USING INTERPRETIVE DESCRIPTION TO EXPLORE AND EVALUATE THE PROVIDENCE HEALTH CARE GOALS OF CARE COMPANION CARD: THE CLINICIANS’ EXPERIENCES

by

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Abstract

End of life conversations are challenging in all health care settings, and health care providers’ (HCPs) fears about holding end of life conversations are a barrier to quality patient centred care. This study explored HCPs’ experiences using a conversation “companion card” to structure end of life discussions and sought to understand HCPs’ experiences with goals of care (GOC) conversations.

A theoretical perspective of relational ethics and a research methodology of Interpretive Description (ID) guided this research study. The methodology produced a qualitative description of experiences from a sample of HCPs.

Over a two month period, the researcher gathered data during four semi-structured focus groups with twenty one participants at one urban acute care setting in Western Canada. In addition to focus groups the researcher relied on other processes to enhance her reflexivity, including journaling and memos; all of which are essential to ID inquiry.

The findings of this study centre around four themes relating to participants’ experiences discussing GOC and the usefulness of the companion card in discussions. These themes are titled, the big struggle; responsibility; building relationships and the utility of the GOC companion card. Recommendations from this study addressed the need for research into the ethics of discussing GOC with patients and families with life
limiting illnesses; organisational prioritisation ensuring therapeutic GOC discussions take place; incorporation of GOC discussions in educational programs across all health care sectors; and policy reform to ensure community care services can support ongoing GOC conversations.
Preface

This thesis is an original product of the author C. McNamee-Clark and was granted ethical approval from the Behavioural Research Ethics Board at Providence Health Care and University of British Columbia; certificate number: H12-02672 in November, 2012.
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Dedication

For Keith

Táim i ngra leat go deo
Chapter 1: Situating the issue

1.1 INTRODUCTION

Helpful communication is foundational in building a therapeutic relationship between the adult patient, family\(^1\) and health care providers\(^2\) (HCPs) (Thorne et. al, 2010). HCPs share partnerships in the care of patient and family, as more than one clinician is required to facilitate all aspects of care (Legare, 2010; Larson & Tobin, 2000). Through helpful communication patient and family understanding of diagnosis, prognosis and treatment options are uncovered and can be based on the patient’s and family’s goals of care. Goals of care discussions influence advance care planning where an adult identifies preferences for potential future medical interventions. When we facilitate conversations based on patient and family centred goals of care we ensure quality end of life care (Collaboration for Homecare Advances in Management and Practice (CHAMP), 2009; Collins, Parks, & Winter, 2006; Larson, & Tobin, 2000; Providence Health Care, 2004; Storch, Starzomski & Rodney, 2013). End of life care can be seen as incorporated under the palliative care\(^3\) umbrella. More specifically, Doyle (1999) defines palliative care as “whole person care” (p.vii) that is central to all

\(^1\) For this work family is considered to be the person or persons involved in or influencing decision making in health care settings for a patient.

\(^2\) HCPs are considered to be all clinicians in a health care setting who interact with the patient and family and are considered members of a team, comprised of different professional disciplines (e.g. medicine, nursing and social work).

\(^3\) Palliative care is an approach to care that improves the quality of life of patients and their families living with life limiting illnesses facing the end of life. This approach to care recognises patient and family at the centre of care and of all care decisions (World Health Organisation [WHO], 2003).
health care. As a palliative care clinician I support Doyle’s perspective on this relationship.

Thorne et al. (2010) suggest that the time of diagnosis of serious illness, or when there is a change in health condition, is an opportunity to take stock of what is important in life and to consider available options. Advances in medical science have extended life expectancy, thus permitting humankind an opportunity to live longer with diseased organs and chronic illnesses (Hall, 2011; Zapka, Hennessy, Carter & Amella, 2006). For some, life expectancy can be extended with aggressive medical interventions. For many adults these interventional therapies, and or treatments, can add months, years and even decades to what might have been a short life before these options were readily available. Given all that medical science has to offer one might understand how the inevitable (death) might be ignored; our society is death denying (Larson & Tobin, 2000; Storch, et al., 2013; Zapka et al., 2006). Yet, as Health Canada’s Canadian Strategy on Palliative and End of Life Care (2007) reports, approximately 90% of the population in Canada will die because of serious illness, not sudden death. Furthermore, the Canadian Institute for Health Information (2011) identifies that between 2009 and 2010 eight of each ten deaths in Canadian acute care hospitals involved older adults with chronic and or life limiting illnesses who were open to palliative care supports.

_____________________

4 Aggressive medical interventions include and are not limited to organ transplant, organ repair; dialysis and therapies including but not limited to chemical and radiation therapy; and respiratory therapies and medications to mitigate long term effects of vascular insufficiency, as well as diabetes and also cognitive impairments such as Alzheimer Disease.
According to Bern-King (2004) there is “…certain death at an uncertain time” awaiting us all. Together, Bern-King’s commentary and the facts offered by Health Canada’s report (2007) and the Canadian Institute for Health Information (2011) indicate that there is a need for adult patients, their families and HCPs to better prepare for end of life. To this end, discussing goals of care supports patient and family self-efficacy (Jacobson, 2009), preventing those with life limiting illnesses from living in fear until death occurs. Recipients of interventions, treatments, procedures and medications should be afforded the opportunity to discuss goals of care and to revisit these goals over time. Most importantly, they ought to be afforded the opportunity to discuss treatment preferences toward the end of life.

1.1.1 COMMUNICATION AND END OF LIFE

The need for HCPs to be adept at facilitating conversations on goals of care has been identified by many in the various fields related to advance care planning, including: elder care, ethics, health literacy, medicine, palliative care and patient autonomy (Canadian Institute for Health Information, 2011; Carstairs, 2010; Collins et al., 2006; Eggertson, 2011; Ferrell, 2012; Hall, 2011; Jacobson, 2009; Larson, & Tobin, 2000; Storch, Starzomski & Rodney, 2013; Thorne et al. 2010; Weiner & Roth, 2006; Zapka et al., 2006). Unfortunately, in this literature it is suggested that health care

5 “Advance care planning is about having conversations with your close family, friends and health care provider(s) so that they know the health care treatment you wish to have, or refuse, if you become incapable of expressing your own decisions” (British Columbia Ministry of Health, 2012, p.4)

6 Health literacy is the ability to access, understand and evaluate communication as a way to promote, maintain and improve health in a variety of settings across a lifetime (British Columbia Ministry of Education, 2010).
providers are not attending to patients’ goals of care and, in fact, the lack of attention may be getting worse (Providence Health Care, 2004). Many health care providers are uncomfortable with such conversations and the opportunity is missed, which too often leads to reduced quality of life for the patient (Jacobson, 2009; Providence Health Care, 2004; Thorne et al., 2010; Ury, Berkman, Weber, Pignotti, and Leipzig, 2003). Many adults arrive at the end of their lives without ever exploring how the experience will be endured (Carstairs, 2010; Hall, 2011; Weeks, 2012).

1.1.2 Advance care planning (ACP)

With mounting evidence suggesting that Canadians are ill prepared for approaching end of life, there is an emphasis across Canada, including in British Columbia, for adults to complete advance care planning work (British Columbia Ministry of Health, 2012; Canadian Hospice Palliative Care Association, 2009). While goals of care conversations influence advance care planning, they are not entirely the same. Advance care planning accommodates the provision of information to help identify who is legally considered the best person to speak on behalf of another adult regarding the goals of medical treatment and the discontinuation of such treatment and care, if s/he should be unable to speak for him/herself at some future point in time (Government of British Columbia, 2013, p. 11). ACP is considered just one component in a series of discussions between patient and family and HCPs to meet goals of care (Collaboration of Home care Advances in Management and Practices, 2009; Collins et al., 2006; Larson & Tobin, 2000).

Legal aspects of ACP include assessing capability, establishing advance directives and appointment of a temporary substitute decision maker (TSDM). Within
these components adults are asked to discuss their medical treatment preferences with those they consider family. The adults’ preferences are then documented and are expected to stay with the adult for their remaining lifetime. These plans are initiated by an adult considered capable to make decisions for him/her- self and can be updated and altered as situations change for each adult (British Columbia Ministry of Health, 2012; Canadian Hospice Palliative Care Association, 2009). When the adult interfaces with a health care setting, the legal documentation is supposed to be copied to the adult patient’s chart to ensure patient autonomy is upheld during a health crisis, preventing poor patient satisfaction outcomes. Thus, ACP requires integration of health, legal and social spheres in order to promote adult patients’ choices. Given the importance of an informed decision making process for individuals to document their treatment preferences the “…content and style of discussions” and “…need for an improved …skillset” is highlighted (Pekmezaris et al., 2011, pp. 154; 155). When HCPs listen to individuals and families about what is important to them rather than over emphasizing the biomedical issues, it can help all involved parties to satisfy the health, legal and social spheres involved in decision making.

It was in this spirit of modelling more listening than speaking on behalf of HCPs that the companion card I am addressing in this thesis was developed. With the open ended style questions within the Goals of Care conversation companion (Appendix A), a HCP is guided to assess patients’ and families’ understanding of the illness situation and also to shed light on the values and beliefs held by individual patients and families. As I will expand on below, given the importance of ACP, my aim for this study was to explore how health care providers take up, experience and evaluate a communication
aide for ACP created by an interprofessional group at a hospital in Western Canada. This communication resource (named as a “companion”) is intended to prompt health care providers to competently and sensitively facilitate goals of care conversations with adult patients and families to ensure that end of life preferences, wishes and desires are understood, and to plan how to meet those goals as a team. It is meant to assist with navigating the myriad of complexities involved in communications around ACP.

1.1.3 Complexities of discussing goals of care

Larson and Tobin (2000) and Weeks (2012) suggest that physicians and other health care professionals have difficulty sharing bad news with patients and families. It is also known that for some, this perceived difficulty is based on lack of education and training with regard to holding sensitive conversations and, unfortunately, some HCPs get less adept as years of practice increase (Providence Health Care, 2004; Ury et al., 2003). However, when goals of care are not discussed carefully conflict can result. Weiner and Roth (2006) report that patients and families are unaware of what options are available to them and clinicians operate from a position of what is thought to be what the adult patient is seeking, which can prompt distress. This is both harmful to the patient and a source of trauma for those staff who want to help the suffering patient. Helpful communication enables the patient and family to develop trust in their health care providers and true patient centred care is legitimized (Heyland et al., 2005; Jacobson, 2009; King & Quill, 2006; Larson & Tobin, 2000). In my opinion goals of care conversations are advisable at every health care system interface. This might be viewed as idealistic; however, there is a need to establish what is important to patient and family with goals of care conversations when serious illness and change in condition
arise. From this perspective, goals of care conversations are opportunities to gain patient and family trust and to exercise caring, empathetic communication; that which constitutes good end of life care (Thorne et al. 2010; Weiner & Roth, 2006).

