognizant to avoid personalizing the grief experiences of children and to avoid overburdening themselves. A social worker used the term "dual awareness" (P4: 42) to describe how HCPs need to develop an ability to state what is happening in front of them and within them. This dual awareness gives HCPs a greater perspective of their role and could quell some of their discomfort. Without practicing self-care and giving voice to those feelings and internal experiences, HCPs are at a greater risk of ignoring their own emotional reactions. This will only increase the discomfort some HCPs feel when interacting with children who have a parent in palliative care.

One participant talked about how self-care involves fostering “exquisite empathy” (P2: 42). The participant referred me to an article that states HCPs practice exquisite empathy when they are “highly present, sensitively attuned, well-boundaried (and have) heartfelt empathic engagement” (Harrison & Westwood, 2009, as cited in Kearney et al., 2009, p. 1160). Under these conditions, HCPs are energized by difficult situations, rather than being subject to burnout and exhaustion. Exquisite empathy and other self-care strategies can help HCPs cope with their own discomfort so they can better support children and families.

**Uncomfortable caring and HCP training.** There was a general feeling amongst some of the participants that their discomfort interacting with children could be quelled if they were given sufficient educational and training opportunities. Desiring more training opportunities regarding how to support grieving children was a key process in the data. Some participants expressed feeling underqualified and ill-prepared by their formal education background:

*You just don't feel qualified. We spend a lot of time learning how to talk to people. I don't think we ever feel really comfortable talking to kids. (P1: 18)*

*Over the past few years since I've been with the (palliative care) program you hear a little bit or people would talk about it, but because we don't necessarily interact with the children often, I really have no clue, in nursing school you learn nothing about it. (P5: 11)*

Participants expressed a desire to attend regular workshops on the topic of child grief and have access to more support. They want to learn how to start difficult conversations, how to answer unexpected questions and how to convey important information to children. These educational training opportunities could be a solution to

the nervousness and fear that HCPs experience, according to participants. It is noteworthy that the social worker participants did not express this same need for further education, which suggests they often adopt the role of educator in these situations, providing support and training for other HCPs.

In my conversations with HCPs, I wanted to explore the extent to which further education would resolve their discomfort when interacting with children. There is no doubt that providing more educational opportunities can be beneficial, but it could be that HCPs have the necessary training but are simply unwilling to engage children due to discomfort. This is a point I raised in the literature review chapter while citing Turner et al. (2007). I asked the participants if they thought HCPs were simply unwilling or reluctant to engage with children who have parents in palliative care. A social worker suggested that requesting more educational opportunities is sometimes used as a fallback:

*Sometimes people are just uncomfortable with the topic and so the fallback is that if I had more education I'd do a better job. Which I'm not convinced is entirely true. (P4: 29)*

The same social worker attributed this sort of behaviour to fear that is felt by adult palliative care providers and the practical implications of not having the time to support children appropriately:

*I think there is some fear. What if I say the wrong thing, what if I hear something I don't want to hear, what if they cry and I can't deal with it, but there's also the constraints of having to look after the rest of your patients. What if you get involved in a conversation with one of these kids and then patient number 4 or 5 gets into a crisis and you need to go and deal with that? Because there's not enough staff to be able to hand it over to somebody else. So I think that might be part of it. (P4: 29)*

One of the nurses I spoke to agreed, suggesting that the reluctance to engage stems from being shy, nervous and wanting to protect yourself from a substantial emotional investment. Another nurse could relate to these reactions and expressed feeling quite uncomfortable when interacting with children, stating that she required much more training before she would be at ease. She felt strongly that educational opportunities would give her the tools to manage her discomfort. However, she felt that HCPs should not use a lack of training in children's grief as an excuse to disengage:

*Even if you don't have the education, I'm always putting myself out there. I know that there are lots of times that situations make me uncomfortable and I always put a toe in the water. (P5: 13)*

The metaphor of "putting a toe in the water" was an in vivo code and acts as a good visual for how other HCPs manage this aspect of uncomfortable caring as well. Participants felt a responsibility to respond to children regardless of their own discomfort. They discussed a desire to be less afraid in conversations with parents and caregivers so that both sides would have an easier time engaging with the other. Others expressed interest in seeking out more contact with children who are grieving:

*It's just like stepping into the deep end of the pool. The more you do it, the more confidence you have, the more you learn and the more you are able to feel comfortable. (P4: 30)*

Whether it is just putting a toe in the water or jumping into the deep end, the act of intentionally immersing themselves in uncomfortable caring is a coping strategy for some HCPs. There is still a desire for more education on the topic of children's grief, but there appears to be a recognition that training opportunities do not constitute a panacea for uncomfortable feelings.

**Uncomfortable caring and HCPs' level of involvement.** Participants' experience with uncomfortable caring extends to how they situate themselves in relation to children and their families. Not knowing where they fit in the process of supporting children and families generates discomfort for HCPs. The participants are always striving to understand what their role is in relation to children and families. They did not want to cause hardship for the families:

*I was very careful not to intrude on their private time, because I believe that's important. You don't insinuate yourself in and say "I want to be with you now". Because you never know what the time limit is, right? (P4: 8)*

As participants struggled to define their role and the appropriate level of involvement, there appears to be an assumption at times that HCPs should be doing *something*, whatever is possible to support children who have a parent in palliative care. One participant was wary about this assumption, citing a personal belief that "'being' is as important as or more important than 'doing'" (P4: 25). This is a key finding, because much of the coding process involved participants "doing" things to support children with a parent in palliative care. For example, talking to the children, educating the families and themselves and assessing levels of need are all things that participants feel the need to "do". In fairness, I intentionally coded for gerunds and action, as described in the coding section of the methodology. Nonetheless, "being is more important than doing" was a useful in vivo code to describe how some HCPs combat the urge to take action by any means necessary.

Participants described a sense of anxiety when confronted with a child who might be grieving, despite knowing that there are no simple actions that can rectify the situation:

*Sometimes I would think "oooh, I better come up with something here". I'd have that feeling, but part of me also knew that was a dangerous road to go down. To always feel that you have to have the answer. (P2: 5)*

*You may never change it so I don't know how people deal with it. Maybe that's with kids, you can't do a lot of things with them. (P1: 26).*

It appeared that one thing that HCPs could "do" is simply "be", meaning that HCPs may need to simply relax, particular when a family is doing well. Rather than entering a state of panic when they encounter children, they can work cooperatively with the family and take their cues from them. Perhaps the reason we do certain things as HCPs is to feel like we are helping a child with a parent in palliative care, even when simply spending time with that child may be the most appropriate route to take. The nurses I interviewed were quite comfortable with the appropriateness of doing nothing under certain medical circumstances, particularly when pain is controlled and there is good symptom management. The care becomes uncomfortable when HCPs are taken outside their comfort zone and are unsure of what to do, if anything.

When HCPs are involved in caring for children who have a parent in palliative care, their role can be direct and indirect. Participants were less comfortable caring for children directly, which also appears to be less common than indirect involvement. A social worker said that some children probably appreciate having an opportunity to speak privately with a care provider, but feels that it is not easy to arrange direct encounters with kids:

*There are probably more opportunities for that. But I think sometimes the parents are protective of their kids and aren't sure about that. Sometimes the set-up of having those kids on their own isn't as easy as you would think, I find. But I think the opportunities are there. (P2: 9)*

A nurse working on an adult palliative care ward agreed that direct involvement with children is rare:

*It's not specific time with them. It's as you go in and try to explain anything to them. Or just talk about what you're doing. You know, "this isn't going to hurt your mom what I'm doing". (P3: 10)*

Other participants felt that HCPs could make an effort to have more direct involvement with children, because this would make the encounters with the medical system less intimidating for children if they became familiar with the people providing care to their parent. However, a social worker recognized that even though there could be more direct involvement, the status quo is "better than adequate" (P4: 41). It is unclear what amount of direct involvement would be inadequate, but it appears that the participants recognize that they have limited opportunities to talk directly with children. The scarcity of these opportunities prevents HCPs from becoming more comfortable in their supportive role.

**Uncomfortable caring and privilege, race, gender and class.** As we discussed supporting children with a parent in palliative care, I asked participants to reflect on issues of privilege, race, gender and class. In some instances, participants reflected on the privilege of certain patients and families. Multiple participants were concerned that privileged people have more access and better advocacy systems, which makes it harder for less privileged people to access the same supports. A social worker described having

a strong sense of social justice and it frustrated her to see favoritism or queue-jumping in the health care system:

*I think that we are so privileged to live in a country where we actually have access to health care for free... I think we need to be grateful for that and that's also the piece of how I see social justice is that we don't take that for advantage and don't abuse that privilege. (P4: 32)*

Privilege was also discussed in terms of religion. One participant discussed her frustrations working in a Catholic hospital where there are crucifixes in every room and the annual memorial service that used to be replete with religious imagery. In this context, the participant was concerned that patients who practice the same faith as those professed by the hospital are privileged to have a more welcoming and accepting environment:

*I would always believe and I have said that if I were a Jew, a Muslim, a Baha'i, an agnostic, an atheist, Buddhist, Hindu sitting in this audience I'd feel really excluded. So we are a community in this city and in this province and this country, but more specifically in that hospital and I really had a hard time with that. And so when people who were admitted, more specifically Muslims or Jews, I would just say to them "want me to take that crucifix down?" Because I would find it offensive if I was that person. (P4: 10-11)*

I tried to encourage the participants to reflect on their own privilege as well. I asked one participant if she thinks her own race, gender and class influences how people experience the palliative care program. She agreed that it probably could have an influence, but was confident in her ability to adapt in order to accommodate a child or family:

*I guess it can. But I also try to adapt about who I am. My different experiences...I had to deal with a diverse group of people so I can leave who...I can't leave who I am...I can adapt who I am and bring different parts of my experience to interactions. (P5: 26)*

As the above quote suggests, some participants acknowledged their own privilege but did not feel that it had a significant impact on their work with children and families. Other participants were more upfront about acknowledging their privilege and how it could create uncomfortable interactions with others. It bears repeating that I have discussed the critical importance of race, gender and class at other points throughout this thesis. Therefore, I think it is problematic to claim an ability to simply adapt one's identity, regardless of the circumstances. This sounds like cultural competency, which Pon (2009) refers to as "new racism" (p. 59). Pon argues that cultural competency "shields students and social workers from the difficult work of self-reflexivity" (p. 69). I agree that we can hold ourselves open to differences, but we must also recognize our own privileges and situatedness.

In fairness, I question whether I did enough to disrupt my own privilege during the interviews, because I was asking the questions and not talking about my own advantages as a White male or as a researcher. Furthermore, being a White man may also have made it easier for me to approach several different parties to obtain interviews in the first place. Clarke (2005) writes that researchers are responsible for designing research in a way that explicitly gathers data in underdeveloped or silenced areas related to race, gender and class. If I wish the data said more about race, gender and class, perhaps I could have done a better job designing and conducting the research in order to extrapolate these issues. This could be perceived as another potential limitation of my research. Despite this possible shortcoming, I did manage to generate

some discussion with participants regarding the impact of race, gender and class issues. It was the topic of race that garnered the most attention.

***Uncomfortable caring and race.*** The notion of uncomfortable caring arose in the context of race several times. Most often, when I asked how issues of race impact their interactions with children, the participants would use the words “culture” and “cultural background” rather than “race”. I also noticed the tendency to equate race with culture in the literature. Participants talked about certain cultures being more family-oriented, communal and multigenerational, but tended to avoid deeper engagement with race issues unless I continued to probe. It appears that HCPs are more comfortable talking in terms of culture rather than race. This seems partly due to the way some participants are more interested in the individual family “micro-culture” (P5: 26), but it also seems that “culture” helps sanitize the conversation. All of the participants told stories about their encounters with people from different cultural backgrounds and how they try to navigate these encounters. A nurse explained why she asks families about their culture:

*It's looking at the situation and trying to be really sensitive. You don't know unless you ask. I think you can pick up on things, but picking up on things is different than actually asking. (P1:31)*

A social worker used the line "it's important for us to know what's important for you" (P2: 33) to navigate cultural differences. Another social worker discussed the importance of seeing each person and family as unique and avoiding generalizations and stereotypes. A nurse expressed how she tries to integrate cultural differences into the care she provides, but there is usually little response:

*Most people that I come across in my work, you ask them what they want from their Aboriginal culture or what it means to them, what does it mean to their*

*health care, how can we integrate that, more people than not don't want to respond to that question. I always love it when people do respond to that question, but often they don't want to talk about it. So I wonder how that can be integrated better in our program maybe. (P5: 28)*

I continued to probe because it appeared that race was another potential site of silence in the data. As I enquired further, racism was addressed by participants to varying degrees. A nurse spoke about the judgement that some HCPs direct at Aboriginal families who come to Winnipeg to support a family member receiving palliative care and use the opportunity to go shopping. During this conversation, I used the term "Aboriginal" rather than "Indigenous" because that is the term the participant used. When I asked if she thought racism was involved in the judgment directed at Aboriginal families, she said "I think a little bit" (P3: 39).

Another participant spoke about feeling torn when there is "a very large family who have enormous expectations, and some of those expectations include having the staff look after the kids" (P4: 32). I then felt compelled to ask if those families tend to be from a different ethnic background and she said yes, "which makes it really difficult because you don't want to be racist, you don't want to, you know?" (P4: 32). I had to ask again to clarify that she was referring to Aboriginal families. She went on to say how she always tries to accommodate those requests, but often cannot due to the staffing and time constraints already discussed. This is another instance where a participant felt uncomfortable in providing care. Her comments about race suggest the racial issues have an impact on her encounters with families, at the very least. She found it difficult to be as fair as possible to all families while trying to accommodate the requests of the larger Aboriginal families.

After one participant expressed that Aboriginal traditions could be better integrated into the palliative care program, I asked her if she thought this lack of integration could be considered a form of institutional racism. She said she felt that it could be, but then said that the system simply needs to be more welcoming for everyone:

*Good question, oh my goodness. I guess it could be considered that. I think we just need to be more inclusive, period. (P5: 28)*

This belief that inclusivity is the solution was debunked by Ayonrinde (2003) in my literature review, who notes that such an approach keeps the focus on the other person, rather than encouraging the HCP to reflect on their own privilege. She then went on to say that it is difficult to understand how institutional racism comes into existence:

*It's not something that you want, but just something that's necessarily there. I guess not necessarily, not unavoidably there... bred to be there at this point in time, I don't know. I don't know. It's an interesting topic. (P5: 29)*

Participants did not appear comfortable engaging with race issues on a broader level. Despite their tentative acknowledgements of racism, participants were relatively silent in respect to how this issue impacts their practice, suggesting it was unlikely to change their approach. A nurse said she is often concerned about how she is perceived:

*I do see that as one of my concerns. White face coming into an Aboriginal home and there are 18 people there, and you're dealing with them all, there's always a bit of a...the conversation stops, people put their heads down, you're thinking "Why? What did I do?" (P5: 28)*

Despite these concerns, the same nurse described herself as a “bit of a Pollyanna” (P5: 29) and then said “race doesn't really resonate a lot with me, which is

probably a bad thing because I think I'd be more culturally sensitive if it did" (P5: 29).

Although she expressed concern about being the only "White face", there appears to be some hesitancy towards grappling with that discomfort, opting to not engage with race issues because they "don't resonate". I then asked "do you think it doesn't resonate with you because you're White or just because of the person you are?" She responded by saying that race does not resonate with her because of the diverse experiences she has had with many different people:

*We are all kind of the same. I think I've just been open to different things. Which I guess sometimes that is a downfall because I don't think necessarily that I'm as culturally sensitive as I should be, if that makes sense. (P5: 30)*

There is a recognition that she is not as sensitive as she should be, but she says there is little she can do since race does not resonate with her. In a way, she is not letting herself off the hook entirely when she says she should be more culturally sensitive, but appeared uncomfortable talking about how this would change her approach. I asked how she could become more culturally sensitive, and she replied by saying she needs to do more reflection and ask more questions when such issues arise. She expressed that these issues make her feel confused and frustrated at times, but feels a need to do what she can to make herself comfortable. This was echoed by one of the other participants, who described how she forces herself to get comfortable in uncomfortable situations:

*So part of my learning has been learning to acknowledge that in myself that I really just want to get out. But making myself stay. Learning to be a bit more comfortable, I'm never going to be really comfortable but hoping to be a bit more comfortable than I once was. (P4: 33)*

As participants discussed racism, I saw a trend where participants would engage with the subject and then back away from it. Backing away took a number of different forms, including describing a situation as just “a little bit of racism”, or proclaiming they “don’t want to be racist” or declaring that matters of race “don’t really resonate” with them. In another example I provided above, I had to explicitly ask if a participant was talking about Aboriginal families who come to Winnipeg for palliative care. I think it is a troublesome trend that HCPs will only talk about race in limited ways, because it makes it awfully difficult to engage with this issues in a meaningful way if HCPs tend to retreat from them. I see this tendency in myself as well and there was an opportunity in one interview to address the matter of race head-on, but I chose not to. Specifically, one participant used the word “gypped” to describe how children might feel when their parent is dying, which is a derogatory word that refers to the Roma people. I asked her to clarify what she meant, to which she said “ripped off” (P3: 5). I did not pursue this further or state my own discomfort with the term. At the time, I did not feel comfortable interrupting her point to draw attention to the pejorative term and I did not want to derail the interview. Evidently, I could be better at engaging with such issues myself.

***Uncomfortable caring and gender and class.*** Although I was able to explore the topic of race in limited depth, there was even less discussion on gender and class. The discussion on gender did not go beyond a surface level discussion, as participants felt that their interactions with children were not greatly impacted by gender. I also explored how the gender of the adult palliative care provider might be a factor. One

participant said the gender of the HCP would likely only matter if there were issues related to abuse. Otherwise, kids are generally indifferent towards gender in her experience:

*If they want to be supported, if they want to engage, they are going to engage. It doesn't matter who it is, unless they've had a bad experience. So certainly if there had been an abusive relationship where they were abused by someone of the other gender, then of course you need to be really careful about that. But for the most part, kids are much more accepting than we are when we become adults. (P4: 34)*

A male participant said he could see that gender might play a role when you are trying to support a family, suggesting that it might not be as easy to come through “the metaphorical door as easily as if you were a woman” (P2: 34). Yet he said that as long as HCPs want to connect with people, then children and families are usually receptive to it. Generally speaking, gender does not create uncomfortable situations for the HCPs that I spoke to.

There was limited engagement with issues of class as well. Some participants mentioned interactions with people with who are poor, but there was little said about how this could affect their interactions with children who have a parent in palliative care. One participant described how she feels when she encounters a family with limited resources:

*Some of the people I've seen over the past few months are quite disenfranchised and my heart breaks, because I think after so-and-so dies, what does this mean for you? And you think about the families in one apartment and they live downtown in the core area in subsidized housing. There is mom and there are their children, plus there are the grandchildren and they are all living together. I think what are we going to do for all of you after? (P5: 27)*

Class and gender both appear to be sites of silence within the data. In the literature review, I described how Lowe (2011) sees gender as a site of silence within health care. I would argue that class matters are as well. For example, families that are supporting someone in palliative care usually require financial flexibility to do so. Lowe argues that HCPs do not examine their privilege nor do they enough to disrupt dominant discourses. She asks “is it possible to maintain a socially accountable practice from the perspective of privilege of healthcare professionals?” (Lowe, 2011, p. 183). Participants were willing to talk about these matters, but the conversation did not include an examination of privilege or dominant discourses. After completing the interviews and analyzing the data, I am left wondering if I should have delved deeper into this area. For example, does class mediate whether HCPs become directly or indirectly involved with particular families? How is class related to the desire amongst many HCPs to work with vulnerable and disenfranchised people? How is class wrapped up in the concept of resilience, in terms of “striving for a better life” and “overcoming the odds”? Can class itself make palliative care uncomfortable for the patient, family and provider?

**Uncomfortable caring and judgment.** Participants talked about being uncomfortable with situations where they feel a sense of judgement towards a family. To address this discomfort, participants talked about intentionally suspending their judgement:

*Swallow hard, take a good breath... when I walk through that door know this is not my environment, I can't judge this. This is not how I live, this is their life. (P1: 13)*

*I think if people can have other perspectives and understand people then they are going to suspend their judgement. (P2: 5)*

*I think you do suspend it to deal with the "now" and taking care of the person, still trying to walk a fine line of being respectful. But there is judgement going in the back of your mind going "how could you have done that? How could you? How could you have done that?" So I think you do suspend it a little bit so that you aren't judgmental in there. Because you don't know the person's story and you don't know what they come from. (P3: 27)*

However, participants expressed feeling judgemental on various occasions, despite their efforts to suspend their judgement. Participants reported feeling more judgemental when families choose not to disclose accurate information about a parent's illness to a child or when they encounter a high-risk situation that is unsafe for children. One participant demonstrated how judgement and race are sometimes intertwined by telling a story about feeling judgemental:

*We had a woman, a lovely, lovely patient who was Native and a teacher and she was amazing and wonderful. She had come so far because she had been through residential school and really was an amazing woman in her 60s. But her grown children, in their 20s, her grown daughter was stealing from her bank account. So you go "aggh". Your mom came so far and now you're looking very stereotypical. Which doesn't sound good because I'm White and privileged and what have you, I did not come from a background like that. So I don't know what her issue is. You think "oh, you're taking so many steps back". I don't know, does that make sense? (P3: 27-28)*

This is a good example of uncomfortable caring, as the participant was very uncomfortable with the situation and was trying to control her own feelings of judgment. Although she feels that the daughter "looks stereotypical", she is also keenly aware that her own position as a privileged White woman influences her reaction. Nevertheless, she still feels that the daughter is taking several "steps back". In a sense, she appears to be taking responsibility for being judgemental but is unable to prevent herself from passing judgement. I noticed that several participants spoke about the

importance of not being judgemental but still wrestled with feelings of judgement, citing the need to use sound professional judgement in certain situations. After this particular participant identified her own privilege, I asked her how her self-awareness informed her feelings of judgement, to which she replied “I really try to think I have not walked in anybody's shoes but mine. So try not to pass judgment” (P3: 28).

The notion of someone “looking very stereotypical” reminds me of the Foucauldian concept of the medical gaze. Foucault introduced the term in *The Birth of the Clinic* (1963/2003) to refer to the way the patient-subject is constructed by modern medicine in a way that dehumanizes them and renders them visible and knowable to the trained medical eye. The gaze of medical professionals places judgement on the subject. Foucault (as cited in Gutting, 2005) describes how the medical gaze constructs the patient as an object of knowledge and the medical professional as the knower. As it relates to my analysis, the term “looking very stereotypical” seems to construct an understanding of that person in a very particular and negative way, even if it is not a “patient” per se. This is one way that HCPs pass judgement on others, which encourages people to act in prescribed ways. I do not take issue with the discomfort felt towards someone stealing money from their mother, as described in the participant’s quote. However, it seems to me that how we address such issues requires a great deal of caution.

Participants work hard to suspend their judgement in uncomfortable situations, but find it difficult to completely eliminate a sense of judgement. It appears that HCPs are aware of the perils involved with judgment, but their professional roles often

require them to judge high-risk situations where children may be at risk. Struggling with the tension between using sound professional judgement and wanting to be non-judgemental is a source of discomfort for adult palliative care providers.

**Uncomfortable caring and abusive situations.** As I alluded to above, judgment is required in potentially unsafe or abusive situations that children might find themselves in. Participants could not recall many examples of abusive situations involving children with a parent in palliative care. One long-time palliative care nurse said she has never encountered an abusive situation in her work with families in the palliative care program. A social worker recounted dealing with one or two abusive situations, although wondered aloud if abusive situations were hard to identify. This is an important point, because abuse may be occurring even though HCPs may not witness it. Although the participants indicated that it was rare for them to encounter abusive situations, it can be insightful to consider the exceptions where participants were aware of abuse occurring.

One participant described visiting a family after the mother had died and becoming concerned about how the father was managing his own anger and whether he might be taking it out on the kids. Without witnessing an incident but feeling concerned about the children's welfare, the participant tried to engage other relatives and checked in with the family regularly. The participant reported that they still think about that family a lot, especially when they drive near the home.

Another participant told me about a family where a 12 year old girl was expected to do the primary care for her mother, who was living with HIV and experiencing severe

diarrhea. The child was expected to do the grocery shopping, run errands and clean the commode in unsanitary conditions. Her mother referred to her younger brother as a “good-for-nothing”. The participant worked hard to have the mother admitted to the hospital for her diarrhea and was able to help create a care plan for the children.

One participant described a time where a grandmother was dying and she had her grandchildren in the hospital room with her when an ex-partner arrived. The ex-partner had a history of sexual abuse and the hospital had the documentation, so the participant confronted the man and told him he had to leave. The participant described feeling quite uncomfortable with the prospect of confrontation and could still clearly remember sitting across from this man who she was sending away:

*It was a hard conversation to have because it was that confrontation and that's not my comfort zone. But there were lots of kids on the ward visiting, not particularly kids who had a parent dying, but kids visiting, so it was a risk. Plus this patient's grandchildren. And that was a risk we weren't prepared to take. (P4: 35)*

It may come as no surprise that participants were not very comfortable dealing with abusive situations or the challenges that accompany it. Abusive situations were another cause of uncomfortable caring for the participants. The lingering effects that participants felt after encountering abusive situations suggest that some interactions tend to stay with HCPs long after they happen. Participants used the term “moral distress” to describe the way certain situations stay with HCPs long after the conversation is over:

*The most difficult situations are those that people do things, that there's lots of moral distress. That's the term, where we watch people do things that are really hard to accept. (P2: 36)*

*If I can't take myself out of that situation or if I'm identifying too much with what's going on, I think that is when those conversations stick with you more. Because we're left with a little more of that moral residue... I think that's when things get confusing and when those things stick with you. (P5: 41-42)*

As I interviewed adult palliative care providers, it became apparent that there are a number of aspects that cause them to feel uncomfortable when supporting children with a dying parent. At times it can be the child's or their own emotional reactions, the feeling that they lack the proper training, lack of clarity of their role or issues related to race, gender and class. Participants also struggled with their own feelings of judgement and felt uncomfortable addressing potentially abusive situations. Collectively, these factors contribute to what I am calling "uncomfortable caring".