In Jacobson (2009) and Thorne et al. (2010) the authors acknowledge the opportunity to provide caring, empathetic communication is lost at times in health care settings because of barriers to professional communication created by health care providers. In my experience as a palliative care clinician, when patient and family hold unrealistic expectations of the usefulness of life sustaining interventions they focus on disease, laboratory values and results versus the patient’s goals, beliefs and values. According to Dr. Downar in an interview in The Globe and Mail “…reluctance to confront the inevitability of death and continuing treatment can do unnecessary harm to patients and relatives during what is an already an extremely difficult period …” (Weeks, 2012, p. L4). Goals of care conversations can be sabotaged when health care providers give patient and family information that is loaded with medical jargon, facilitating mixed messages and misunderstanding on the part of patient and family. The health care provider may sigh in relief that the difficult task of telling a patient and family bad news is over, yet understanding of the information delivered has not been reviewed with the patient (Heyland, et al., 2005; Jacobson, 2009; Larson & Tobin, 2000; Storch et al., 2013; Weiner & Roth, 2006).

End of life goals of care discussions with patient and family take time (Collaboration of Homecare Advances in Management & Practices, 2009). Time is often perceived as scarce; too scare for long conversations where the patient and family might have a lot of difficult questions to be answered. I believe that if time is spent
discussing patient goals of care early and regularly the system could save wasted resources on interventions, treatments and hospitalizations that the patient and family might not have opted for. Through conversations with HCPs, patients and families might explore palliative care approaches exclusively or in addition to seeking disease modification for those with serious and or life threatening illness (Collaboration of Homecare Advances in Management & Practices, 2009; Larson & Tobin, 2000; Weeks, 2012).

1.1.4 Goals of care companion card

1.1.4 (1) Significance and range of application of goals of care companion card

The Goals of Care (GOC) Companion Card pieces together adult patient and or family readiness for a palliative approach and provides guidance on the process and recommended content and style of conversations when there is a diagnosis of serious illness. By using this resource it is expected that improvement in health literacy for all members of the health care team—which includes the adult patient and family as well as health care providers-- will result. Health literacy, according to the United States Department of Health and Human Service, is “… the degree to which individuals have the capacity to obtain, process and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness” (para. 1). From a Canadian perspective it is considered a barrier to health if a user is unable to speak the language of the health provider, to “…communicate in the language of the service providers” (Bowen, 2000, p. 19). Furthermore Bowen adds “(t) here is ______________

7 This GOC Companion Card has been developed by a health authority located in British Columbia.
evidence that language itself, not ethnicity or socio-economic factors, may explain many differences in service utilization and health outcomes” (2000, p. 8).

Given this knowledge, HCPs have a moral obligation to ensure all adults understand the illness situation and what care, treatments and interventions are available from diagnosis and as illness progresses (Storch, Starzomski & Rodney., 2013). The adult patient and or family must rationally decide about disease modification and care before HCPs can take any action if informed consent is considered (Collaboration of Homecare Advances in Management & Practices, 2009; Weeks, 2012). Therefore, HCPs must assess what the adult patient and or family understands. In determining whether a palliative approach is desired this essential perspective of assessing the patient's and family's understanding of the situation in the context of their preferences and values is offered to support clinicians to determine a treatment plan for adults with serious illness (Collaboration of Homecare Advances in Management & Practices, 2009; Weeks, 2012). The plan is established by the health care team with input from adult and or family.

It must be stressed that health care providers cannot assume the adult's plan is always life prolongation. There are many factors that could affect the adult's plan that should be addressed by HCPs through goals of care conversations. These factors include beliefs, values, personality, life expectancy and illness experience (Collaboration of Homecare Advances in Management & Practices, 2009; Larson & Tobin, 2000). With conversations, goals of care are discussed and in some instances indicate preference for a palliative approach to care (Collaboration of Homecare Advances in Management & Practices, 2009; Weeks, 2012). In the development of the
GOC resource to be studied in this thesis it was anticipated that with the goals of care companion card, HCPs would provide the adult patient and family the opportunity to consider alternatives to aggressive therapies.

1.1.4 (2) Background of the goals of care companion card

The GOC companion card is an artefact\(^8\) of an interdisciplinary group; a community of practice in an acute care hospital in an urban centre in British Columbia. This group became known as the ‘End of Life Council’ (EOLC). Since 2006, the Community Hospital\(^9\) has utilized a specialized palliative consultation service consisting of a full-time nurse and a part-time physician. This kind of service model is expected to support improved patient outcomes at any stage of advanced disease (Hall 2011; Higginson et al., 2002; Weissman, & Meier, 2011). As I have indicated earlier, the literature supports that those patients and families who accept a palliative approach\(^10\) earlier in the illness trajectory are more satisfied with their care (Lee & Coakley, 2011; Mitchell et al., 2012; Torke et al., 2010). Despite the presence of the consultation service, a 2010 unpublished palliative care report by the local health authority on the number of patients accessing palliative care services at Community Hospital identified that a limited numbers of patients with life limiting illness were introduced to this service.

\(^8\) An artefact is “...something created by humans usually for a practical purpose” (Miriam-Webster’s online dictionary).

\(^9\) Community Hospital is the acronym given to the setting where the research study takes place in order to protect anonymity of the research participants.

\(^10\) A palliative approach is an application of the principles of palliative care to people living with life limiting illnesses. A palliative approach encompasses a broad focus on conversations about preferences based on cultural beliefs and values of each person and family unit of care (Initiative for a Palliative Approach in Nursing: Evidence & Leadership [iPANEL], 2011).
These figures supported the concerns of the Community Hospital palliative consult team that most patients with a life-limiting diagnosis were referred quite late—if at all—in their illness trajectory, and sometimes only when imminent death approached. This illustrates that the philosophy of palliative care has not been well developed across disciplines and units, reaffirming a detrimental lack of palliative care awareness across professional groups (Bruera, 2004) that is also reflected in the literature I have cited earlier.

The quality of palliative care in this Community Hospital population was deemed suboptimal and thus the EOLC, composed of different disciplines in the hospital, gathered to explore potential barriers and solutions to palliative care delivery. In order to deliver palliative care to the population who would most benefit from it the EOLC agreed to engage care providers through resources and information to explain how best to achieve identification of patients and families who might require and subsequently embrace a palliative care approach. To do this there needed to be clarity on the definition of palliative care and how to facilitate goals of care conversations to establish if a palliative approach was acceptable to patients and families. Furthermore, the EOLC was not satisfied with simply stating that all patients with advanced disease should have the opportunity to discuss goals of care. For this reason, the Goals of Care Companion Card was developed.

1.1.4 (3) Development of the companion and literature reviewed

Initially the EOLC wanted to create posters that would illustrate questions asked during goals of care conversations. A draft document was created which included a series of questions that should be asked. However, after revision, the posters were
never created. Rather, the council opted to create portable reference cards that health care providers could carry with them at all times. Content within these reference cards was developed from literature on involving patients and family in discussions on selecting palliative care and named ‘Goals of Care Companion Card.’

This card was shared with 200 participants at a palliative care awareness week at Community Hospital in September 2011, and made available at the hospital. However, until now there has been no formal evaluation of the efficacy or utility of this communication companion. The GOC card is a clinical resource that was created to remind and enable HCPs to accept the responsibility of ensuring treatment goals are identified and followed once the patient and family clarifies their understanding of the illness situation. This intent is aligned with health literacy\textsuperscript{11} and patient centred care literature (British Columbia Ministry of Education, 2010; Canadian Public Health Association, 2010; Guwande, 2010; Larson & Tobin, 2000; Smith-Stoner, 2011; Zapka et al. 2006).

1.2 PROBLEM STATEMENT

As I have discussed in this chapter, health care providers’ missed opportunities for goals of care conversations regarding diagnosis, prognosis and care options impacts adult patient and family care and experience in negative ways (Collaboration of Homecare Advances in Management & Practices, 2009; Larson & Tobin, 2000; Thorne, et al. 2010; Weiner & Roth, 2006). Furthermore, the Canadian Council on Learning

\textsuperscript{11} Health literacy is the ability to access, understand and evaluate communication as a way to promote, maintain and improve health in a variety of settings across a lifetime (British Columbia Ministry of Education, 2010).
(2008) suggests that six of every ten Canadian adults do not have the skills needed to adequately manage their health and health care needs. Some frail older adults and those with end stage chronic illness are transported back and forth to emergency departments for symptoms associated with advancing disease and frailty despite the knowledge surrounding futility of medical interventions for these populations (Canadian Institute for Health Information [CIHI], 2010; Collaboration of Homecare Advances in Management & Practices, 2009; Kruthaup, 2008). Establishing goals of care at times outside of health care crisis has been proven to result in less lifesaving interventions for those with life limiting illnesses (Au et al., 2012; Curtis & Vincent, 2010; Mack et al., 2012). Goals of care conversations ensure that patients and families make informed decisions toward end of life. Goals of care conversations ensure HCPs engage with patients and families to inform and prepare them about their illness, treatment, prognosis and what dying might be like. Yet a study by Heyland et al. (2013) demonstrates that slightly more than one half of older patients in hospitals, deemed at risk of dying within the next six months, had not engaged with any HCP to discuss goals of care. Of these patients over three quarters had contemplated their end of life care preferences, which emphasizes the need for processes and structures to be in place to ensure those conversations take place in acute care settings to reach achievable goals of care. The GOC companion card is one resource that possibly can support these processes and must be evaluated.
1.2.1 Research Question

How do HCPs interpret the use of the GOC companion card for effective\textsuperscript{12} end of life communication with patient and families? Furthermore, what do HCPs experience as they engage in complex goals of care discussions in the clinical arena?

1.2.2 Purpose of the study

The purpose of this study was to explore the utility of a Goals of Care Companion Card for health care providers as a communication resource to help guide end of life care conversations with patients and families. With this research approach health care providers’ experiences with a specific communication resource (the GOC Companion Card) were analysed. Ultimately the objective was to better understand what modifications or support might be needed in order to ensure helpful communication takes place with patients and families as end of life approaches.