### **The Team Concept in Palliative Care**

Every participant spoke about the concept of teamwork and the influence that the palliative care team has on their work, including their interactions with children who have parents in palliative care. The indispensable role of the team is a major finding of my research. Being part of the palliative care team helps make the work more comfortable for HCPs, which is notable when juxtaposed with the uncomfortable caring discussed in the last section. All of the participants spoke about the appeal of working with the team in palliative care and how it is a good fit for them:

*Wouldn't ever go back and say I made mistakes in choosing that role, it was the right role. I was lucky. (P1: 1)*

*What really attracted me to palliative care was the team. The concept of team. (P2: 1)*

*When I got into palliative care I loved it. It was just like home. (P3: 1)*

*It just felt like this was a good fit. I believe I had the best job in the hospital. Loved it. (P4: 1)*

*It really was a natural fit and progression for me because it took everything that I ever believed in how to treat people as a whole and brought it into our program. (P5: 1)*

Participants described feeling privileged to work with people at the end of their lives and that there is an open-minded approach in palliative care that is not always present in other areas of health care. Participants spoke enthusiastically about the positive environment on the palliative care team and expressed a deep level of trust that the team would provide the necessary support to children and their families.

*I have great respect for the program. It's not just the person it's the program. I know they will follow through. I have no doubt about that. (P1: 7)*

*I've learned over the years that a group is a lot more powerful than an individual and can provide a different kind of care. (P2: 2)*

*The team is a huge concept and actually the team on palliative care was really well integrated and worked well together. (P4: 4)*

Participants described the team as interdisciplinary and all of them felt that their opinions were valued and respected. There are debriefing opportunities after challenging encounters with children who have a parent in palliative care and HCPs can consult and coordinate with other members of the team. One participant said that the palliative care team will often “go full hog” on a family (P1: 8). Overall, the team environment makes it easier to support children who are in contact with the adult palliative care program. In fact, some participants declared that they had never witnessed a situation where a child did not receive the necessary support:

*I know they follow through because that's been my experience. I've never seen anybody dropped. I have great respect for the program. It's not just the person,*

*it's the program. I know they will follow through. I have no doubt about that. (P1: 7)*

After the first time that I heard the claim that no one is “dropped”, I tried to uncover exceptions to this. Although some participants admitted that they have seen adults receive insufficient follow-up, there was confirmation that the team is particularly vigilant when children are involved. However, there are three caveats to that claim. One is that the palliative care team tends to provide support on a short term basis, meaning that sometimes the participants make referrals elsewhere and there might be inadequate support after contact has been ended with the family. A second caveat is that the perception of being “dropped” often differs between HCPs and families. Participants noted that sometimes families have unrealistic expectations, but that the palliative care team does what it can with the resources that are available. A third caveat that concerns me is that if someone was “dropped”, meaning they were forgotten about or not provided with the necessary resources, then it is hard to remember somebody who was forgotten in the first place. It is interesting to consider how the participants spoke about having opportunities to debrief and feel confident in the ability of the palliative care team to provide the appropriate follow-up, yet they also shared their concerns about staffing shortages and resource strains. It seems that participants feel that there is a very strong team, but it could be made even stronger with the appropriate resources.

Despite several statements that were strongly supportive of the team, participants feel that there is room for improvement in ways that would benefit children with parents in palliative care. One participant proposed that the adult palliative care

program would benefit from having a child life therapist who specializes in working with children. A social worker told me that nurses, doctors and social workers on the palliative care team still disagree on occasion and this leads to tension and confrontation within the team, which can negatively affect children and families. An experienced nurse commented on the tendency amongst younger palliative care nurses to take on too much. Another participant talked about how the mentality of the palliative care team has changed over time. Rather than doing whatever is needed in the moment, team members are less flexible and cooperative than they once were. The participant suggested that there might be a sense of entitlement amongst some newer members of the team who insist on not working evenings or weekends.

With some exceptions, participants had many positive things to say about the team and its ability to react and respond to children's needs. These include having trust in other members of the team and feeling supported. The team concept emerged as a key process in the data. It informs participants' professional identities and plays a major role in their interactions with children who have a parent in palliative care.

**The team and the social worker role.** The role of the social worker within the team was a sub process in the data. The nurses I spoke to talked about relying on social workers in adult palliative care to help in difficult situations involving children and dying parents. The nurses rely on social workers for education, support and difficult referrals when they feel a situation is beyond their level of training or expertise. Social workers frequently follow-up with nurses to let them know how a particular family is doing.

Nurse participants acknowledged the large burden and pressure this could entail, but they were adamant about the crucial role that social workers play:

*My go-to is our social worker. Ok, I think there might be a problem, here you go. (P3: 25)*

*Sometimes we're with the social worker which is great, we really like that. We're still involved, we form an attachment with those kids and family, but not always, because you have other people to see. Ideally nurses like to be involved with the social worker, or even with the doctor, but can't always. (P1: 17)*

One social worker expressed some irritation about the pressure and expectations that are often placed upon social workers:

*A position I didn't like was the one where "oh, what would \_\_\_\_\_ do?"... Or "oh, I wish I could talk like you"... There would be a really difficult situation and all eyes would come down the table to me, you know? (P2: 4)*

Social workers talked openly about the importance of knowing their own limitations and not trying to solve other people's problems for them. Part of the social worker's role is to support other members of the health care team, which includes finding ways for nurses and other professionals to use their own skills when supporting children and families. The social workers were concerned about the perils of having rigid roles and worked hard to facilitate contact between nurses and children within the adult palliative care program:

*The majority (of nurses) are very much well rounded, very skilled, very psychosocially-oriented people and I think our job as social workers sometimes is to tap into that. To help them and say "you've got the skills to deal with this, I think what you need is some support in dealing with it and some opportunity to debrief about it and where you go from there." (P2: 6)*

Above all, the social workers in the study wanted other HCPs and families to know that their role is not to be a "fixer" who resolves problems or difficult situations.

This is a message that social workers spending a lot of time conveying to other members of the team:

*I spent a lot of time explaining that I don't fix things. That's not the social worker's role and what you try to do is help the people find the tools to move themselves through it, that there's no Mr. Fix-it going on here. (P4: 17-18)*

The social workers also described their role as forming connections, training students and staff and supporting people during a “critical, awful, intimate time of their lives” (P4: 2). It is interesting that both social workers I spoke to used the term “planting some seeds” to describe how they support children and their families. Participants suggested that it is impossible to provide good support if you are unable to connect with others:

*The biggest part of how palliative care operates and the biggest part social work I would say operates is forming connections and relationships with people. You can be well-schooled in therapy and well-schooled in counselling principles, but if you don't have the ability as a human being to connect with another human being, you're going to be in big trouble... our raison d'être is connecting with people and families in particular as a unit of care. (P2: 35)*

The importance of connection cannot be understated. A social worker reflected on how social workers and palliative care providers in general can sometimes start believing that every family and every child is accepting of palliative care involvement. This can be a dangerous assumption, because sometimes HCPs cannot connect with certain children and their families, resulting in potentially damaging relationships. The participant warned that some HCPs get caught up in what they think the child and family “should” do or what is in their best interest. The role of the social worker is to recognize their own limitations and help others see when it is time to back away:

*So there are some people that you won't connect with no matter what, for whatever reason. You really need to recognize that, and to not stop trying to connect necessarily, but also recognize not to spin your wheels. Or not do things that are crossing a line to the 'shoulds'. (P2: 36)*

The social workers in my study said that they occasionally encounter resistance to social work involvement. Although the social workers involved in my study echoed the sentiment that their opinions and respected and valued, they described what is was like to work within a biomedical model:

*You walk into a medical setting which is predominantly medically oriented and social work is seen very much as a secondary profession for lack of a better term. We do view the world differently... I think we brought to the table a very unique perspective but also an important perspective of understanding why people do what they do and understanding how people can relate to one another. (P2: 2)*

Despite feeling like a “secondary profession”, social workers still feel that their opinions are respected and valued by other members of the palliative care team. It is difficult to determine how this tension is reconciled. In other words, why are the social workers in my study not more concerned with the professional hierarchy in the biomedical model? After some reflection, I believe that social workers are concerned with the hierarchy in the biomedical model, but also place tremendous value on being part of an interdisciplinary team. I am reminded of Payne’s (2006) work on social worker professional identity, which is shaped by interactions within interdisciplinary teams. One social worker in my study confirmed the value placed on interdisciplinary teams:

*What's powerful about teams is that people, individuals and family members can kind of choose who they want to relate to. Not only as a doctor, nurse, social worker or whatever, but as a person. (P2: 4)*

It appears that the social workers in my study consider their role to be embedded within a interdisciplinary team. This does not change even within a

biomedical model that elevates the medical profession over social work. The social workers were still concerned that the biomedical model tends to position medical concerns over psychosocial ones. One social worker considered this to be problematic because “every day is psychosocial” (P2: 46), meaning psychosocial concerns undergird much of the work that goes on in palliative care:

*It's a medical model. So it's doctors, nurses, and then allied health. But it wasn't that evident. I would organize family meetings, for example, and no one said to me ever "I'll organize it. I'm the doctor, I'll organize it" or "I'm the nurse". That was part of my job and that's what I did. (P4: 4)*

The above comment reiterates the hierarchy in the biomedical model, but also speaks to the interdisciplinary team involved in palliative care. I feel that working across disciplines is important, but I agree with Dybicz (2010) who I cited in the literature review, who argues that social workers must adopt a critical consciousness that resists dominant discourses about professionalism. Many HCPs recognize the instrumental role that social workers play in supporting children with a parent in palliative care and families in general, so it is crucial that social workers remain critical towards the biomedical model that diminishes the importance of the social work profession. The role of the social worker appears to be one of connecting, supporting, debriefing, educating and relationship-building. The importance of social work in supporting children who have a parent in palliative care is evident from the data, but social workers still face some challenges in trying to provide the necessary support.

**The team and the divide in adult and pediatric palliative care.** My research question of “how do adult palliative care providers respond to the needs of children who have a parent in palliative care?” contains an assumption that should be made

visible. Specifically, I assume that there are distinct adult and pediatric palliative care worlds. Thus, I asked each participant to share their thoughts on whether there is in fact a difference and if they had observations on the topic.

The interview data indicates that there is some level of a divide between adult and pediatric palliative care. A large part of the divide appears to stem from feelings of discomfort that HCPs feel when interacting with children, as I already discussed. The participants, all of whom are adult palliative care providers, lauded people who work in pediatrics but there was little desire to participate in it:

*I think if people want to work in pediatrics, that's great. I'm glad they do. I don't even like working with sick children. (P1: 33)*

One participant had difficulty answering the question, explaining that she has no experience with pediatric palliative care and it rarely comes up in conversation with her coworkers:

*I don't hear talk about it. We know that it is a piece of palliative care, it's over there. And most of us that work adult can't imagine working pediatric palliative care, like how hard that would be. (P3: 31)*

A lack of familiarity with pediatrics and the comment that “it’s over there” suggests that there is a divide between adult and pediatric palliative care. It appears that HCPs who have only worked in one of the two areas see them as separate from each other. A participant mentioned that one of her coworkers recently made the transition from adult to pediatric palliative care and claimed to not see a huge difference. Yet the participant sees a difference in what HCPs are able to do within pediatric palliative care:

*She starts talking about how she worked after...the follow-ups she would do with families and such. I mean, that's very different from what we do here. We're not that involved. You know they may have twenty people in the air, we have...I don't know, way too many. (P5: 37)*

This comment about follow-ups and the smaller number of people receiving palliative care at one time provides a concrete example of one way that adult and pediatric palliative care diverge. The participant added that pediatric palliative care providers tend to use the language of “symptom management” rather than talking about palliative care with kids and families. Although it does not directly pertain to children with a parent in palliative care, the participant identified the difficult transition that some dying 18 year olds face when they age out of the pediatric program and into the adult one. The divide between pediatric and adult palliative care is not always smooth because the teams are not often required to work together and this has ramifications for the care of patients who are trying to make that transition. Furthermore, the participant sensed that the pediatric environment is better equipped to support children’s grief:

*I think there are probably more tools to support, you know, if your sister is in the hospital and you're sitting in the room, there are going to be crayons and paper there, so you can draw a picture about how what's going on. (P5: 38)*

There appear to be more opportunities for peer support in the pediatric palliative care world and an environment more conducive to supporting children. Another participant discussed how working in pediatrics would likely give you opportunities to engage with children who are grieving on a more regular basis. Without those opportunities, children’s grief is something that is “easy to just kind of brush off and ignore” (P4: 43). Another participant questioned whether there are in fact more

resources and supports in the pediatric program than the adult program. The participants assume there are more resources, but are curious to know if there is a different approach to child's grief in the pediatric palliative care world.