1.2.3 Significance of the study

Diverse communications support tools and programs are available to assist health care providers to engage meaningfully with patients and families to discuss goals of care in health care settings (Eggertson, 2011; Larson & Tobin, 2000; Providence Health Care, 2010). However, few HCPs, including those in the study setting in BC, have had the opportunity to discuss what their experiences using them have been, or how helpful such resources are to HCPs. Despite the focus of ‘patient centred care’ and ‘shared decision making’ within most clinical settings (including the one being studied in

\textsuperscript{12} Informed participation in end of life decisions regardless of whether promoting more treatment or withdrawal of treatment
this thesis) little is known of the effect or ineffectiveness of recommended and
developed resources. For this reason this study will provide information about how
clinicians take up a communication companion to guide end of life care and how they
ought to have effective goals of care conversations with adult patients and family. It is
my hope that this study will add to research on communication and preparation for end
of life goals of care within palliative care, interprofessional practice and adult chronic
illness fields.

1.2.4 A methodological introduction

The research question dictated the use of Interpretive Description (ID)—a
relatively new qualitative methodology—in this study because with Interpretive
Description the researcher can “shed light” on the circumstances that influence
methodology has helped me as a researcher delineate how the participating HCPs
engaged with patients and families in goals of care conversations and their responses
to such conversations and the usefulness of the GOC companion card. With the data
collected from individual and collective experiences it was possible to appreciate the
communication barriers and challenges they (HCPs) have encountered and also the
suggestions and recommendations they offered for those developers of the GOC
companion card. Findings from the study will highlight HCPs’ views as they relate to a
Goals of Care Companion Card. Using Interpretive Description analysis approaches,
HCPs’ experiences of the GOC companion components were collected and analysed
concurrently and a descriptive account of the experience of HCPs in relation to the GOC
companion and goals of care conversations from the perspective of the HCPs was produced. ID will be explained in more detail in Chapter 3.

1.3 ASSUMPTIONS

As a palliative care nurse I hold a set of values and beliefs that shape my nursing perspective toward patient family centred therapeutic care. I am oriented towards a social mandate to provide moral, ethical, and relational and evidence informed care to all individuals and society. I recognised that my values and beliefs shaped how I interpreted and responded to the experiences of the HCPs at the Community Hospital and I have paid attention to this as I situated myself as a researcher in Chapter 3. I held the following assumptions in relation to this study:

- Helpful communication is a skill that can and must be learned and practiced by all health care providers
- Health care providers must invite patients and families to discuss goals of care because many are reluctant to raise concerns because of issues related power, values, beliefs and culture
- Family are those adults considered as family to the adult patient. Family is comprised of individuals who are bound by “strong emotional ties, a sense of belonging, and a passion for being involved in one another's lives” (Wright & Leahy, 2009, p. 50).
- Skills related to communicating with the patient and family around end of life care goals continue to lack support in education curricula and training for health care providers.
• Some HCPs are fearful of discussing end of life with patients and are hopeful for assistance to have these discussions.
• Using ID research methodology requires me to reflect on my own situatedness (including writing in the first person) to explain the particular orientation I bring to this research study.

1.4 CHAPTER SUMMARY

Helpful communication is a must for therapeutic relationships in all health care settings, particularly when end of life issues are to be discussed. To be therapeutic, health care providers are required to provide the adult patient and family with opportunities to discuss goals of care at time of serious illness and/or when health condition changes to ensure patient and family needs are met. End of life conversations are challenging in all health care settings and health care providers’ fears about holding end of life conversations are a barrier to quality patient centred care. End of life communication requires tools and prompts for HCPs; however, despite multiple resources HCPs continue to lack the guidance for such interpersonal skill.

In this study I aim to add to the literature on how HCPs experience conversations using a communication card. Specifically, I aim to add to the knowledge base informing goals of care conversations surrounding end of life care, by documenting how HCPs experienced using a companion prompt card to structure those conversations. The companion card was developed with the intention that HCPs would attend to the complexity of a communication “process…recognis(ing) the diversity of cultures, life stories and relationships for those for whom we care” (Ferrell, 2012, p.3).
Chapter 2 - Literature review

2.1 INTRODUCTION

In the words of Thorne, 2008 the literature review “…explicitly documents what is (or seems to be) known and the nature of inquiries upon which we have come to that knowledge” (p. 61). It is within the review of literature that a researcher becomes aware of how much or how little is known on a topic of interest. Furthermore, the researcher is then set to articulate a logical argument towards conclusion. Essentially the review of literature for this study was to prompt me as researcher to “…establish what we wish to know, where the knowledge may reside, and why it matters” (Thorne, 2008, p.64). Thus, my intent is to share the review of the current literature related to goals of care discussions and communication support resources detailing particular aspects of health care provider preparation for goals of care conversations; communication challenges and end of life; and HCP perspectives on end of life conversations and communication supports.

2.1.1 Systematic review

The research questions for this thesis are how do HCPs interpret the use of the GOC companion card for effective end of life communication with patient and families? Furthermore, what do HCPs experience as they engage in complex goals of care discussions in the clinical arena? This literature review expands on the literature I introduced in Chapter One to evaluate current research on health care providers’ communication experiences using supports or resources with patients and families.
facing life limiting illness and transitioning toward end of life. In order to review the literature based on the research question asked, a systematic review of the goals of care and end of life conversations literature from the clinicians’ perspective was conducted. I also paid attention to Thorne’s advice on engaging in a literature review supporting interpretive description. She recommends the review is “grounded in existing knowledge…critically reflects on what exists and what does not…offer commentary on strengths and weaknesses with overall body of knowledge” (p. 61).

Two search engines were accessed during the search process; Medline (OVID) and EBSCOhost. Medline using OVID was my first selection based on a conversation with University of British Columbia (UBC) librarian (personal communication B. Saint August 26, 2012). In her expert opinion Medline using OVID is the best search engine that UBC is connected to and it is the most user-friendly search engine. This search was followed by using EBSCOhost which searched a collection of databases online including Ageline, CINAHL with full text, Eric, PsycINFO and Web of Science.

Following the advice of UBC librarian and faculty I established a PICO. From PICO a list of keywords pertinent to the research topic were generated and used to start, as well as refine the search process. Keywords identified included: advance care planning, adult, goals of care, communication, patient and family, health care provider, clinicians, decision making, health literacy, language, end of life and end of life and transition, quality of life, communication tools, communication skills, communication

13 PICO an acronym used in literature searches includes Population, Intervention, Control and Outcome. For this study PICO development is based on Clinicians’ experiences using supports and resources for conversations with patients and families to discuss end of life care preferences.
preparedness, patient readiness, clinician readiness, transition to palliative care, ethics and end of life, culture and end of life, death, dying, terminal, and communication resources. The search was further limited to articles written in English, the language of the researcher. Titles and article abstracts were then evaluated to identify publications that met the following criteria: they were primary research studies or secondary analysis of end of life related data and focused on health care provider communication with patient and family and decision making.

2.1.2 Inclusion and exclusion criterion

Articles were included from the above mentioned data-based searches. In addition, references of key studies were reviewed to identify any significant publications that were not found during the systematic search and as a means to ensure that noteworthy articles had not been overlooked. An inclusion criterion encompassed health care providers’ communication interactions with an adult population approaching end of life with life limiting illness. In order to focus the review to those articles that addressed goals of care communication support resources it was necessary to exclude articles with a focus on a particular treatment or intervention or articles on scales for measuring conflict in decision making or articles on euthanasia (which is unavailable in Canada). In this way I could attend to the current information through which goals of care discussions is constructed. An exclusion criterion was applies to those duplicate articles, opinion or discussion articles and or integrative review articles, not in English and those that involved research with children. The above criteria can be reviewed in Table 1.
Table 1- Inclusion and exclusion criteria for literature review

<table>
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<tr>
<th>Inclusion Criteria</th>
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<tbody>
<tr>
<td>Primary Research/Secondary Analysis/Case Study</td>
</tr>
<tr>
<td>Related to End of Life Conversations in Context of Life Limiting Illness</td>
</tr>
<tr>
<td>Health Care Provider Communication with Adult Patients and or Family Members</td>
</tr>
<tr>
<td>Eliciting Patient Preferences/Goals of Care</td>
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<tr>
<td>Use of Communication Resource/Teaching Tool</td>
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<td>Language - English</td>
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<table>
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<tr>
<th>Exclusion Criteria</th>
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<tr>
<td>Focus on a Particular Intervention, Treatment or Procedure e.g.</td>
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<tr>
<td>- Pacemaker, Defibrillator, Resuscitation, CPR, DNR, Advance Directives, Radiation/Chemical Therapy, Pain/Symptom Management, Articles on Scales for Measuring Conflict, Euthanasia</td>
</tr>
<tr>
<td>Opinion/Discussion Articles</td>
</tr>
<tr>
<td>Integrative Reviews</td>
</tr>
<tr>
<td>Non Adults i.e. Children</td>
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<tr>
<td>Non English Language</td>
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Thorne (2008) urges the researcher using Interpretive Descriptive methodology to be cautious with limitation in the search of literature. She cautions against using limitations such as selected dates, selected journals and data-based research\(^{14}\).

According to Thorne these self-imposed limitations on research will prevent a thorough search of the work completed by a variety of disciplines. However, I selected limiters in my search engine reviews as I have also engaged in non-data based research through web based notifications of current research in nursing with a particular focus on older adults, palliative care both national and international. Additionally I have explored text

\(^{14}\) Data-based research is that literature which is specific to one methodology or another e.g. qualitative (subjective experience) versus quantitative (based on figures) versus mixed methods (combination of qualitative and quantitative) studies.
books suggested to me by my thesis supervisor and palliative care experts. These notifications and text books have informed some of the literature that has guided my work on this masters degree thesis.

2.1.3 Yields

An iterative process of searching in both data bases yielded a significantly large amount of articles. The Medline in OVID search that I performed produced a total 556 results. Given the volume of results I added limits to the search including those articles with available abstracts, in English language, involving humans and all adult. Adding limits prevents a researcher from finding everything there is to know on a topic of interest and promotes finding those articles specific to the topic of interest (personal communication P. Rodney September 2012). This yield result was 199 and then limited to core clinical journals (aim). The end result was 44 titles with abstracts. Without the limit of core clinical journals (peer reviewed), the list was reviewed and refined to yield 158. Further scrutiny of titles and abstracts was required to ensure the search was specific to the question under study. On September 19, 2012 I saved 25 titles from MedLine search in OVID to Refworks\textsuperscript{15} for the purpose of examining all articles. This figure was subsequently reduced to 14, then 7 relevant articles. EBSCOhost searching with MeSH terms and astrixed words to yield a (6\textsuperscript{th}) save of 135 items. I aimed to reduce to this number by adding some limits to the search including ‘abstracts’, ‘English

\textsuperscript{15}RefWorks- is supported by University of British Columbia. It is an organising tool for research findings, citations and articles; allowing me to refine my search and incorporate the necessary organisation with inclusion and exclusion criteria
language’, ‘adults’ (in age group). However when I tried this I yielded 43 searches and on scanning the 43 titles I did not feel that I had a yield that had anything to do with PICO. Because of this result I returned to the pre limit setting search and started a review of titles leading to abstract review. On September 19, 2012 I returned to EBSCO to review and update my search. Using the saved keyword searches I reran the search for a yield of 63 results. Using a limiter for peer reviewed journals only, I gathered 59 results. These titles and abstracts were searched for relevance to the research question attending to inclusion and exclusion criterion.

Reviewing abstracts led to the selection of certain, but not all of the studies initially retrieved. Within this selection process there is a need to order the selection based on closest to the question asked to less appropriate alignment with the question. Those selected are ranked based on inclusion criteria of population of choice, intervention of interest, and method of study implied by the question. Using the inclusion approach to screen articles led to the final review of the entire content of each article. The inclusion criteria were satisfied for thirteen articles.

2.1.4 Review matrix

I used the matrix method approach as described by Gerrard (2007) and also Thorne (2008) to review the literature. A review matrix was created that systematically organized the information gathered and assisted with summarizing, analyzing and efficiently using the evidence. Guided by Garrard (2007), each matrix consisted of the following nine column topics: author(s), title, journal, year and location, purpose and research question(s), study design, methodology and methods, sample characteristics, data collection methods, findings, study limitations, study strengths, and additional
comments. Thorne’s (2008) work suggests fewer categories and positioned me to consider who conducted the study; how the study was conducted; what problems did the researchers encounter and what conclusions were drawn from the studies. Furthermore, I had a specific interest in adult population studies. After all relevant articles were grouped chronologically, the matrixes were analyzed to identify each study’s purpose and research question(s) and then articles were grouped together based on concepts as suggested by Thorne (2008).

2.2 A COMPREHENSIVE UNDERSTANDING

There has been a tremendous amount of research in the literature with regards to communication between physicians and patients regarding end of life care preferences. However, limited research has examined the role of other health care providers in this context, and specifically as part of interdisciplinary approach to patient and family care. In fact, few sources were located that oriented to a multidisciplinary group of health care providers (Kelley, Habjan & Aegard, 2004; Paul et al., 2007). Interestingly the majority of studies were conducted in the United States and not Canada, which impacts the state of evidence from a Canadian perspective because of health care system differences and possible training differences.

The literature review illuminated themes, including health care provider preparation for goals of care conversations; communication challenges and end of life; and HCP perspectives on end of life conversations and communication supports.
2.2.1 Health care provider (HCP) preparation for GOC conversations

From this review there were articles that discussed the participants’ emic\textsuperscript{16} perspective of the level of preparation each shared on discussing goals of care and or end of life care with patients and families. Other articles provided an etic\textsuperscript{17} perspective that is one where the providers’ preparation was understood based on the opinion and perspective of others. I also noted that medical school graduates consider that they receive insufficient preparation for communicating with patients and families with little classroom teaching, clinical observation and or clinical experience (Ury et al., 2009). Specifically, the communication domains indicated were giving bad news, discussing advance directives, discussing prognosis with patient and discussing prognosis with patient’s family - encompassed under an umbrella category of provider preparation. Furthermore Buss, Mark and Sulmasy found cognitive and experiential deficiencies in education preparedness of medical school graduates (1998). Due to this perceived lack of preparation the participants expressed a lack of comfort with end of life communication discussions and as such it was concluded that skills must be improved to prevent bad outcomes for patients (Buss, et al., 1998; Ury et al., 2009).

Canadian institutions were also identified as offering insufficient core preparation in end of life aspects of care for those in schools of medicine, nursing and social work (Kelley, Habjan & Aegard, 2004). This demonstrates a lack of perceived improvement in the academic arena in over a decade. When health care providers engage in end of life

\textsuperscript{16}“Involving analysis or relating to the cultural phenomena from the perspective of one who participates in the culture being studied” (Merriam-Webster, 2013)

\textsuperscript{17}“Relating to or involving analysis of cultural phenomena from the perspective of one who does not participate in the culture being studied” (Merriam-Webster, 2013).
conversations with patient and family it is equally important to provide relational support as information. Curtis, Patrick, Caldwell and Collier explored the barriers surrounding effective end of life communication among pulmonary care providers in a prospective cohort study in the United States. Their study found that when care providers attended to patient’s emotional needs, end of life communication improved overall (2000). This conclusion was shared by Au et al. (2012); Back et al. (2010) and Skinner, et al. (2009) in addition to recommending that how end of life communication takes place requires further studies.

2.2.2 Communication challenges and end of life

As I indicated in Chapter One, the importance of incorporating goals of care into end-of-life discussions has become more obvious in light of evidence questioning the ability of intervention-oriented advance directives to improve end-of-life care (Back, et al., 2007; Curtis et al., 2005). Such evidence leads to the conclusion that advance care planning should focus more on goals of care and less on specific interventions, because advance directives usually cannot anticipate the specific clinical circumstances that will pertain in a patient’s future (Alexander, Keitz, Sloan & Tulsky, 2007). To be more goal oriented, end-of-life decision making requires communication that allows interventions to be situated within a framework of agreed upon goals (Au et al., 2012; Curtis et al., 2005; Weiner & Roth, 2006). Without such a framework of meaning, choices can be made that are not aligned with an individual’s underlying values, and are thus not person centred (Back et al., 2007).

As important as goals of care are, they are not without challenges. Without goals of care conversations interpretations will be necessary at times of health crises.
Preferably, goals of care are discussed in primary care settings when a person is in a state of health stability, regardless of prognosis (Au et al., 2012; Nelson et al., 2011). Goals of care conversations can assist providers to understand patient preferences and also align those preferences with care provision planning (Au et al., 2012). Yet goals of care discussions are often avoided because of healthcare provider discomfort with engaging in these discussions, fear of distressing patients and families, providers considering the timing inappropriate and scarce, and lack of preparedness (Nelson et al., 2011; Pekmezaris et al., 2011). When this is the case there will be conflict or tension and risk of feelings of mistrust between patients and care providers. Through this review of relevant literature these common challenges surfaced from 1990s to present day to demonstrate that little is changing in this aspect of end of life communication.

Goals of care also shift over time because of changing biological realities and personal preferences as diseases progress and therefore it is considered an indication of quality care when providers engage with patients and families to elicit preferences for care along the illness trajectory. Mack et al. (2012) concluded that when patients discussed preferences for care the patients were more likely to choose palliative versus aggressive interventional therapies. Furthermore, less aggressive therapies led to improvements in quality of life. However, even in situations where care providers consider a patient has less than one year to live there is reluctance to engage patients in goals of care conversations until a patient is often in terminal stage of illness (Mack et al., 2012; Nelson et al. 2011).
2.2.3 HCPs’ perspectives on EOL conversations and communication supports

Engaging patient and families in goals of care conversations is a process that requires careful attention and skilful orchestration. My literature review yielded demonstrated a variety of educational strategies, materials and methods for communication with patients and families with life limiting illnesses. Those physicians in training who underwent a 12 hour module to improve comfort levels in discussing preferences for care among patients with end stage cancer diagnoses demonstrated improvements in their perceived comfort with having end of life conversations over their cohorts in the control arm of the study (Pekmezaris et al., 2011).

Oncologists enrolled in the Studying Communication in Oncologist Patient Encounters [SCOPE] trial reported that a tailored interactive CD -Rom improved their skills for discussing goals of care with patients (Koropchack et al., 2006). The CD Rom development was informed by social cognitive theory in an attempt to show physicians how to address patients’ emotions during care discussions (Skinner et al., 2009).

Similarly, groups of multidiscipline care providers self-report improvements in overall communication preparedness and comfort in engaging in end of life conversations through use of adult learner oriented online courses in palliative care approaches (Kelley, Habjan & Aegard, 2004; Paul et al., 2007). Interestingly, only one study acknowledged that skills training and review requires an investment of time to support lessons offered, and these skills also require ongoing practice (Alexander, Keitz, Sloane & Tulsky, 2006).
Eliciting opinions of blinded coders during review of medical oncology fellow interviews following a residential education program ‘Oncotalk’ demonstrated that these post-graduate students improved overall communication skills. While the results show an improvement it is worthwhile to pay attention to the fact that the interviews were not held in clinical settings and used patient ‘actors’ during the interviews (Back et al., 2007). Using a patient prompt questionnaire Au et al. (2012) also demonstrated that oncologists attended to conversations with patients around end of life care preferences. However, like many other studies included in this review the quality of these discussions was not measured, which illuminates the need for further research into how communication occurs, especially focusing on the relational aspect of end of life conversations and the role that power plays on whether the patient and family are treated as partners.

2.3 CHAPTER SUMMARY

Together with the literature I cited in Chapter One, the studies I have reviewed here provide invaluable insight into the research topic; however there are limitations to note. The majority of studies were conducted in the United States, which operates differently to the Canadian health system. Additionally, most of the studies that offered evidence on goals of care communication methods, strategies and interventions were focused on providers who care for patients predominantly with cancer, which is not reflective of those other patients with non-cancer, life limiting illnesses requiring goals of care conversations. Generally, the participants were enrolled in medical training, demonstrating a void in research on practicing physicians, nurses, social workers and other allied care professionals.
This literature review has helped me appreciate the state current knowledge of HCPs experiences as they are engaged with goals of care communication resources and education programs to improve communication skills, particularly around end of life preferences for care. Study participants self-reported that communication interventions were helpful for improving communication skills, and their perceived comfort to engage in these conversations. In other studies improvements were noted in frequency of conversations, and also based on interpretation of others through the use of measurements scores and questionnaires.

The studies commonly demonstrated that goals of care need to be a basic part of our dialogues with patients so that treatment alternatives can be seen for what they are worth against a backdrop of meaning that is derived from patients’ values, grounded in biomedical realities, and meet literacy levels of all those involved in decision making. Communication with patients and their families will inevitably be challenging when care providers perpetuate barriers to communication, but addressing goals of care has the potential to enhance the quality of care by improving the relationship between patient family and care provider.