There are spatial and temporal factors in the participants' milieu that contribute to the divide between adult and pediatric palliative care as well. Spatially, pediatric and adult palliative care services are located in different facilities in Winnipeg, making it more difficult for the participants who are adult palliative care providers to be familiar or comfortable with the pediatric world. Temporally, the pediatric palliative care program in Manitoba is much younger than the adult palliative care program, which was established in 1974 (Pilkey, Harlos, & Hohl, 2011). A social worker described how this difference contributes to the divide between the adult and pediatric palliative care worlds:

*I do think there is a sense of a divide. Pediatric palliative care in this province is pretty new. So it's kind of high profile. Palliative care has been around for a while, so it's not the new kid on the block anymore. Pediatric palliative care is. (P4: 43)*

Another participant talked about the difficult process involved in creating the pediatric palliative care program over the last 15-20 years, partly due to resistance within the broader pediatric community to the presence of palliative care. For the social workers in my study, there has been little involvement with the pediatric palliative care program. Although children on the pediatric palliative care program receive some support from child life therapists that work with all sick children regardless of diagnosis, there has been virtually no connection between the adult psychosocial care providers and the pediatric palliative care world.

## Chapter 5: Discussion, Recommendations and Conclusion

### Thoughts on Theorizing

This research has provided a wide array of insightful findings regarding how adult palliative care providers respond to the needs of children who have a parent in palliative care. Since this study was conducted using GT methodology, it would seem appropriate to identify an overarching, unified, substantive and formal theory that explains the situation being analyzed. However, I do not have a tidy and succinct theory that captures the fundamental “truth” about HCP-child interactions. Using the constant comparative method throughout data collection and analysis, I played with the data and findings in a number of different ways. The desire and temptation to declare a unified and workable theory grounded in the data is undeniable. I suspect this is due to the continued hegemonic status of postpositivist and objectivist research. Despite my antifoundationalist and postmodern ontology that I have described throughout this thesis, I still find myself wanting to make a universal truth claim by formulating a theory that acts as an “in a nutshell” statement. Remarkably, the prospect of not advancing a unified theory can be panic-inducing and cause feelings of inadequacy, since the sway of postpositivist research is very strong.

Initially, I thought I might be able to blend the three major processes I identified in the data analysis chapter into some generalizable theory. For example, “adult palliative care providers use the positive team environment to tackle the needs of children with a parent in palliative care and their own discomfort”. Setting aside the sheer awkwardness of that sentence, such a phrase does not work as an overarching

theory for my research. The statement is not categorically false, but it does not capture the complexities present within the situation of concern. Remember, Clarke's (2005) postmodern GT approach calls for the situation to be the unit of analysis, including its human, nonhuman, discursive and conceptual elements. The situation being analyzed is still centered on the interactions between adult palliative care providers and children with a parent in palliative care, but I have expanded my analytical lens in an attempt to account for some of the complexities, partialities and positionalities present in the situation. After immersing myself in the data, I am unable to construct a formal theory that satisfies or accurately captures the complexities of the area of inquiry.

Regardless of the potential for a substantive and formal theory, there is still significant theoretical content to discuss, some of which I already mentioned in the data analysis chapter. Before I do so, allow me to specify what this chapter is *not* intended for. This chapter is not written for the purpose of rehashing the findings that have already been presented. As I mentioned in the methodology, it is not intended for thematic analysis, which is sometimes a criticism levelled at GT studies that do not generate theoretical ideas. Nor is it meant to provide a basic summary of what HCPs do when they are responding to the needs of children with a parent in palliative care. This last point is important, because my work certainly offers insight into this, but the research is mainly intended to analyze the situation and examine an array of processes that are operating within the situation. Examining these processes helps theoretical ideas emerge and provides a deeper understanding of a situation that has very real material consequences on children, families and adult palliative care providers.

As mentioned in the methodology chapter, I have opted for an abductive approach, rather than the inductive approach that characterizes traditional GT. The abductive approach calls for the exploration of theoretical ideas that illuminate particular sections of data, using theoretical agnosticism, pluralism and playfulness (Thornberg, 2012). In other words, abductive research requires a critical eye, a sense of openness and a willingness to be creative. From an abductive perspective, emerging theoretical ideas are not fodder for universal truth claims but should entice further investigation. It is worth repeating that Clarke (2003) calls for “provisional theorizing” (p. 559) and cautions researchers to avoid forcing the data into a core process, which is a postmodern criticism of traditional GT. Below, I discuss what I consider to be the most pertinent of these emerging theoretical ideas related to the three key processes I identified in the data: identifying needs, uncomfortable caring and the team concept. I will also explore possibilities for resistance in each area.

### **Identifying Needs With Caution**

The findings on this particular process covered a large area, including educational needs, resources, family concerns, childhood developmental stages, normal/pathological/complicated grief and more. It appears that identifying needs of children with a parent in palliative care requires an abundance of caution on behalf of adult palliative care providers. Although the need for caution when interacting with children is already well-known (Librach & O'Brien, 2011; MacPherson & Emeleus 2007a), I am advocating for caution in the process of identifying needs. On a basic level, every child has different needs, so it is problematic to assume specific needs are

universal. HCPs must also exercise caution by using tentative language when they are speaking and educating children and families. The participants tried to use similar restraint when applying childhood development concepts to the grieving process.

The participants' responses reinforce the importance of working with parents and families when children are involved, which is supported by extant literature (Christ & Christ, 2006; Mahon 2009; Sweetland, 2005). How a child copes will be greatly influenced by their family's coping skills, which is not a new finding. Parents often act as "guardrails" (P2: 16) in a sense. However, my theoretical agnosticism leads me to wonder if this established theory can be broadened a little bit. In particular, I think it is important to remember that children have their own identities and they are often capable of interacting with HCPs independently, as the findings demonstrate. Although parents and families play a significant role, HCPs must be cautious so that children's identities are not entirely subsumed by their family identity.

A cautious approach was equally evident in the way participants talked about normal and pathological grief. Trying to determine what is "normal" grieving behaviour and what is not is fraught with complications. As previously discussed, so-called "pathological" or "complicated" grieving behaviours create a binary between normal and abnormal, which can construct people who are grieving in very particular and restrictive ways. Research by Goodrum (2008) examines how grieving norms do not reflect the experiences of bereaved people, forcing them to manage their emotions or face possible sanctions. When HCPs are intentionally cautious towards the normal/pathological binary, they are opening up space for resistance. As described by

Foote and Frank (1999) in the literature review, “complicated grief” disrupts what is considered “normal” and elucidates how pathology is something that is externally imposed. When the participants and other HCPs are wary of common conceptions of normalcy, it can potentially reduce stigma and have real material benefits for people who are grieving.

I would also caution HCPs to be wary about the ways neoliberal economic policies infiltrate their professional landscape, resulting in resource shortages that are seemingly unavoidable. As an example, Mahon (2008) illustrates how the Canadian social policy framework evolved in the 1980s from social liberalism to neoliberalism, leading to a drastic reduction in social services and welfare programs. Much like the decisions involved in the research that I have tried to make visible throughout this thesis, there are explicit decisions that are made that result in resource shortages that affect staffing and services. The neoliberal economic system was a site of silence in the data, making it even more crucial for HCPs to be critical towards its impact on their ability to respond to the needs of all people, including children with parents in palliative care.

### **Getting Comfortable with Being Uncomfortable**

At the beginning of my Master of Social Work program, I took part in an on-campus seminar. In one of the initial sessions, I was introduced to the idea of “getting comfortable with being uncomfortable” (D. Jeffery, personal communication, August 28, 2013). As we grapple with difficult concepts that challenge us academically, professionally and personally, it is unsurprising that this can cause some discomfort.

Rather than simply trying to ignore or erase these uncomfortable feelings, facing our discomfort can help us grow on multiple levels. After conducting my data collection and analysis, I see potential benefits for adult palliative care providers who get comfortable being uncomfortable around children with a dying parent.

Uncomfortable caring stands in stark contrast to the concept of comfort care. Comfort care is an approach to health care that can be adopted in many contexts, but is especially relevant at the end of life (Schenker et al., 2012). Comfort is a major goal of palliative care, where the focus is on comfort rather than recovery (Parravicini, 2012). Janice Morse (1992, 2000), a nurse researcher who has worked with Adele Clarke in developing postmodern approaches to GT, has suggested that promoting comfort is the ultimate purpose of nursing and health care in general. In a sense, the emergence of uncomfortable caring in this research study signifies a divergence from comfort care. However, the discomfort lies with HCPs in the present situation, not the palliative care received by patients and families. Getting comfortable with being uncomfortable represents an opportunity to provide better support to children with a parent in palliative care.

The research findings indicate an assortment of issues that cause discomfort for HCPs, including lack of familiarity, an inability to take a child's grief away and a shortage of opportunities to interact with children who have a parent in palliative care. Some participants also expressed that they would be more comfortable if they received better education on childhood grief, which is a trend I cited in the literature review. The stated desire for more education was a key sub process operating in the data. However, a

commitment to theoretical pluralism leads me to question this desire and entertain a different explanation. Specifically, some HCPs use a supposed lack of education as an excuse for not responding to children's needs, and this bore itself out in the data. Participants talked about still having professional responsibilities to those children and forcing themselves to put "a toe in the water" (P5: 13). The HCPs that do this get comfortable with being uncomfortable, while others remain mired in their own discomfort.

The participants also talked about suspending judgment, another social process extrapolated from the data. Suspending judgement presents an opportunity to get comfortable not knowing what is right or wrong for a child or family. HCPs are so often constructed as "knowers", but suspending judgment allows participants and other HCPs to challenge their position as the knower. This can destabilize the Foucauldian medical gaze that situates the medical professional as the knower and the subject as an object of knowledge. Rather than feeling uncomfortable about their inability to do something that will take away a child's grief, adult palliative care providers can learn to simply be present with the child. This notion that "being is more important than doing" (P4: 25) is another sub process in the data and it is a way HCPs can resist the expectation that they should be the purveyors of knowledge.

Getting comfortable with uncomfortable caring will also require HCPs to be aware of their own positions of privilege and make a conscious effort to disrupt dominant discourses related to grief. Another social process in the data on uncomfortable caring was a back and forth on issues of race, gender and class, where

there would be some engagement and then a retreat to “safer” topics of conversation. In order to ensure that race, gender and class issues do not remain sites of silence, all HCPs including myself must get comfortable with the uncomfortable feelings that these discussions bring up. This is an opportunity for HCPs to resist hegemonic conceptions of grief.

### **Constructing the Concept of a Team**

Collectively, the participant responses help construct an understanding of the palliative care team and its internal dynamics. Participants expressed fondness for the palliative care team and say they feel respected and happy working in that area. These positive feelings regarding the interdisciplinary approach in palliative care have been mentioned by other researchers as well (Davison & Hyland, 2002; Hermsen & ten Have, 2005). As I conversed with participants, it appeared that some of their comments were constructing the team as a rather idyllic concept. Members of the palliative care team speak highly of the work environment and this overwhelmingly positive perception of the palliative care team comes to be accepted as an established truth. However, I was also able to evoke some discussion on aspects of the palliative care team that can be found wanting, such as staffing and teamwork.

Different members of the palliative care team and their roles were constructed in the data as well. One area that calls for more focused theoretical attention is the role of the social worker, particularly because there were some notable disciplinary differences between the social worker participants and nurse participants. For example, the social worker participants expressed concern for the role of the DSM-V in

pathologizing grief, they are often asked to discern if a child's behaviour is grief-related or development-related and they are frequently relied upon by nurse participants. The central role of the social worker in these processes is borne out in the literature (Paul 2013; Sheldon 2000). They were also the participants who talked about "planting some seeds" with children and families and they were less concerned about the need for education and training on childhood grief, likely because education was part of their daily reality.

The social worker participants helped construct their own identity within the team. They saw themselves as a supportive presence for nurses and other staff. Their role in building relationships and connecting people was another visible sub process in the data. They resolutely rejected the notion that social workers are intended to "fix" difficult situations. Perhaps most importantly, it became apparent that social work is often constructed as a secondary profession within the biomedical hierarchy.