Clearly, according to the research I have reviewed above, HCPs are ill prepared for goals of care conversations and this influences their ability engaging in effective conversations with patients and families who have an expressed desire for providers to initiate such conversations. Without enhanced training and performance review it is unlikely that the state of preparedness among HCPs will improve. Suggestions from within this review have indicated a need for academia, palliative care and ethics specialists to come to the aid of those providers in training and those in the clinical
arena in order to make necessary changes to the landscape. For these reasons I hope that this study will add to research on communication and preparation for end of life goals of care within palliative care, interprofessional practice and adult chronic illness fields.
Chapter 3 - Methodology and methods

In Chapter 1, I provided the background and rationale for holding goals of care conversations with patients and families to ensure person-centred end of life care. Additionally, in Chapter 1 I introduced the companion card and presented its background in terms of its development by an interprofessional health care team. Providing this background set the stage to explore the experiences of HCPs who are familiar with the companion card as a communication prompt to help guide end of life care conversations with patients and families.

The purpose of this study was to explore the HCPs’ perspectives about communicating with adult patients and families with life limiting illnesses at end of life and also their (HCPs’) responses to the companion card from a relational ethics perspective, which I articulate below. In Chapter 2 I offered a review of relevant literature and how it informs me of what is known about HCPs’ communication preparation and experiences in end of life care, complexities of goals of care conversations and ACP. Here in Chapter 3 I present the qualitative research methodology and theoretical perspective used to address the research study questions.

According to Polit and Beck (2004), qualitative research is applied to understand the “…dynamic, holistic and individual aspect” (p.16) of human experiences within context. Using the qualitative methodology of Interpretive Description (ID) and situating the research within a relational ethics perspective was, in my opinion, the best fit for the research questions to deepen my understanding of the way in which participants
experience aspects of goals of care conversations. This perspective also required me as a researcher to approach the study with a commitment to the participants’ point of view (Stubbs, 2008).

In this chapter I will discuss the ID research methods that were employed for the study, including data sources, strategies for sampling, data collection and analysis and the use of credibility indicators. I will discuss the research process and how I situate myself in the research role. Furthermore, I will describe accessing the study setting and maintaining confidentiality and data collection in relation to options, managing and protecting data, sorting and organising data and data analysis. In conclusion I will explain how I obtained ethical approval in order to commence this study.

3.1 INTERPRETIVE DESCRIPTION (ID) RESEARCH

Exploring the emic perspective prompts a researcher to use a qualitative research approach to a study (Cohen & Cameron, 2009; Newell & Burnard, 2006; Ploeg, 1999; Polit & Beck, 2004). Qualitative research represents multiple methodologies and research practices, is drawn from several disciplines (especially anthropology, sociology and psychology), and tends to be interpretive in nature (Cohen & Cameron, 2009; Guba & Lincoln, 1987; Newell & Burnard, 2006; Thorne, 2008).

Interpretive Description was used as an analytic framework to address the first research objective. With this methodology, the focus was on HCPs’ experiences of the companion card when engaged in discussions with patients and family with life limiting illnesses about end of life care goals. In this study I am interested in exploring HCPs’ experiences using a companion card to facilitate goals of care conversations and
whether those HCPs have found the companion card useful. The processes through which HCPs experience and respond to the companion card during goals of care conversations at the end of life was examined. Interpretive Description methods are particularly useful in the analysis of clinical practice experiences and build on clinical knowledge, social relations and dynamic processes (Giddings, Roy & Predeger, 2007; Thorne, 2008; Thorne, Reimer-Kirkham & MacDonald-Emes, 1997).

As I have argued in Chapter 1, my research questions are well suited to the use of qualitative research methods. Exploring the experiences and responses of HCPs towards a prompts card intended to encourage conversations with patients and families commits the researcher to collecting data in textual form. Those words collected in interviews with HCP offered me, the researcher, the perceptions and meanings of the companion card from the HCPs’ world views, which is in line with qualitative research methodology (Cohen & Cameron, 2009; Guba & Lincoln, 1987; Newell & Burnard, 2006; Tetley, Grant & Davies, 2009).

3.1.1 Theoretical perspective

The theoretical perspective is the “…set of interrelated concepts that structure a systemic view of phenomena for the purpose of explaining or predicting” (Liehr, Smith & Cameron, 2009, p. 35). In qualitative research the researcher’s theoretical perspective guides data collection, analysis and conclusions which are parallel to ID design. I assume that what was learned of HCPs’ experiences surrounding effective communication with patient and families will influence clinical practice. My assumption is based on relational literature offered in Cunliffe and Eriksen’s (2011) and Kunyk and Austin’s (2012) work, in conjunction with the methodological approaches suggested by
Tetley, Grant and Davies (2009) and Thorne (2008). This perspective is reflective of how HCPs’ thoughtful consideration for patients and families when discussing goals for care will elicit what is important to patients and families as they navigate the difficult transitions presented towards end of life. This perspective will also inform me of how HCPs relate to patients and families, as complex and complicated conversations are held at pivotal times in this transition.

Rodney, Burgess, Pauly and Phillips (2013) describe relational ethics as a “newly emerging concept” that necessitates consideration of context “at every level” and to be forever mindful of our own culture and power “positionality” at every level (p.96). Being mindful of power inequities was a foundational block upon which the companion card was built upon and one I support. As I stated previously in Chapter 1, HCPs are guilty of moving ahead with treatments and interventions for patients without clearly explaining all benefits and burdens and degrees of risk inherent in those interventions in end of life situations. These complex situations are imbued with power and who controls power in relationships, demanding consideration using a moral relational lens (Cunliffe & Eriksen, 2011).

More specifically, Gabriel (2008) defines relational ethics as a construct of moral, principled narrative between client and practitioner that “both influences and is influenced by, a complex multidimensional context” (p.1). In clinical practice this statement translates to HCPs’ respect for patient and family participation in all end of life care decisions that requires clarity around what medical science can offer and when patients’ and family values and beliefs are appreciated by HCPs.
In order to gain this insightful data, partnerships were made. Together, patient and family, HCPs as study participants and I as researcher produced knowledge from these complex issues that will have value in a clinical setting (Cunliffe & Eriksen, 2011; Fisher, 2006; Tetley, Grant & Davies, 2009). Given the importance of the relationship of patient and family with HCPs and myself as researcher I selected a relational ethic perspective to inform this research study.

Additionally, this relational approach is also how the End of Life Council will gain feedback on the usefulness of the companion card in preparing HCPs and encouraging effective conversations on end of life goals of care. As a member of that Council and co-creator of the companion card I have an ethical responsibility to ensure I appreciate the experiences of HCPs in its use by way of obtaining feedback through interviews. In this way I am not erroneously providing a prescription for facilitating goals of care conversations and assuming that the companion card is helpful.

Using a relational ethical perspective I link healthcare providers’ experiences of how useful the companion can be in fostering effective end of life conversations with patients and families with how effective those conversations have been from HCPs’ perspectives (Rodney, personal communication July 18, 2012). In establishing dialogue with those HCPs I use the “small details” gathered in data collection and analysis to make changes as necessary to the companion card, as supported by Cunliffe and Eriksen (2011, p.1428).
3.1.2 Study sources

The most common method for collection of subjective data in qualitative research is the interview (Tetley, Grant & Davies, 2009; Thorne, 2000; 2008). Interpretive Description studies’ interviews are supported with other written data sources which include researcher journals, literature and detailed observation of study participants. Cross referencing data from these sources offers a rich tapestry for review.

With any study where the investigator is interested in the experiences of individuals it is necessary for the researcher to engage those individuals in conversation to elicit experiences. With this study my primary source of data was from focus group interview sessions held with HCPs who had particular experience with the phenomena (Guba & Lincoln, 1987; Ploeg, 1999; Tetley, Grant & Davies, 2009; Thorne, 2000). Obviously it was outside the scope of this thesis work for me to be able to interview all HCPs at the setting where the companion card was introduced, and therefore I aimed to engage a sample of HCPs to interview.

3.1.3 Sampling

Knowing that study population consists of HCPs involved in discussions with patients and families around goals for end of life care I attended to making “…concrete and explicit decisions…” related to sampling (Thorne, 2008, p. 87) Ideally, every HCP involved with each patient would be engaged in patient and family discussions at end of life as each member has valuable insight based on professional perspective. At Community Hospital discussions with patients and family includes nurses, physicians and social workers. Based on my experiences as a palliative care nurse this is typical of
those professional “voices” attending at patient/family meetings when discussing end of life issues in acute care hospital settings. HCPs involved in patient and family care include but are not limited to pharmacists, pastoral care workers and physical or occupational therapists, who would add breadth and depth to the study based on their varied perspectives. I considered their inclusion in this study ideal but possibly not achievable (Thorne, 2008) since those HCPs might not see themselves as potential participants in the study, as they are infrequently represented at family discussions.

To achieve an understanding the experiences of HCPs using a companion card to prompt goals of care conversations at end of life with patients and families living with life limiting illnesses I was seeking study participants from the Community Hospital where the companion was introduced in 2011. My goal was to have representation of all HCPs at the care setting. For the purpose of this study sampling was purposive, that is, to include those who usually have experience with the companion and or end of life conversations to join the study. Based on my experiential knowledge, purposive sampling would guide me (the researcher) to attract the participation of nurses, physicians and social workers. Purposive sampling is the term used to describe the recruitment of specific individuals based on their experience, as s/he will help provide richer understanding of a situation (Ploeg, 1999). “…(T)he strategy of purposive sampling is to try to identify, in advance of the study, the main groupings or conditions that you will want to have ensured you include in your study so that the eventual findings you produce have the potential of ringing true or seeming reasonable to your intended audience” (Thorne, 2008, p.91).
I received a rapid response to recruitment advertisement (Appendix B) from HCPs at the site and as such was in a position to set up focus groups sessions in January 2012. On reflection I believe that my previous familiarity with the site, the history of the EOL council at this setting where the GOC was developed, the presence of a palliative care team supporting the research study and the offer of lunch were all factors influencing the response to the call for research study participants. Yet, only 6 of the 21 participants had ever used or reviewed the GOC companion card before being introduced to the GOC during study recruitment period or at the actual focus group sessions. While it was important to me to hear what all HCPs had to say about the companion card it was unlikely that HCPs other than nurses, physicians or social workers might have had an opportunity to discuss goals of care with a patient and family facing end of life which was verified by participants at the focus group sessions.

In qualitative research studies an adequate sample size is hard to predict and is based on data saturation, which is achieved with a rich sense of knowing the participants’ experiences (Ploeg, 1999; Sandelowski, 1986; Sandelowski, 1995). Using an ID approach to research necessitates awareness of the question the researcher is asking and this awareness will determine sampling. According to Thorne (2008), ID methodology is “conducted on samples of almost any size” (p. 94). This allows for samples of small and or large numbers in inquiry work, an approach supported by Ploeg (1999). Thorne (2008) warns the researcher that it is unfair to think that more informants would not add more depth to the data collected. And this is why it is “…important to generate a rationale that is consistent with the research question” (p.94). Thorne, (2008) recommends a framework for projecting sample size that includes the knowledge that is
needed, how close the researcher can get to that knowledge and maintaining respect for the participant in enacting the inquiry. Using this framework I projected a sample size (described below) to use in this study.

From the literature I have reviewed in both Chapters 1 and 2 and from my clinical experience as a palliative care nurse I know that it is common for HCPs to be uncomfortable with end of life conversations. Therefore it was important to explore in depth with participants the particular experiences of those closest to the phenomenon. I acknowledged that not all potential study participants might be willing to share experiences in a group setting and therefore I offered to accommodate those participants with individual interviews in order to respect the needs of each participant in the collection of his/her rich experience. Nonetheless, group settings have many benefits over individual interviews for the collection of rich data according to Thorne (2008). However no interest in individual interviews was shown at Community Hospital. As a novice researcher I am not sure why this was the case, but my supervisor and I agreed that HCPs who wanted to participate may have felt comfortable with the group format.

Given this understanding, and working within Thorne’s framework as articulated above, I anticipated study participant sample size between 10 minimum and 15 maximum, in order to get representation of nurses, physicians and social workers that was still manageable within the scope of a master’s thesis project. With these limits I hoped to gain a variety of disciplinary lenses on the problem. These limits were set to facilitate 2 to 3 focus group meetings of 4 to 6 members (minimum to maximum) in consultation with my thesis supervisor, who is familiar with qualitative and descriptive
interpretation research. As I reached a point of proceeding toward focus group session three, I discussed my initial data analysis with my thesis committee and we as a group made a decision to extend the focus groups to 4 to allow for a review and confirmation session. In doing this I was able to demonstrate rigor in my data collection methods. To this end I ensured transparency in my data collection that added to the final research outcomes. In the following section, I have situated the participants from the various health care provider disciplines and provided a table to explain the demographic configuration of the participants.

3.1.4 Situating participants

Over a period of time between January 23 and March 6, 2013 four focus groups took place at Community Hospital, involving a total of 21 participants. The first group attracted 6 participants with 7 attending sessions two and three. The fourth focus group was an opportunity for selected participants to return to review and offer feedback on initial data analysis. In addition to previous participants in this fourth group one new participant was included to offer another perspective. This final focus group attracted 4 participants in total. Table 2 provides the demographic information of study participants.
### Table 2-Table of participant professional group and practice area

<table>
<thead>
<tr>
<th>Profession</th>
<th>Number of Participants</th>
<th>Familiarity with GOC Companion Card&lt;sup&gt;18&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Therapy</td>
<td>1*</td>
<td>0</td>
</tr>
<tr>
<td>Pastoral Care Worker</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Physician</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>7*</td>
<td>2</td>
</tr>
<tr>
<td>Social Worker</td>
<td>5*</td>
<td>1</td>
</tr>
<tr>
<td>Speech Language Pathology</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Practice Area</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Department</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Elder Care Unit</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>General Medicine</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>General Surgery</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Geriatric Medicine</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Geriatric Psychiatry</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Geriatric Rehabilitation</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Palliative Care Service</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

*One participant from this group joined focus group number 4 to ensure the validity of researcher’s analysis*

The participants were all health care providers at the site and held various positions, including nurses, occupational and physical therapists, a pastoral care worker, a pharmacist, physicians, social workers, and a speech language pathologist. I acknowledge the influence my experience with this site exerted over the process, as the desired representation of professional groups at the setting was achieved. There was a breadth of clinical experience; from relatively new clinicians to those with 20 plus years

<sup>18</sup> Member of End of Life Council and or used the GOC Companion Card in the past during patient, family meetings
of clinical practice. Notably, years of experience were not related to degrees of comfort with goals of care discussions, but clinical practice supported by a palliative outreach team had a positive effect on some participants’ perceived ability to engage in effective communication and palliative care delivery. Additionally, there was varied clinical practice experience at Community Hospital, as some participants have worked at the site for many years to those recently employed clinicians. No participant was a new graduate from his/her professional training even if they were new to the organisation or the site itself. Some participants had cross site experience which was exposed during discussions. Interestingly, those with cross site experience described a variety of approaches to discussing goals of care and identifying the need for end of life care planning among those patients and families living with life limiting illnesses, dependant on the setting. The different health care environments that participants discussed included Community Hospital, Large Hospital\(^\text{20}\) and residential care\(^\text{21}\) sites.

Having two physicians, five social workers and seven nurses attend was encouraging for me as a researcher, as there was representation from all disciplines typically involved in most patient family centred meetings in this acute care setting. Only

\(^{19}\) Cross-Site in this work refers to those who as organisation employees will and can move within their department to another site within the organisation. Other sites within the organisation are located at an acute tertiary hospital setting, and residential care sites.

\(^{20}\) Large Hospital is an acronym for an acute care setting serving over 400 in patients with many specialists and specialised services, medical and other health care learners in an urban area in western Canada.

\(^{21}\) Residential Care sites are also known as long term care facilities where individuals live when s/he no longer can be cared for in their home environment because of physical or cognitive deterioration.
people with experience in family meetings can provide firsthand accounts of those experiences; however those HCPs who are typically excluded from family centred meetings still have opportunities to be involved in goals of care conversations that are more informal. A desired sampling outcome for me as a researcher was to engage nurses, physicians and social and others in order to speak to the cross discipline experiences with goals of care discussions and clinicians’ responses to the GOC card. To participate in the study participants may or not have used the companion card in the past.

What became apparent was that despite its development at this site, few participants had ever seen the companion card and/or used it in a clinical setting prior to the focus groups sessions. As I explained in Chapter 1, an End of Life Council composed of a multiple disciplinary group at Community Hospital envisioned and developed the Goals of Care Companion Card as part of the work they undertook to improve awareness of palliative care and to increase the capacity of all HCPs at the site to offer the benefits of palliative care for patients and families with life limiting illnesses. As key participants on the Council moved on to other positions and other practice settings the Council’s momentum declined and eventually the Council disbanded once the initial palliative care awareness work was introduced at the site. Unfortunately, there was no plan in place to sustain the work of the Council, including marketing the GOC companion card along with modelling how to use the companion card, beyond the group (of Council members) who had initially become familiar with it and how to use it effectively. Subsequently the GOC Companion Card became invisible at the site as those who had become familiar with it and how to engage in goals of care conversations
as a relationship between HCP, patient and family, no longer required a conversation companion during such discussions. This notion of sustainability raised by these observations will be addressed in the final chapter.

Because the companion card had been invisible at the site, participants got to know of the card only during advertisement for the focus group sessions. The palliative care nurse at the site circulated the companion card that I had printed out as part of advertising to generate interest in the research study. In order to resist the opportunity to place my own interpretation on the disappearance of the GOC companion card, I must temper my own interpretations with meaningful interpretation of the research data I collected.

3.1.5 Dealing with data collection and data analysis

While I will address the processes of data collection and data analysis separately in this chapter I would like to note at this point that data collection and analysis did take place concurrently. Indeed, dealing with data is an iterative process in qualitative research (Guba & Lincoln, 1987; Sandelowski, 1986; Thorne, 2000).

In this Interpretive Description study, participants’ experiences informed and expanded upon how data collection was structured for focus group settings. The researcher’s constant engagement with data is required in order to be in a position to explore knowledge gained from each interaction with participants, as too is the need to reflect on how the researcher’s own prejudices and biases are influencing interviews (Sandelowski, 1986; Roper & Shapira, 2000; Thorne, 2000; 2008). In order to build credibility into this qualitative research study I have approached this inductive data
process by collecting oral narratives from focus group interviews and by analysing with rigorous reflection and critical examination (Grace & Powers, 2009; Sandelowski, 1986; Thorne, 2000; 2008; 2010). I also used my supervisory committee to assist with my credibility.

3.2.1 Situating self in the research role

As a palliative care clinician I am fortunate to have developed confidence with practice to engage with patients and families and discuss goals for end of life care in situations of life limiting illnesses. Through the research process in this study I have been given an opportunity to hear first hand experiences from HCPs interacting with patients and families in similar situations. This was my inaugural experience as a researcher, and as a novice researcher I acknowledge how my inexperience required support and coaching from my thesis committee members and from the literature. Thorne (2008) suggests a number of practicalities when engaging in Interpretative Description that I followed. These practicalities include Tracking Reflections; Learning not to Lead; Disclosing the Discipline; Revealing and Concealing; Negotiating Informed Consent; Finding your Tongue and Constraining your Influence. All of these practicalities will be discussed here in relation to how I prepared for and enacted my role as student researcher. And interestingly, these practicalities are reflective of palliative care nursing guidelines, which are necessary to deliver exceptional palliative care (Canadian Hospice Palliative Care Association [CHPCA], 2009). Nursing standards in palliative care support nurses practicing patient family centred care which requires palliative care nurses to be reflexive and present in practice, allowing patient and family centred care planning without nurses’ influence.
3.2.2 Tracking reflections

Thorne’s (2008) term “tracking reflections” is interpreted by me as journaling, as she recommends the researcher is “…documenting something of what is happening to you subjectively and conceptually within the research engagement becomes a core element informing your inductive analysis process” (p.109). This reflexive technique is recommended for qualitative study approaches (Guba & Lincoln, 1987; Tetley, Grant & Davies, 2009). Journaling what was happening to me as I journeyed along the path of researcher provided me “…with a critical lens for any potential biases, prejudices or misconceptions prior to entering the field” (Kruthaup, 2008, p. 50) that influenced my interviewing techniques and the approaches I took to data collection and analysis.

In fact, this reflexive process began for me even before data collection commenced. Since I set out to write the study proposal I have maintained a notebook that is home to three sections entitled analytic; observing and hearing; and personal feelings. That journal accompanied me along to all interviews with study participants so I was able to capture, and tried not to lose, the activity surrounding me as I engaged with this iterative process.