Since the concept of the team and the role of the social worker are constructed, it is possible to challenge and destabilize these constructions, including the construction of social work as a secondary profession. In the literature review, I discussed Foucault's (1988a) observation that "as soon as there is a power relation, there is a possibility of resistance" (as cited in Foote and Frank, 1999, p. 172). Like all hierarchies, the biomedical hierarchy suggests the existence of power relations amongst different members of the hierarchy. Therefore, there is room for social work to resist its "secondary profession" status. To do so, Payne (2006) calls on social workers to adopt "resistance identities" (p. 142). By adopting a critical consciousness and struggling

against the dominance of the biomedical hierarchy, social work (and social workers, it should be explicitly said) can resist inaccurate constructions of the profession. This would require social workers to work together to challenge their status within the biomedical hierarchy or do away with it altogether.

### **Evaluation and Assessment**

I laid out several evaluative criteria in the methodology chapter and it is necessary to revisit them now that the data has been analyzed. My first set of criteria were fit, workability, relevance and modifiability, taken from Glaser and Strauss' (1967) seminal work on GT. I believe that the emergent theoretical ideas I laid out above fit within the adult palliative care world that the participants find themselves in. One example of fit is how the notion of uncomfortable caring provides a fitting contrast for an area often known for "comfort care". In terms of workability, I suspect participants and other adult palliative care providers would be the best judge of this evaluative measure. However, I think that the results can be useful to HCPs who want to challenge DGD and disrupt the status quo, particularly if they are willing to engage with challenging and "uncomfortable" subject matter. In terms of relevance, the participants are once again the best assessors of this criterion. Yet from my perspective, the research addresses an identified gap in the literature and its focus on HCPs provides a perspective that has hitherto been under-examined. With regard to modifiability, my work with the situational map has convinced me that the theoretical ideas discussed here can adapt and evolve over time.

My research must also be evaluated for its contribution to social justice. There are a number of considerations to take into account when evaluating research from a social justice lens. As mentioned in the methodology chapter, Charmaz (2005) considers resources, hierarchies and policies/practices to have significant implications for social justice research. I made a conscious effort to integrate each of these into the data. My findings analyzed resource shortages, neoliberal economic policies and the biomedical hierarchy. It is not sufficient to say that I included these topics, but did their inclusion help the research contribute to social justice? I believe identifying neoliberal economic policies as a site of silence and calling for a more critical analysis of the deliberate decisions that lead to resource shortages has useful social justice implications. Similarly, calling on social workers to resist the dominance of the biomedical hierarchy is also tied to social justice efforts.

My examination of the race, gender and class is another way I hope my research contributes to social justice. My analysis delved into race, gender and class issues and problematized the tendency amongst HCPs to briefly engage with these issues before retreating. Although calling on people to recognize their privilege *and* take steps to disrupt the status quo is hardly a ground-breaking idea, it may contribute to social justice within the situation being researched. By specifically looking at race, gender and class, I have contributed empirical data that is context-specific and relevant to this particular milieu.

A third set of criteria used to evaluate my research comprises rigour, validity and accuracy, using the interpretive and subjective definitions outlined in the methodology

chapter. By applying an abductive approach and closely following Clarke's (2005) methodological advice, my research has advanced a plausible interpretation of reality. This qualifies as rigorous research within a framework that does not seek objective or universal truths.

I have already discussed how my research constructs a deeper understanding of the research area and could be used for resistance, which are both part of my definition of validity. My research also has crystalline validity in the way it examines multidimensional aspects of the research area by using the situational map. Catalytic validity, where research participants are motivated to take action and work for social justice, is another evaluative measure I included in my methodology. I discussed the potential contribution to social justice above and it is difficult for me to assess whether participants will be stirred to take action in any way. However, I am reminded of a discussion I had with a participant about race, gender and class. I have already mentioned the hazards of cultural competency, but this particular participant feels that she is not as culturally sensitive as she should be. I asked her "how do you become more culturally sensitive?" and her reply suggested that she is trying to take action:

*How do I become more culturally sensitive? That's actually something that I'm working on, and I read up on a lot about it. (P5: 30)*

Perhaps having the sort of in-depth discussion involved in my research interviews is enough to "catalyze" people into action, whether that is learning more about a topic, changing their behaviours, challenging the status quo or otherwise. It is also possible that the findings will not propel any of the participants into action. In their examination of the methodological approach known as participatory action research,

Smith et al. (2010) discuss the challenges involved in catalyzing participants to take action. It should be said that this is sometimes more of a reflection of the researcher rather than the participants, especially if the researcher does not design the research in a way that promotes social action.

My definition of accuracy requires my research to be salient and rooted in empirical data. My research meets both of these standards. Accuracy is also tied to internal validity, meaning there is enough data to support the analysis, the findings are coherent and the roles of the participants and researcher are made visible. With my literature review, memos and interviews, I have enough data to support the analysis and findings. The data analysis chapter included several excerpts from the research interviews, helping to make the roles of the participants clear. I will now address my own role in the research process in a separate section in order to give it the attention it deserves.

### **Reflections on My Role in the Research Process**

*Maybe part of it is recognizing within ourselves why we feel we need to do what we need to do. Because there is always a reason for it. (P4: 40)*

*What is my role in this whole thing? (P2: 5)*

While the quotes above are referring to the participants' roles in their interactions with children who have a parent in palliative care, the message also applies to situating myself within the research. Self-reflexivity is essential for both adult palliative care providers in their professional roles and me as a researcher. I tried to make myself visible throughout this thesis, writing in the first person and making my decisions and assumptions clear. I deliberately included an ongoing analysis on race,

gender and class, because I agree with Clarke (2005) that researchers must be responsible for including such issues or risk being “complicitous with the powers that be and the all-too-normalized practices of racism, sexism, homophobia that we too have internalized as participants in our cultures” (p. 76). Rather than simply locating myself as an economically privileged White, able-body, heterosexual, cisgender male, I made an effort to contribute to social justice and disrupt dominant discourses, particularly those pertaining to grief. I have some lingering questions about my efforts to situate myself in the research process. I do not know if I did enough to make my own privilege visible to participants and people reading my analysis. I am uncertain if I generated sufficient discussion on race, gender and class. When considering these misgivings, I find it helpful to remember that wrestling with these doubts and tensions are part of the self-reflexive process involved in critical research. McIntyre (1997, as cited in Jeffery, 2005) writes about the ways White people often refuse to acknowledge or address their privileged status, which shows an inability “to live with ambiguity, contradiction, and personal and collective responsibility for racial injustice” (p. 136). I must be willing to grapple with these ambiguities and contradictions if I want my role in the research to remain visible.

It does not surprise me that I am uncertain if I generated enough discussion on race, gender and class. From the moment I began recruiting participants, I felt uneasy about the prospect of discussing race, gender and class during the interviews.

“Discomfort recruiting” was included as an element on my situational map. Much like the discomfort that HCPs can feel around children with a parent in palliative care, I felt uncomfortable while I was recruiting participants for this study. I think it is appropriate

to disclose this because it makes my role in the research more evident. I felt uncomfortable for two main reasons. First, I was uncertain how to ensure these potential sites of silence were part of my data collection and analysis. After the first participant made allusions to issues of race, gender and class, I decided to explicitly name these terms and ask about them directly, a pattern I followed for the remainder of the interviews. This question was generally well-received and provoked some thoughtful reflection on these issues, which quelled some of my anxiety and made my concerns seem unwarranted.

The second reason I felt uncomfortable during recruitment was because I worried about how the participants would view an analysis that included race, gender and class. In particular, I was concerned about the reactions of participants who are professional contacts, even though they are not immediate coworkers. Before I even knew what the interview data would look like or what the findings would be, I was cognizant that many people find it upsetting when issues of privilege are raised and the status quo is disrupted, two things I tried to do with my research. See Sensoy (2007) and Sensoy and DiAngelo (2009) for a thoughtful analysis on the complex challenges involved in provoking people to acknowledge and challenge their privileged positionalities. On several occasions, I asked myself the following question: If the research is intended to assist adult palliative care providers in their interactions with children, should I be responsible for protecting the participants in some way? A corollary to that was: If the analysis contains a challenging discussion on race, gender and class, what will be the ramifications of my research?

My long-considered response to the first question is that I am responsible to the participants from an ethical research perspective. There is much literature that supports and affirms this type of responsibility (Breault, 2006; Cook & Hoas, 2011; De Koninck, 2009). As per my ethics protocol, I took steps to mitigate potential risks to participants, including possible emotional distress. I also made sure the participants gave their free and informed consent and knew of their right to withdraw at any time. I am required to share transcripts and results as desired by the participants. In addition, I tried to ensure that the data was co-constructed through the shared experiences between the participants and myself (Berger & Luckmann, 1966). However, I am not responsible for participants in terms of protecting their place of privilege as HCPs. If I want my research to be anti-oppressive and challenge the status quo, I cannot protect those privileges (Becker, Zawadzki, & Shields, 2014; Potts & Brown, 2005). I am not beholden to a dominant discourse that maintains the biomedical hierarchy and relations of power. Furthermore, I am accountable to parties that are relatively silent in the data. When discussing the biomedical model, it is worrisome that race, gender and class issues are often overlooked. Although my discussion on the biomedical model focused on social workers' position within the hierarchy, it is worth noting that White male doctors are usually situated at the top of the hierarchy while others are left to fill positions that are often considered less desirable. Once again, I am reminded that there is personal and collective responsibility for injustice and I must address these issues or I will remain complicit.

As for the secondary question on ramifications, I am no longer as concerned about this issue now that I have completed my data collection and analysis. Nor did I feel uncomfortable during later interviews or after discussions on race, gender and class had taken place. I do not think the analysis will have an impact on my professional relationships and I think this is mainly because I fulfilled my responsibilities to the participants from an ethical research perspective. Participants and other HCPs (including me) have to disrupt DGD, challenge the biomedical hierarchy, make neoliberal resource shortages visible and understand the race, gender and class dimensions involved with helping a child who has a parent in palliative care. This is all part of a larger interpretation of what it means to get comfortable with being uncomfortable. Although I think disclosing my initial discomfort is important in the process of making my role in the research clear, feeling uncomfortable is not a limitation to the research. It is simply a reminder that the researcher is very much involved in the final outcome.

Making myself visible in the research involves an examination of my role in the interviews. I was initially concerned that some of my verbal tics, such as “yeah” or “uh-huh”, were inappropriate in some way. I wondered if this would create some response bias or cushion some of the more challenging questions. On the other hand, I believe it is impossible to erase bias and no researcher is a *tabula rasa*. I chose to conduct semi-structured conversational interviews for some very good reasons that I laid out in the methodology chapter. I ended up minimizing my verbal tics as the interviews went on, mainly because it was irritating for transcription purposes. I also want to be transparent about the difficult time I had trying to decide whether I should recruit a sixth participant

for the research. I considered asking a physician or perhaps a rural social worker to participate, but I ultimately decided against it because I was not aiming for saturation in my sample size. I did not want a sixth participant to appear tokenistic and I felt I had enough data for my analysis.

Although I found that GT methodology and situational analysis went quite smoothly, there were a couple of challenges that I do not want to ignore. I found line-by-line coding to be difficult at times. Although I was able to use gerunds, in vivo codes and sensitizing concepts, I found it difficult to code with language that was different than the actual words that were uttered by the participant. I was very conscious that coding is done from the researcher's point of view and can never fully grasp the participants' responses. Yet again, the need to declare my influence on the research was glaringly obvious. The mapping process provided its own challenges. For one, Clarke (2005) does not provide a lot of instruction on what to write when relating one element of the map to another. This is probably intentional on Clarke's part, because the lack of instruction prompted me to write several memos about those map connections, which allowed my analysis to flourish on its own. A second challenge was my ability to use the map for analyzing and theorizing. Although working with the situational map was crucial for moving my analysis forward, I do not self-identify as a visual learner. Rigorous memoing was essential so I could analyze with visual (the map) and written (memos) data. It is fair to say that another researcher would have constructed a different map, but this only goes to show the role the researcher has in the process.

### **Further Implications for Practice and Policy**

In preceding sections of this chapter, I outlined some possibilities for resistance and various implications of the research. These included getting more comfortable engaging with race, gender and class, challenging the biomedical hierarchy and disrupting dominant discourses. On a policy level, HCPs must be mindful of the ways neoliberal economic policies produce resource-starved health care environments. The devastating effects of neoliberalism and its resulting resource shortages are well-documented (Brown, 2005; MacGregor, 1999). HCPs have to be aware of and resist the narrowing of so-called “normal” grief expressions to the point that few reactions are considered non-pathological. An adequate amount of attention has already been paid to these implications. All of the resistance activities listed above require engagement, as does involvement with children who have a parent in palliative care, their families and other HCPs. The involvement does not necessarily translate into “doing” concrete tasks, but simply “being” with the child and family as needed. In the data analysis chapter, I mentioned one participant who was less willing to engage with conversations with children after a parent demanded to know what her child had talked about. Although this reaction is understandable, adult palliative care providers must continue to engage with children and respond to their needs wherever possible. It should be evident by now that there are real material consequences when HCPs accept the status quo and do not challenge dominant discourses related to grief.