3.2.3 Learning not to lead

Making a transition from experienced clinician to novice researcher involves ‘foreign’ practices, according to Thorne (2008). As an experienced clinician it is standard practice for me to meet with a patient and or family and to know not only the broad purpose of our meeting, but also what information I will need in order to complete my assessment and initiate a plan. On occasion if any unexpected information or issues
has arisen, I have explained the need to address that issue at a future meeting. As an experienced clinician working with patients and families I am expected to enact the role of expert palliative care consultant.

In research work, however, I took on a new role. The participants were the experts and I as learner was unable and unwilling to “…shap[e] the conversation as it unfolds” (Thorne, 2008, p. 110). As I read the literature on conducting group interviews and actually engaged in the interviews, I became more aware of the challenges in learning not to lead. Not leading the participants required a lot of practice for me, and also coaching under the guidance of my committee supervisor.

3.2.4 Disclosing the discipline

As I addressed each of the practicalities suggested by Thorne (2008) in her text on Interpretive Description I became aware of how many potential risks I brought to this research process. In the section on process “Disclosing the Discipline” (p. 110) the need for me to disassociate myself from my clinical involvement with the HCPs and from the development of the companion card was highlighted.

It was important for me to not capitalise on my familiarity with the site and those who worked there in order to attract study participants. I could not influence HCPs to join the study because of my background or previous relationships with them as this would harm the ethical responsibilities involved. I approached participants as an authentic researcher, interested in the HCPs and learning of their subjective experiences. Once again, in this aspect of avoiding “inappropriate expectations” (p.
I was guided by Thorne (2008). I advertised the study in areas of the hospital that are frequented by HCPs, rather than approaching HCPs individually.

The only attachment of my name to this study was in the contact information. Additionally, I removed my titling and clinical responsibilities at the organisation in an effort to establish myself foremost as researcher. In this way I aimed to attract HCPs to the study based on the intent of the study, while ensuring I was not obscuring relevant information. Specifically, I intended to “make explicit that the benefit of the research (would) be knowledge that may help enlighten fellow professionals for the benefit of future patients” (Thorne, 2008, p. 111). Nonetheless, I received quick response to the advertisements for the research study which I must acknowledge is likely related to the fact that many HCPs at the site were familiar with me and, as such, were willing to participate in this study.

3.2.5 Stepping out of the role

Thorne (2008) acknowledges that “despite all good intentions to be true to the researcher role, [she] doubt[s] that it is really possible to discard one’s larger social mandate as a health care professional engaging in the research of one’s profession” (p. 111). As I indicated previously, I hold the perspective that HCPs have a moral obligation to patients and families to discuss goals of care at least as frequently as at times of change or crisis in the patient’s illness experience. It is this perspective that motivates me within my clinical work as a palliative care consultant team member supporting other HCPs to hold conversations on end of life goals of care.
During my researcher role some discussions took place where a HCP talked of difficulties in holding goals of care conversations. I knew, as a palliative care clinician with knowledge and experience of how to approach such discussion, that I had helpful suggestions to offer. In order to mitigate such a situation and avoid harming the study I delayed a therapeutic response to the particular HCP that could improve patient centred care until the session was completed. I used the journal to record my reactions and thoughts to these clinical issues in the sections ‘observing and hearing’ and ‘personal feelings’ and also consulted frequently with my thesis supervisor. Additionally, I used a referral process to the palliative outreach consult team for those research participants with concerns.

3.2.6 Revealing and concealing

There is a significant connection for me between this section, Revealing and Concealing and that of the former section Stepping out of the Role. As a palliative care clinician I have experienced holding conversations with patients and families on end of life goals of care where the illness is life threatening. Many HCPs involved in the study were familiar with this despite my introduction as a student researcher, and there was a potential for them to question me on my experiences with goals of care conversations, thinking we share experiences. The risk, according to Thorne (2008), is that when participants consider there is common understanding of the phenomena there can be “…reluctance to go into depth on what might be the key elements” (p. 113). What this can do is potentially influence how participants answer some questions if a participant considers there is a ‘right answer’ that is expected by me the researcher.
My responsibility as a researcher in these situations was to refocus participants on my aim to understand the experience for the HCP in the situation, and not to share my own clinical experiences. As in Disclosing the Discipline, my approach was to suggest the issue of my own experiences could be addressed once the interview session was complete, in order to avoid influencing participants’ accounts.

3.2.7 Negotiating informed consent

Thorne (2008) dedicates a section in her text on how to negotiate informed consent using Interpretive Description methods in research. Given that this methodological approach was developed by Thorne, it was prudent of me to address this section of the proposal based on the suggestions she made in her text. Thorne cautions the Interpretive Description researcher that it is impossible to engage participants in interviews with predetermined structured interview questions. Predetermined interview questions do not fit with qualitative methodology (Thorne, 2008). Specifically, in qualitative research the aim is to follow “leads suggested by the study participants and capitalize on linkages of bits of data” (p. 114). What is recommended by Thorne (2008) is the use of a set of concepts and trigger questions\(^{22}\) that can help get conversations started and keep discussions on track with the aim of the study. Trigger interview questions and concepts are included in this work as Appendix C.

\(^{22}\) Trigger questions are open ended questions to encourage the study participant to explore deeper their experiences and thought processes. Trigger questions are used by the researcher to “…signal sustained interest” and to “facilitate (e) the flow of the interview” (Thorne, 2008 p 115-116).
As I considered the notion of informed consent for interviewing participants in the study I was very mindful of the fact these participants were HCPs--more practiced at being interviewer than interviewee--which offered potential for perceived power differences to be experienced in the interview context. In clinical settings the HCP is responsible for data collection from patient and family in order to assess, plan and implement treatments. In order to remain ethical and true to the purpose of the study I ensured that the participants could trust that their information remained confidential and that in no way would content be judged as a reflection of clinical competence or professional practice or personal character (Appendix D –Study Information and Consent Form). With each focus group I commenced with a statement to remind participants of my responsibilities to maintain their information confidential. I also ensured that the research assistant\textsuperscript{23} signed a confidentiality agreement. This agreement is offered as an appendix (Appendix E) to this work.

It was possible that as a researcher I risked digging for rich deep discussion that might cause a participant to feel s/he was disclosing too much information. In order to continually negotiate consent it was my responsibility to allow that participant to pause in order to consider if s/he wished to continue with the conversation or disclosure. In doing so I ensured that I remained ethical in my practice as researcher and protect the participant revealing only that information s/he is “…comfortable with and no more” Thorne, 2008, p.114).

\textsuperscript{23} The role of the research assistant was to guide participants into the focus group session meeting room, ensure the information form was read and that the confidentiality form was signed.
3.2.8 Finding your tongue

When clinicians work with clients to obtain histories for assessment purposes it is not unusual to use certain prompts that have value attached to them. Prompts such as “I understand” and “that must have been painful” can inadvertently tell the client that the clinician is sympathetic to the situation. For the purpose of research this prompting behaviour is “forbidden” (Thorne, 2008, p. 115). For this reason a researcher must develop techniques for engaging the study participant to clarify further and enlarge on comments that are made. In her text Thorne (2008) encourages the researcher to have and to practice with a “…repertoire of ‘good questions’…” (p. 115). These questions are what Professor Hall in an MSN N 558F course lecture in February 2010 described as “trigger questions”.

While trigger questions can open up conversation among participants another technique for finding your tongue as a researcher, as suggested by Thorne (2008), is to make connections between interviews. This is achieved by introducing a wider data set to a group. Throughout the data collection period I offered anonymous comments and concepts from previous interviews and asked for participants’ thoughts on those concepts. As I concluded the interviews a summary of the themes was offered to the participants ensuring the data collected was reflective of their views of the conversations that took place.

3.2.9 Constraining your influence

Considering this final practicality involves reflection on the privileged position I held as researcher in this study. In both sections Revealing and Concealing and
Disclosing the Discipline I drew attention to my position of privilege based on my experience as a practised clinician experienced in the art of end of life discussions with patients and families and also my privileged prior familiarity with HCPs who participated in this study. In addition to these factors I was also privileged with control of data and how it was treated. Specifically, my potential influence on data collection and analysis as my theoretical perspective influenced the process as I attended to comments and small details. My theoretical perspective shaped how I related to data and that which sparked my interest led to the potential for me to be curious on one aspect than another. In addition to theoretical perspective, the matter of informed consent was also very important. I did not stray from the intent of the study for which participants agreed to join. When I became aware during data collection that the discussion was leading to data that was in no way related to the aim of the study then I was vigilant to remain close to the objectives and steered the conversation back on track.

3.2.9 Situating self in the setting

Getting into the setting in order to conduct research is indeed a different matter than entering the same setting as a clinician, as I have witnessed when some of my colleagues have taken on researcher roles in the past. My relationship with the same setting was different as I “don[ned]] the researcher hat” (Thorne, 2008, p. 118). These differences will be addressed below in Insiders and Outsiders; Navigating Access; Watching and Doing; Staying Safe and Honouring Confidentiality.
3.3.1 Insiders and outsiders

Thorne (2008) cautions the researcher on the benefits and burdens of insider and outsider researcher. Insiders are those who have prior knowledge of the setting, whereas outsiders are unknown at the setting. I identify as an insider at the research setting since I have worked on site there between 2007 and 2013. I am known by many HCPs at that site which offers me both privilege and disadvantages.

3.3.2 Navigating access

The clinical setting where I gathered data for this study was well known to me, yet I was obliged to treat my role as researcher at this site differently than as a clinician. Despite the benefit of research to furthering the improvement of patient care, researchers can be seen as a nuisance in a clinical setting (Thorne, 2008, p. 119). In order to minimise my ‘nuisance factor’ I approached the site leader for the clinical setting to get permission to hold the study on site. Being privileged to know the site leader and also some of the operations leaders at this setting was helpful in obtaining a swift response to my permission request.

Accessing the site as researcher required permission seeking and information sharing. In order for me to engage participants at the setting I needed permission to attract clinicians from the site leader and administrators for the various clinical areas. When I contacted the administrators individually I assured each one that the collection of data would in no way compromise the day to day care of patients at the setting and, too, that I would treat all participants with respect, not compromising their ability to provide care.
3.3.3 Watching and doing

Being responsible for focus group sessions facilitation had an influence on the interview process. In no way did I want to taint the data collected by influencing participants’ answers to my questions, yet it was possible that my experience and background would prevent my observations being “pure” (Thorne, 2008 p. 120). The right thing to do was for me to pay attention to how I influenced the participants and ensured it was tracked in my journal. Potentially, I could help out the clinical setting by holding these interviews; therefore it was likely to be considered a positive step to promoting a respectful relationship between the researcher and staff or gatekeepers at the setting (Thorne, 2008). With this in mind I made sure that all clinical units at the site had a supply of available companion cards. My palliative outreach nurse colleague also stored cards at her site office in case any HCP or potential participant wanted to obtain a card.