## Recommendations for Future Research

Now that I have researched the situation using a situational map, future research could create a social worlds/arenas map and a positional map, the two other major analytical tools in Clarke's (2005) situational analysis method. A social worlds and arenas map could look at the participation of and relations between HCPs, children, families and other human/nonhuman actors in various social worlds. A positional map could look at the various positions and discursive issues taken and not taken up by the different actors in the situation. Some promising work has already been done in this regard, as Strong et al. (2012) used positional maps to portray the various positions HCPs adopt in respect to the DSM-IV, which has since been updated to the DSM-V. Applying these two different types of maps would deepen our collective understanding of the situation and complement the situational map I have produced here.

Another fertile research area in my view is the team concept within palliative care. Although significant research has already been done on the role and concept of palliative care teams (Brennan et al., 2015; DeMiglio & Williams, 2012; Meier & Beresford, 2008), it appears that the team concept has yet to be examined from a situational analysis perspective. It could constitute its own research "situation" and be the subject of a situational map in its own right. It is fascinating that adult palliative care providers speak so highly of the team and opportunities for debriefing and feedback, yet lament the lack of available resources. There are numerous other human, nonhuman and discursive elements that help construct the concept of the palliative care team that could be the site(s) of further investigation. The divide between the adult and pediatric

palliative care worlds is equally beguiling and it would be interesting to discuss this with pediatric palliative care providers to see if there is a different approach to children's grief.

### **Conclusion**

Using Clarke's (2005) situational analysis approach to GT, I was able to distinguish three robust sub processes in the data. First, adult palliative care providers must use caution when identifying and responding to the needs of children who have a parent in palliative care. Second, these same adult palliative care providers, who are often distressed when supporting children who have a dying parent, benefit when they get comfortable with being uncomfortable. Third, adult palliative care providers tend to see themselves as part of a larger interdisciplinary team that informs their interactions with children who have a parent in palliative care. To be sure, these sub processes are interrelated and provide a concise summary of my theoretical observations. However, I will intentionally stop short of amalgamating them into a singular theory. In other words, I refuse to force the data into a basic core process, a directive advanced by positivist and postmodern GT researchers alike (Charmaz, 2006; Clarke, 2005; Glaser, 2005). Instead, my efforts have been focused on theorizing and highlighting possibilities for resistance and social justice.

The potential sites for resistance and social justice abound. One is for adult palliative care providers to be diligent regarding how they discuss and reify "normal" and "pathological" grief expressions. Second, HCPs can collectively challenge neoliberal economic policies that are often left unperturbed, despite causing damaging resource

shortages. Adult palliative care providers would be well-served to be continually aware of their own positions of privilege and work to disrupt dominant discourses related to grief, which could lead to positive social justice outcomes. Furthermore, maintaining a critical perspective of the biomedical hierarchy would be advantageous. In particular, social workers can resist their status as a “secondary profession” within this hierarchy. When supporting children with a parent in palliative care, HCPs should be open to changing their approach as necessary, even if it involves simply “being” rather than “doing”.

This postmodern GT research provides useful insight into a previously under-examined issue in the field of palliative care and children’s grief. My analysis of the interactions between adult palliative care providers and children with a parent in palliative care allowed me to highlight policy and practice implications. By integrating a critical perspective of DGD within my analysis, the research makes a meaningful contribution to extant literature.

## Bibliography

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> Ed.). Arlington, VA: American Psychiatric Publishing.
- Anderson, H. (2010). Common grief, complex grieving. *Pastoral Psychology*, 59(2), 127-136.
- Andrew, T. (2006). The Literature Review in Grounded Theory: A response to McCallin. *The Grounded Theory Review: An International Journal*, 5(2/3), 29-41.
- Atkinson, W. (2007). Beck, individualization and the death of class: A critique. *The British Journal of Sociology*, 58(3), 349-366.
- Auman, M. J. (2007). Bereavement support for children. *The Journal of School Nursing*, 23(1), 34-39.
- Ayonrinde, O. (2003). Importance of cultural sensitivity in therapeutic transactions. *Disease Management & Health Outcomes*, 11(4), 233-248.
- Baines, D. (2004). Caring for nothing work organization and unwaged labour in social services. *Work, Employment & Society*, 18(2), 267-295.
- Baskin, C. (2011). *Strong helpers' teachings: The value of Indigenous knowledges in the helping professions*. Toronto, Canada: Canadian Scholars' Press.
- Beale, E. A., Sivesind, D., & Bruera, E. (2004). Parents dying of cancer and their children. *Palliative & Supportive Care*, 2(4), 387-393.
- Becker, J. C., Zawadzki, M. J., & Shields, S. A. (2014). Confronting and reducing sexism: A call for research on intervention. *Journal of Social Issues*, 70(4), 603-614.
- Berg, B. (2004). Focus group interviewing. In B. Berg (Ed.), *Qualitative research methods for the social sciences* (pp. 123-144). Boston, MA: Allyn and Bacon.
- Berger, P. L., & Luckmann, T. (1966). *The social construction of knowledge: A treatise in the sociology of knowledge*. Garden City, NY: Doubleday.
- Bhattacharya, K. (2007). Consenting to the consent form: What are the fixed and fluid understandings between the researcher and the researched? *Qualitative Inquiry*, 13(8), 1095-1115.
- Black, D. (1998). Bereavement in childhood. In C. M. Parkes & A. Markus (Eds.), *Coping with loss* (pp. 28-35). London, United Kingdom: BMJ Books.

- Bonanno, G. A., Papa, A., & O'Neill, K. (2002). Loss and human resilience. *Applied and Preventive Psychology, 10*(3), 193-206.
- Brabant, S. (2002). A closer look at Doka's grieving rules. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 23-38). Champaign, IL: Research Press.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- Brayne, S. (2010). *D-Word: Talking about dying: A guide for relatives, friends and carers*. London, United Kingdom: Continuum.
- Breault, J. L. (2006). Protecting human research subjects: The past defines the future. *The Ochsner Journal, 6*(1), 15-20.
- Brennan, C. W., Kelly, B., Skarf, L. M., Tellem, R., Dunn, K. M., & Poswolsky, S. (2015). Improving palliative care team meetings: Structure, inclusion, and "team care". *American Journal of Hospice and Palliative Medicine*, March, 1-9.
- Brown, M. (2008). *She hits like a girl: Contexts and constructs of femininity, use of violence and living in group homes* (Unpublished doctoral dissertation). Memorial University, Newfoundland, Canada.
- Brown, W. (2005). *Edgework: Critical essays on knowledge and politics*. Princeton, NJ: Princeton University Press.
- Brown, L. & Strega, S. (2005). Transgressive possibilities (Introduction). In L. Brown & S. Strega (Eds.), *Research as resistance* (pp. 1-18). Toronto, Canada: Canadian Scholars Press.
- Bryant, A., & Charmaz, K. (2007). Grounded theory in historical perspective: An epistemological account. In A. Bryant & K. Charmaz (Eds.), *The Sage Handbook of Grounded Theory* (pp. 31-57). London, United Kingdom: Sage.
- Bucholtz, M. (2000). The politics of transcription. *Journal of Pragmatics, 32*(10), 1439-1465.
- Bugge, K. E., Darbyshire, P., Røkholt, E. G., Haugstvedt, K. T. S., & Helseth, S. (2014). Young children's grief: Parents' understanding and coping. *Death Studies, 38*(1), 36-43.
- Burman, E. (2007). *Deconstructing Developmental Psychology*. Retrieved from <http://www.ebilib.com>

- Burman, E. (2012). Deconstructing neoliberal childhood: Towards a feminist antipsychological approach. *Childhood, 19*(4), 423-438.
- Calderwood, K. A. (2011). Adapting the transtheoretical model of change to the bereavement process. *Social Work, 56*(2), 107-118.
- Charmaz, K. (1990). 'Discovering' chronic illness: using grounded theory. *Social Science & Medicine, 30*(11), 1161-1172.
- Charmaz, K. (2002). Stories and silences: Disclosures and self in chronic illness. *Qualitative Inquiry, 8*(3), 302-328.
- Charmaz, K. (2004). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y.S. Lincoln (Eds.), *Strategies of Qualitative Inquiry* (2<sup>nd</sup> ed.) (pp.249-291). Thousand Oaks, CA: Sage.
- Charmaz, K. (2005). Grounded theory in the 21<sup>st</sup> century: Applications for advancing social justice studies. In N. Denzin & Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (3<sup>rd</sup> ed.) (pp. 1-32). Thousand Oaks, CA: Sage.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative research*. London, United Kingdom: Sage.
- Charmaz, K. (2008). View from the margins: Voices, silences and suffering. *Qualitative Research in Psychology, 5*(1), 7-18.
- Christ, G. H., & Christ, A. E. (2006). Current approaches to helping children cope with a parent's terminal illness. *CA: A Cancer Journal for Clinicians, 56*(4), 197-212.
- Cipolletta, S., & Oprandi, N. (2014). What is a good death? Health care professionals' narrations on end-of-life care. *Death Studies, 38*(1), 20-27.
- Clarke, A. (2003). Situational analyses: Grounded theory mapping after the postmodern turn. *Symbolic Interaction, 26*(4), 553-576.
- Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage.
- Clarke, A. (2009). From grounded theory to situational analysis: What's new? Why? How? In J. M. Morse, P. N. Stern, J. Corbin, B. Bowers & A. Clarke, (Eds.), *Developing grounded theory: The second generation* (pp. 194-223). Walnut Creek, CA: Left Coast Press.
- Connor, S. R. (2009). *Hospice and palliative care: The essential guide* (2<sup>nd</sup> ed.). New York,

NY: Taylor & Francis.

- Cook, A. F., & Hoas, H. (2011). Protecting research subjects: IRBs in a changing research landscape. *IRB: Ethics and Human Research*, 33(2), 14-19.
- Corr, C. A. (1998). Developmental perspectives on grief and mourning. In K. J. Doka & J. D. Davidson (Eds.), *Living with grief: Who we are and how we grieve* (pp. 143-160). Philadelphia, PA: Hospice Foundation of America.
- Corr, C. A. (2010). Children's emerging awareness and understandings of loss and death. In C. A. Corr & D. E. Balk (Eds.), *Children's encounters with death, bereavement, and coping* (pp. 21-37). New York: Springer.
- Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31(6), 1476-1484.
- Davidson, C. (2009). Transcription: Imperatives for qualitative research. *International Journal of Qualitative Methods*, 8(2), 36-52.
- Davison, G., & Hyland, P. (2002). Palliative care teams and organisational capability. *Team Performance Management: An International Journal*, 8(3/4), 60-67.
- De Koninck, T. (2009). Protecting human dignity in research involving humans. *Journal of Academic Ethics*, 7(1-2), 17-25.
- DeMiglio, L., & Williams, A. (2012). Shared care: The barriers encountered by community-based palliative care teams in Ontario, Canada. *Health & Social Care in the Community*, 20(4), 420-429.
- den Outer, B., Handley, K., & Price, M. (2013). Situational analysis and mapping for use in education research: A reflexive methodology?. *Studies in Higher Education*, 38(10), 1504-1521.
- Denzin, N. K. (2007). Grounded theory and the politics of interpretation. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 454-471). London, United Kingdom: Sage.
- Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3<sup>rd</sup> ed.) (pp. 1-32). Thousand Oaks, CA: Sage.
- Doka, K. J., & Martin, T. L. (2002). How we grieve: Culture, class, and gender. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 337-348). Champaign, IL: Research Press.

- Draper, A., & Hancock, M. (2011). Childhood parental bereavement: the risk of vulnerability to delinquency and factors that compromise resilience. *Mortality*, 16(4), 285-306.
- Driscoll, D. L. (2013). *Social Work Literature Review Guidelines*. Retrieved from <https://owl.english.purdue.edu/owl/resource/666/01>
- Dunne, C. (2011). The place of the literature review in grounded theory research. *International Journal of Social Research Methodology*, 14(2), 111-124.
- Dybicz, P. (2010). Confronting oppression not enhancing functioning: The role of social workers within postmodern practice. *Journal of Sociology & Social Welfare*, 37(1), 23-45.
- Ekström, H. (2006). Aspects on McCallin's paper, "Grappling with the literature in a grounded theory study". *The Grounded Theory Review: An international journal*, 5(2/3), 45.
- Ens, C., & Bond, J. B., Jr. (2005). Death anxiety and personal growth in adolescents experiencing the death of a grandparent. *Death Studies*, 29(2), 171-178.
- Esterberg, K. (2002). *Qualitative methods in social research*. Boston: McGraw Hill.
- Fine, M. (1994). Working the hyphens: Reinventing self and other in qualitative research. In N. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (1<sup>st</sup> ed.) (pp.70-82). Thousand Oaks, CA: Sage.
- Fine, M., Weiss, L., Weseen, S., & Wong, L. (2003). For whom? Qualitative research, representations and social responsibilities. In N. Denzin & Y. Lincoln (Eds.), *The landscape of qualitative research: Theories and issues* (pp. 167-207). Thousand Oaks, CA: Sage.
- Fontana, A., & Frey, J. H. (2005). The interview: from neutral stance to political involvement. In N. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3<sup>rd</sup> ed.) (pp. 695-728). Thousand Oaks, CA: Sage.
- Foote, C. E., & Frank, A. W. (1999). Foucault and therapy: The disciplining of grief. In A. S. Chambon, A. Irving & L. Epstein (Eds.), *Reading Foucault for social work* (pp. 157-187). New York, NY: Columbia University Press.
- Foucault, M. (2003). *The Birth of the clinic: An archaeology of medical perception*. (A. Sheridan, Trans.). London, UK: Routledge. (Original work published 1963)
- Gibbs, G. (2010a, June 19). *Grounded theory: Line by line coding* (Video file). Retrieved

from [https://www.youtube.com/watch?v=Dfd\\_U-24egg&feature=related](https://www.youtube.com/watch?v=Dfd_U-24egg&feature=related)

- Gibbs, G. (2010b, June 19). *Grounded theory: Open coding Part 2* (Video file). Retrieved from [http://www.youtube.com/watch?v=vi5B7Zo0\\_OE&feature=related](http://www.youtube.com/watch?v=vi5B7Zo0_OE&feature=related)
- Gibbs, G. (2010c, June 19). *Grounded theory: Core elements Part 2* (Video file). Retrieved from [https://www.youtube.com/watch?v=dbntk\\_xeLHA&feature=related](https://www.youtube.com/watch?v=dbntk_xeLHA&feature=related)
- Gibbs, G. (2010d, June 20). *Grounded theorists and critiques of grounded theory* (Video file). Retrieved from [http://www.youtube.com/watch?v=hik-NKtl\\_vY&feature=related](http://www.youtube.com/watch?v=hik-NKtl_vY&feature=related)
- Glaser, B. G. (2002). Constructivist grounded theory? *Forum: Qualitative social research* 3(3), 1-14. Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/825>
- Glaser, B. G. (2005). *The grounded theory perspective III: Theoretical coding*. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying*. Chicago, IL: Aldine de Gruyter.
- Glaser, B.G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Aldine de Gruyter.
- Golombok, S., Perry, B., Burston, A., Murray, C., Mooney-Somers, J., Stevens, M., & Golding, J. (2003). Children with lesbian parents: a community study. *Developmental psychology*, 39(1), 20-33.
- Goodrum, S. (2008). When the management of grief becomes everyday life: The aftermath of murder. *Symbolic Interaction*, 31(4), 422-442.
- Green, D. O., Creswell, J. W., Shope, R. J., & Clark, V. L. P. (2007). Grounded theory and racial/ethnic diversity. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 472-492). London, United Kingdom: Sage.
- Griffiths, M. (2007). Death understanding and fear of death in young children. *Clinical child psychology and psychiatry*, 12(4), 525-535.
- Grounded Theory Institute. (2011). *What is grounded theory?*. Retrieved from <http://www.groundedtheory.com/what-is-gt.aspx>
- Guba, E. G., & Lincoln, Y. S. (1981). *Effective evaluation: Improving the usefulness of evaluation results through responsive and naturalistic approaches*. San Francisco, CA: Jossey-Bass.

- Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage.
- Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3<sup>rd</sup> ed.) (pp. 191-216). Thousand Oaks, CA: Sage.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods* 18(1), 59-82.
- Gutting, G. (2005). *Foucault: A very short introduction*. Oxford, UK: Oxford University Press.
- Haine, R. A., Wolchik, S. A., Sandler, I. N., Millsap, R. E., & Ayers, T. S. (2006). Positive parenting as a protective resource for parentally bereaved children. *Death Studies*, 30(1), 1-28.
- Hall, C. (2014). Bereavement theory: Recent developments in our understanding of grief and bereavement. *Cruse Bereavement Care*, 33(1), 7-12.
- Handy, F., & Srinivasan, N. (2004). Valuing volunteers: An economic evaluation of the net benefits of hospital volunteers. *Nonprofit and Voluntary Sector Quarterly*, 33(1), 28-54.
- Haraway, D. (1988). Situated knowledges: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, 14(3), 575-599.
- Harper, B. C., Lartigue, M., & Doka, K. (2001). Cultural differences: Sensitivities required for effective caring. In K. J. Doka & J. D. Davidson (Eds.), *Caregiving and loss: Family needs, professional responses* (pp. 139-151). Washington, DC: Hospice Foundation of America.
- Hart, M. A. (2009). Anti-colonial Indigenous social work: Reflections on an Aboriginal approach. In R. Sinclair, M. A. Hart & G. Bruyere (Eds.), *Wicahitowin: Aboriginal social work in Canada* (pp. 25-41). Halifax, Canada: Fernwood Publishing.
- Heath, H. (2006). Exploring the influences and use of the literature during a grounded theory study. *Journal of Research in Nursing*, 11(6), 519-528.
- Hermesen, M. A., & ten Have, H. A. M. J. (2005). Palliative care teams: Effective through moral reflection. *Journal of Interprofessional Care*, 19(6), 561-568.
- Heron, B. (2004). Gender and exceptionality in North-South interventions: Reflecting on relations. *Journal of Gender Studies* 13(2), 117-127.

- Heyes, C. (2007). *Self transformations: Foucault, ethics, and normalized bodies*. New York, NY: Oxford University Press.
- Hick, S. (2010). *Social work in Canada: An introduction* (3<sup>rd</sup> ed.). Toronto, Canada: Thompson Educational.
- Hickey, G. (1997). The use of literature in grounded theory. *Nursing Times Research*, 2(5), 371-378.
- Himebauch, A., Arnold, R. M., & May, C. (2008). Grief in children and developmental concepts of death #138. *Journal of Palliative Medicine*, 11(2), 242-244.
- iPANEL. (2002). *About Us*. Retrieved from <http://www.ipanel.ca/about-us>
- Jeffery, D. (2005). 'What good is anti-racist social work if you can't master it?': Exploring a paradox in anti-racist social work education. *Race Ethnicity and Education*, 8(4), 409-425.
- Jeffreys, J. S. (2011). *Helping grieving people: When tears are not enough*. New York, NY: Routledge.
- Johnson, K., & Loscocco, K. (2015). Black marriage through the prism of gender, race, and class. *Journal of Black Studies*, 46(2), 142-171.
- Jordan, J. R., & Neimeyer, R. A. (2003). Does grief counseling work? *Death Studies*, 27(9), 765-786.
- Kearney, M. K., Weininger, R. B., Vachon, M. L. S., Harrison, R. L., & Mount, B. M. (2009). Self-care of physicians caring for patients at the end of life: "Being connected... a key to my survival". *JAMA*, 301(11), 1155-1164.
- Keeley, D. (2000). Telling children about a parent's cancer: Parents want help but don't get it. *BMJ: British Medical Journal*, 321(7259), 462.
- Kincheloe, J. L., & McLaren, P. (2005). Rethinking critical theory and qualitative research. In N. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3<sup>rd</sup> ed.) (pp. 191-216). Thousand Oaks, CA: Sage.
- Kübler-Ross, E. (1969). *On death and dying*. New York, NY: MacMillan.
- Kühne, F., Krattenmacher, T., Beierlein, V., Grimm, J. C., Bergelt, C., Romer, G., & Möller, B. (2012). Minor children of palliative patients: A systematic review of psychosocial family interventions. *Journal of Palliative Medicine*, 15(8), 931-945.

- Ladson-Billings, G. (2000). Racialized discourses and ethnic epistemologies. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 257-277). Thousand Oaks, CA: Sage.
- Lamb, M. E. (2012). Mothers, fathers, families, and circumstances: Factors affecting children's adjustment. *Applied Developmental Science, 16*(2), 98-111.
- Lather, P. (1993). Fertile obsession: Validity after poststructuralism. *The Sociological Quarterly, 34*(4), 673-693.
- Librach, S. L., & O'Brien, H. (2011). Supporting children's grief within an adult and pediatric palliative care program. *The Journal of Supportive Oncology, 9*(4), 136-140.
- Lowe, W. (2011). Silences in healthcare education and practice: Gender and sexuality. *Gay and Lesbian Issues and Psychology, 7*(3), 180.
- MacConville, U. (2009). Research methods in palliative care. *Mortality, 14*(1), 90-91.
- MacGregor, S. (1999). Welfare, neo-liberalism and new paternalism: Three ways for social policy in late capitalist societies. *Capital & Class, 23*(1), 91-118.
- MacPherson, C., & Emeleus, M. (2007a). Children's needs when facing the death of a parent from cancer: part one. *International Journal of Palliative Nursing, 13*(10), 478-485.
- MacPherson, C., & Emeleus, M. (2007b). Children's needs when facing the death of a parent from cancer: part two. *International Journal of Palliative Nursing, 13*(12), 590-597.
- Mahon, M. M. (2009). Funeral directors and bereaved children: beliefs and experiences. *Death Studies, 33*(9), 828-847.
- Mahon, R. (2008). Varieties of liberalism: Canadian social policy from the 'Golden age' to the present. *Social Policy & Administration, 42*(4), 342-361.
- Martin, V. B. (2006). The relationship between an emerging grounded theory and the existing literature: Four phases for consideration. *The Grounded Theory Review: An International Journal, 5*(2/3), 47-57.
- Mathar, T. (2008). Making a mess with situational analysis? Review essay: Adele Clarke (2005). Situational analysis—Grounded theory after the postmodern turn. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 9* (2). Retrieved from <http://nbn-resolving.de/urn:nbn:de:0114-fqs080244>

- McCallin, A. M. (2003). Grappling with the literature in a grounded theory study. *Contemporary Nurse, 15*(12), 61-69.
- McClatchey, I. S., Vonk, M. E., Lee, J., & Bride, B. (2014). Traumatic and complicated grief among children: One or two constructs?. *Death Studies, 38*(2), 69-78.
- McGhee, G., Marland, G. R., & Atkinson, J. (2007). Grounded theory research: literature reviewing and reflexivity. *Journal of Advanced Nursing, 60*(3), 334-342.
- McKee, M., Delaney, R., & Brownlee, K. (2002). The deconstruction of professional knowledge: Accountability without authority. *Families in Society: The Journal of Contemporary Social Services, 83*(5), 493-498.
- Meier, D. E., & Beresford, L. (2008). The palliative care team. *Journal of Palliative Medicine, 11*(5), 677-681.
- Merriam, S. B. (2002). Introduction to Qualitative Research. In S. B. Merriam (Ed.), *Qualitative research in practice: Examples for discussion and analysis* (pp. 3-17). San Francisco, CA: Jossey-Bass.
- Mills, S. (2004). Ch. 1: Introduction. In *Discourse: The new critical idiom* (pp. 1-28). London, United Kingdom: Routledge.
- Mitchell, T. L., & Radford, J. L. (1996). Rethinking research relationships in qualitative research. *Canadian Journal of Community Mental Health, 15*(1), 49-60.
- Moosa-Mitha, M. (2005). Situating anti-oppressive theories within critical and difference-centered perspectives. In L. Brown & S. Strega (Eds.), *Research as resistance* (pp. 37-72). Toronto, Canada: Canadian Scholars Press.
- Morley, C., & Macfarlane, S. (2010). Repositioning social work in mental health: challenges and opportunities for critical practice. *Critical Social Work, 11*(2), 46-59.
- Morse, J. M. (1992). Comfort: The refocusing of nursing care. *Clinical Nursing Research, 1*(1), 91-106.
- Morse, J. M. (2000). On comfort and comforting. *The American Journal of Nursing, 100*(9), 34.
- Nathaniel, A. K. (2006). Thoughts on the literature review and GT. *Grounded Theory Review, 5*(2/3), 35-41.
- Neimeyer, R. A. (1999). Narrative strategies in grief therapy. *Journal of Constructivist*

*Psychology*, 12(1), 65-85.

- Neimeyer, R. A., Klass, D., & Dennis, M. R. (2014). Toward a social constructionist account of grief: Loss and the narration of meaning. *Death Studies*, 38, 485-498.
- Olesen, V. L. (2007). Feminist qualitative research and grounded theory: Complexities, criticisms, and opportunities. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 417-435). London, United Kingdom: Sage.
- Oliver, C. (2012). Critical realist grounded theory: A new approach for social work research. *British Journal of Social Work*, 42(2), 371-387.
- Oliver, D. G., Serovich, J. M., & Mason, T. L. (2005). Constraints and opportunities with interview transcription: Towards reflection in qualitative research. *Social Forces*, 84(2), 1273-1289.
- O'Rourke, M. (2010, February). Good grief: Is there a better way to be bereaved? *The New Yorker*. Retrieved from <http://www.newyorker.com/magazine/2010/02/01/good-grief>
- Oudkerk, M., & Ristić, D. (2012). The literature review. In Ristic, D. (Ed.), *Fundamentals of research methodology for health care professionals* (pp. 70-82). Cape Town, South Africa: Juta and Company Ltd.
- Parker, A. (2005). The other of class. *Rethinking Marxism*, 17(1), 15-18.
- Parkes, C. M. (1998). Assumptions about loss and principles of care. In C. M. Parkes and A. Markus (Eds.), *Coping with loss*. London, United Kingdom: BMJ Books.
- Parravicini, E. (2012). Is 'comfort' care a 'medical' care? Observations on a neonatal population. *Journal of Medicine and the Person*, 10(1), 41-45.
- Parton, N. (1998). Risk, advanced liberalism and child welfare: The need to rediscover uncertainty and ambiguity. *British Journal of Social Work*, 28(1), 5-27.
- Patterson, P., & Ranganadhan, A. (2010). Losing a parent to cancer: A preliminary investigation into the needs of adolescents and young adults. *Palliative and Supportive Care*, 8(03), 255-265.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods*. Thousand Oaks, CA: Sage.
- Paul, S. (2013). Public health approaches to palliative care: The role of the hospice social worker working with children experiencing bereavement. *British Journal of Social*

*Work*, 43(2), 249-263.

- Payne, M. (2006). Identity politics in multiprofessional teams palliative care social work. *Journal of Social Work*, 6(2), 137-150.
- Penman, E. L., Breen, L. J., Hewitt, L. Y., & Prigerson, H. G. (2014). Public attitudes about normal and pathological grief. *Death Studies*, 38, 510-516.
- Pilkey, J., Harlos, M., & Hohl, C. (2011). Designing a Canadian pediatric palliative care residency program. *Journal of Palliative Care*, 27(2), 175-80.
- Pon, G. (2009). Cultural competency as new racism: An ontology of forgetting. *Journal of Progressive Human Services*, 20(1), 59-71.
- Potts, K., & Brown, L. (2005). *Becoming an anti-oppressive researcher*. In L. Brown & S. Strega (Eds.), *Research as resistance* (pp. 255-286). Toronto, Canada: Canadian Scholars Press.
- Prochaska, J. O., & DiClemente, C. C. (1983). Stages and processes of self-change of smoking: Toward an integrative model of change. *Journal of Consulting and Clinical Psychology* 51(3): 390-395.
- Puddephatt, A. J. & Charmaz, K. C. (2006). An interview with Kathy Charmaz: On constructing grounded theory. *Qualitative Sociology Review*, 2(3), 5-20.
- Rando, T. A. (1993). *Treatment of complicated mourning*. Champaign, Ill: Research Press.
- Reeves, N. C. (2005, Fall/Winter). Making effective decisions while grieving. *Voices of Healing and Growth*, 20-22.
- Rose, N. S. (1999). *Powers of freedom: Reframing political thought*. Cambridge, United Kingdom: Cambridge University Press.
- Rowling, L. (2002). Youth and disenfranchised grief. In K. J. Doka (Ed.), *Disenfranchised grief* (pp. 275-292). Champaign, IL: Research Press.
- Rozas, L. W., & Klein, W. C. (2010). The value and purpose of the traditional qualitative literature review. *Journal of Evidence-Based Social Work*, 7(5), 387-399.
- Rutman, D., Strega, S., Callahan, M., & Dominelli, L. (2002). 'Undeserving' mothers? Practitioners' experiences working with young mothers in/from care. *Child & Family Social Work*, 7(3), 149-159.
- Rysst, M. (2010). "Healthism" and looking good: Body ideals and body practices in

- Norway. *Scandinavian Journal of Public Health*, 38(5), 71-80.
- Said, E. (1978). *Orientalism*. London, UK: Routledge & Kegan Paul.
- Saldaña, J. (2011). *Fundamentals of qualitative research*. New York, NY: Oxford University Press.
- Schenker, Y., Tiver, G. A., Hong, S. Y., & White, D. B. (2012). Association between physicians' beliefs and the option of comfort care for critically ill patients. *Intensive Care Medicine*, 38(10), 1607-1615.
- Sensoy, Ö. (2007). Pedagogical strategies for disrupting gendered Orientalism: Mining the binary gap in teacher education. *Intercultural Education*, 18(4), 361-365.
- Sensoy, Ö., & Diangelo, R. (2009). Developing social justice literacy: An open letter to our faculty colleagues. *The Phi Delta Kappan*, 90(5), 345-352.
- Sheldon, F. M. (2000). Dimensions of the role of the social worker in palliative care. *Palliative Medicine*, 14(6), 491-498.
- Shor, R. (2000). Child maltreatment: Differences in perceptions between parents in low income and middle income neighbourhoods. *British Journal of Social Work*, 30(2), 165-178.
- Smith, L., Bratini, L., Chambers, D., Jensen, R. V., & Romero, L. (2010). Between idealism and reality: Meeting the challenges of participatory action research. *Action Research*, 8(4), 407-425.
- St. Pierre, E. (2000). Poststructural feminism in education: An overview. *Qualitative Studies in Education*, 13(5), 477-515.
- St. Pierre, E. (2002). Methodology in the fold and the irruption of transgressive data. In S. B. Merriam (Ed.), *Qualitative research in practice: Examples for discussion and analysis* (pp. 175-189). San Francisco, CA: Jossey-Bass.
- Strauss, A., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Thousand Oaks, CA: Sage.
- Strauss, A., & Corbin, J. M. (1998). *Basics of qualitative Research: Grounded theory procedures and techniques* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Strauss, A. L. & Glaser, B. G. (1975). *Chronic illness and the quality of life*. St. Louis, MO: Mosby.

- Strega, S. (2005). The view from the poststructural margins: Epistemology and methodology reconsidered. In L. Brown & S. Strega (Eds.), *Research as resistance* (pp. 199-236). Toronto, Canada: Canadian Scholars Press.
- Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies, 23*(3), 197-224.
- Strong, T., Gaete, J., Sametband, I. N., French, J., & Eeson, J. (2012). Counsellors respond to the DSM-IV-TR. *Canadian Journal of Counselling and Psychotherapy, 46*(2), 85-106.
- Sweetland, C. (2005). The palliative care nurse's role in supporting the adolescent child of a dying patient. *International Journal of Palliative Nursing, 11*(6), 294-298.
- Szymanowska, J. (2014). A child in the face of a parent's death: Aspects of children's loneliness. *Progress in Health Sciences, 4*(1), 118-123.
- Takei, Y., Ozawa, M., Ishida, Y., Suzuki, S. I., Ohno, S., & Manabe, A. (2012). Clinicians' perspectives on support for children with a parent who is diagnosed with breast cancer. *Breast Cancer, 21*, 463-471.
- Thornberg, R. (2012). Informed grounded theory. *Scandinavian Journal of Educational Research, 56*(3), 243-259.
- Tracy, S. (2010). Qualitative criteria: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry, 16* (10), 837-851.
- Turner, J., Clavarino, A., Yates, P., Hargraves, M., Connors, V., & Hausmann, S. (2007). Oncology nurses' perceptions of their supportive care for parents with advanced cancer: Challenges and educational needs. *Psycho-Oncology, 16*(2), 149-157.
- Walsh, K. (2012). *Grief and loss: Theories and skills for helping professionals*. Upper Saddle River, NJ: Pearson Education.
- Warin, J. (2011). Ethical mindfulness and reflexivity: Managing a research relationship with children and young people in a 14-year qualitative longitudinal research (QLR) study. *Qualitative Inquiry, 17*(9), 805-814.
- Wong, H. L. (2007). Hopework: Health care providers caring for cancer patients facing end of life (Master's Thesis). Retrieved from <https://dspace.library.uvic.ca:8443/handle/1828/2379>
- Worden, J. W. (1996). *Children & grief: When a parent dies*. New York, NY: Guilford.

Worden, J. W. (2008). Grieving children and adolescents: Lessons from the Harvard child bereavement study. In K. J. Doka & A. S. Tucci (Eds.), *Living with grief: Children and adolescents* (pp. 125-137). Washington, DC: Hospice Foundation of America.

World Health Organization. (n.d.). WHO definition of health. Retrieved from <http://www.who.int/about/definition/en/print.html>

## Appendix A - Interview Screening Questions

Is it ok if I ask you a few questions to assess your suitability for the research?

YES / NO

*If the answer was "YES", the potential participant was asked the following questions:*

### **Participant checklist:**

- Do you work with adults in palliative care or have you worked with adults in palliative care?

YES / NO

- Have you worked in palliative care for at least one year?

YES / NO

- Do you work in pediatric palliative care? Have you worked in pediatric palliative care?

YES / NO

- Do some of the adults in your care have children?

YES / NO

- Do you have opportunities to interact with those children?

YES / NO

- Are you willing to take part in an interview?

YES / NO

(Participants must answer "NO" to working in pediatric palliative care and "YES" to all other questions to be considered for participation in the research.)

## **Appendix B - Informed Consent Form**

*Adult Palliative Care Providers and Their Interactions with Children* is a Master of Social Work Thesis. My name is Ian Scott and I am researching this topic as a University of Victoria student living in Winnipeg, Manitoba. You may contact me by email (ianbscott@gmail.com) or phone (204-330-1920).

The purpose of the study is to examine how adult palliative care providers respond to the needs of children who have a parent in palliative care. Health care providers who work in pediatric palliative care have many opportunities to interact with children in palliative settings, but little is known about the interactions between health care providers and children in the adult palliative care world. The research will hopefully uncover useful information about the interactions of adult palliative care providers and the children who have a parent in palliative care.

You are invited to take part in a 1-to-1 interview. It is expected the interview will not exceed two hours in length and will take place at a convenient meeting place where confidentiality and anonymity can be maintained. In the interview, you will be asked to describe your experiences and opinions regarding your interactions with children in the workplace.

Participants in this study: 1) Work or have worked in adult palliative care; 2) Have worked in adult palliative care for at least one year; 3) Care for adults who have children (e.g. minors); 4) Have had opportunities to interact with patients' children; 5) Are willing to be interviewed.

### **Potential Benefits:**

A potential benefit is that the research might provide information that is useful for your work.

### **Potential Risks:**

There are minimal risks associated with the research, but due to the subject matter it is possible you might experience some minor emotional or psychological distress. If you desire, we can take a break or change the topic of conversation for a period of time. If you desire further support, I can help you contact your employee assistance plan for counselling or I can refer you to free counselling in the community. Remember, you can withdraw at any time.

**Participation:**

Taking part in the study must be completely voluntary. You may choose to stop the interview at any time without consequences or explanation. You can choose to not answer a particular question. If the research project changes in a way that affects the nature of your participation, you will be given updated information in a timely manner. If you choose to end the interview halfway through, I will ask you if I can include your contributions and responses up to that point. You will have the opportunity to review your interview transcript and the research findings once the thesis is completed. Again, this is entirely voluntary and there will be no further requests for your time. I can also buy you lunch or provide a small denomination (\$15) gift certificate as a way to compensate you and thank you for your time.

**Privacy and Confidentiality:**

In order to ensure the accuracy and usefulness of the data, your interview will be audio recorded. If you do not want to be recorded, you can refuse. If you refuse, the interviewer will take notes, if you agree. The recordings will be kept on a password protected computer, backed up on a USB stick that will be kept inside a locked container. At the end of the study, audiotapes will be erased. However, the typed transcripts obtained in this study will be retained for 5 years to be used for secondary analysis and to publish academic papers with the understanding that any additional research projects that use the data will be approved by the appropriate university research and ethics committees. It is possible that the data will be used for secondary analysis by other researchers, but the data will be fully anonymous, meaning that your personal information and identity will be protected. Identifying information will be removed from the transcripts and pseudonyms will be used. If the data is used by other researchers, it is possible that copies of the data may not be destroyed within five years. The findings may be disseminated through scholarly and professional presentations, publications and it will be available on the public database of theses at the University of Victoria. You may also receive the research results by email if you indicate this desire on the signature page of this document. I may discuss the interviews with my thesis committee, but will not use identifying information. Confidentiality will only be breached in the event of a disclosure requiring mandatory reporting (i.e. harm to self, a child or another human being). If you know my committee member Dr. Kelli Stajduhar, please be advised that it might be possible for you to be recognized even though identifying information about you will be changed or omitted in the research results and publications.

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca)). You may also contact my thesis supervisor Susan Strega (250-721-8333 or [sstrega@uvic.ca](mailto:sstrega@uvic.ca)). As the researcher, I do not have any conflicts of interest to declare.