3.3.4 Staying safe

Thorne (2008) adds a section on ensuring personal safety for the researcher when involved in data collection outside the usual clinical setting. Given that the participant population for this study were HCPs and the fact that the focus group sessions were all held on site at the clinical area, there was no risk to my personal safety in this particular case. Being safe in my researcher role required my adherence to the ethical responsibilities of a researcher.

3.3.5 Honouring confidentiality
It was important for me to be considerate and reflexive about my professional role and history with the companion card and HCPs and the setting itself. As a palliative care clinician my clinical perspective has been exposed to other HCPs at the hospital setting as we have discussed various clinical issues and shared experiences at patient family meetings and team care updates. I was conscious that I could not enter the field anonymously and that lack of anonymity might bias how participants responded to my interview questions and enrolment in the study. Over the five past years I had become familiar with the hospital setting and those HCPs who work within that setting. Over that time period I have practiced on site in my role as palliative care resource nurse and have chaired the End of Life Council that developed the goals of care companion card. I could not remove my mark on the setting and the impression I have made upon HCPs at that site: “… I doubt … it is … possible to discard one’s larger social mandate as a health care professional …” (Thorne, 2008, p. 111).

I was therefore mindful to ensure I identified myself in this study as student researcher and not as companion card producer or palliative care resource nurse. I considered that if I lived by the rules suggested by Thorne (2008) that I could be successful as a researcher. I gave myself the challenge to stay focused on the data for collection and analysis and to suspend assumptions based on my clinical experiences.

3.4 DATA COLLECTION

3.4.1 Access and confidentiality

As the researcher I approached each in-patient clinical area within the setting (medicine, surgery, geriatrics: rehabilitation and psychiatry) and provided an
informational letter about the study that outlined the following: research goals and purpose, participant recruitment process, type of data collection and collection procedures, potential risks and benefits of participation, length of the study, participant time commitment, and how the data would be used. The participant information letter is included in the appendix of this thesis work (Appendix D). Once the leader for each clinical setting agreed to participate in the study s/he was asked to help with the recruitment process by raising awareness at unit meetings and giving permission for recruitment posters in the clinical areas. Potential participants were provided with a study information letter through their disciplinary departments at the hospital.

   It was made clear in the informational letter that participant’s confidentiality would be maintained throughout the study and that participants had the right to withdraw from the study at any time. If potential participants had further questions or concerns regarding the study they were directed to contact the researcher through the contact information provided on the informational letter. After reviewing the study information, HCPs who agreed to participate were given a participant consent form and a request for dates for focus group or individual interview.

3.4.2 Options for data collection

The study question determined the methodology involved in this study. As I am interested in the experiences of HCPs I needed to gain an appreciation for more than a superficial understanding of how HCPs relate to patients and families when discussing goal of care at end of life. In order to gain this depth of understanding I had to engage the participants in a setting where their feelings could be explored. In order to do this I decided to engage participants in interviews, both in a focus group setting and or
individual setting. Although an individual interview was an option for all participants no participant requested this option.

3.4.3 Focus group interviews

The focus group\textsuperscript{24} is an opportunity to gain understanding of the collective voice. It works well for health care research in so far as it is an opportunity to gain public opinion while engaging multiple voices at the same time. Cohen and Cameron (2009) and Thorne (2008) write that the North American style focus group is a product of market research to inform on the shared voice of the market. The focus group provided an opportunity to get many opinions on the companion card and about effective discussions with patient and families in end of life situations. For the purpose of this study, my goal in selecting focus group interviews was to facilitate discussion among study participants. It was hoped that one participant’s experience might be congruent or not with another’s to generate rich discussion among the group. Specifically, Thorne (2008) indicates the focus group setting is “… the opportunity to meet distinct individuals each with some experiential knowledge about a phenomenon and see what happens when they engage with one another” (p.131). In addition to discussion, the group interaction provided rich data for analysis. In fact, Duggleby (2005) considers group interactions key to the benefit of focus group interviews over individual interviews.

There are no hard and fast rules on numbers to be considered sufficient for a study of this kind, yet qualitative research experts suggest that focus groups of numbers

\textsuperscript{24} Focus group refers to a group of participants who are `focused' on a “…collective activity…” occurring “…within a social context” (Duggleby, 2005 p. 832).
between 6 to 10 maximum work best (Cohen & Cameron 2009; Thorne 2008) Given this I had an expectation of engaging sufficient numbers to fill 3 focus group meetings, with an option for HCPs to attend individual interviews if it suited. It was my hope that focus groups would feed other focus groups. What is meant by this is that focus groups members will engage other participants by snowball effect if they have a positive experience at a focus group interview. I learned through participants that some enrolled in the study based on feedback from colleagues who had participated in previous focus group sessions. Catering a lunch meal was another draw for participants to the research process.

Planning the focus groups interviews required preparation and resources. Focus group interviews are best planned for onsite at the hospital in order to make the experience accessible for all HCPs. Room reservation was required in advance which was difficult given that a selection of dates were offered to potential participants. It was difficult to know whether there might be a sufficient number of participants for each date that a meeting room was reserved. Based on my practical experience I was aware that “lunch and learn” sessions have caught the interest of HCPs at the site in the past and I elected to host the focus group sessions between 1200 and 1300hrs on Wednesdays and added those potential dates with a location to the information posters. This plan was successful and, as I have explained, I had 21 participants engaged over four focus group sessions, three of whom attend the fourth group session. Because the interviews

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25 Snowball effect is a term used in qualitative research to explain how interview group participants attract other individuals to interviews (personal communication W. Hall, 2010).
were scheduled over a typical lunch time hour I provided food and refreshment to participants to capitalise on their availability for a maximum of 60 minutes.

Interviews were semi structured as it is important to allow “…detailed exploration and the opportunity of the respondent to tell their own story” (Newell & Burnard; 2006, p. 26). These interviews were recorded on tape and transcribed in word format to ensure no comment or words were lost to the researcher for data analysis. All interviews were led by me as researcher despite my novice researcher preparedness. With the help and guidance of my thesis committee supervisor, I rehearsed facilitating a focus group session. The rationale for me facilitating the discussions was that I was the person most familiar with the study purpose and the concepts behind the companion card. This familiarity allowed me to guide discussion when a concept was raised that I could direct toward further comment from other participants. I was also in the best position to look for clarity as I understood the nature of the questions. Developing the research question and facilitating focus group sessions were all skills that will improve my performance as a researcher.

As part of my plan around the collection of data I anticipated the need for another person recording the interviews and paying attention to group interactions, body language and other participant nuances (the research assistant). This provided me an opportunity for both reflexivity on how to facilitate future interviews in this study and to incorporate group dynamic and relationships into data analysis. Each data collection process presented me with another opportunity to analyse data collection including how I asked questions and encouraged discussion. In this way I met the requirements of
Interpretive Description methodology in ongoing reflexivity and the concurrent process of data collection and analysis (Ploeg, 1999; Thorne, 2008).

3.4.4 Managing and protecting data

All information recorded both in written field notes and by tape recording (transcripts, audiotapes and computer discs of interviews) was stored in a secure office within a locked cabinet at the hospital. As research data collector, I had sole access to this secure cabinet. Another strategy was to remove identifiers (such as name) and a digital identifier was assigned each participant. Data entry was performed on password protected computers and only password protected data devices was used for transferring study information between computers. Collected study data will be kept for five years post data analysis and study reports have been completed, including academic publications and education material. After this five-year period all study interviews and computer files will be erased and paper copies will be shredded. Finally, I will share findings of the study with HCPs at the hospital setting and the organisation. Recommendations for improvements and changes to the companion cared will be shared with those members of the End of Life Council who created the companion card.

3.4.5 Sorting and organisation

Collecting data required a plan for organising and sorting the data. Indeed Thorne (2008) warns that the data can expand “exponentially” and a researcher can quickly become overwhelmed with the volume of information (p.137). I planned to deal with information immediately after each interview setting to avoid being overwhelmed quickly with an unfamiliar role. This plan was aimed to prevent me getting quickly buried
under information and risk having a huge volume of data to manually sort through at the end of the data collection process.

3.5 DATA ANALYSIS

According to Thorne (2008), data analysis is “unquestionably the most painfully difficult and yet the most essential element in what constitutes a credible interpretative description study” (p. 141). And so it is the responsibility of the researcher to ensure the data is analysed based on what is learned versus based on a researchers bias and prior knowledge of a phenomenon (Roper & Shapira, 2000).

Terminology such as validity and rigor are considered aligned with quantitative rather than qualitative research methods, yet their principals of quality have relevance and are considered in this study. To be considered a quality study I followed the guidance in literature such as that from Thorne, (2000) and Grace and Powers, (2009). Factors determining good quality qualitative research are “…systematic, rigorous and auditable analytic processes…” (Thorne, 2000 p. 70). What this means in practice is well documented data collection strategies and logical processes for the reader to follow regarding how my theoretical perspective and understanding of what data was relevant to the research question to be considered credible by a critical reader. Achieving this credibility was dependant on availability of an audit trail so my research was detectable throughout the process. In this way I attempted to describe the analytic process using clear language and logical progression, and not by creating findings incongruent with the data collected (Grace & Powers, 2009).
Data analysis, as an inductive process, began with the initial focus group session using material from recorded focus group sessions and field notes, moving back and forth to identify patterns and themes (Roper & Shapira, 2000). Journaling and maintaining field notes added supplemental data to the raw interview data that was transcribed from the interview recordings. These notes made a collection of my “…impressions about each interview, each interview and the interview process…” (Stubbs, 2008, p. 35). In this way it was possible for me to rework the order for prompt questions, how I introduced the focus group session, introduced potentially relevant themes from previous focus group transcriptions and or the amount of dialogue I offered during the focus group time period. For this reason, and following guidance of my thesis supervisor, I was mindful not to schedule group meetings too closely together as each session required time for me to work on data analysis post interview (Rodney, July 2012 personal communication). Thorne (2008) advises the “neophyte” to stick with the transcription process because nuances, words and phrases could be lost to a transcriber unfamiliar with the interview session (p. 143). However, I engaged the help of a transcriptionist to assist with transcribing interview data as I was not familiar with this process and needed to move forward with data collection based on the number of interested study recruits. As I identified in the section in this chapter on sampling, I received a lot of interest in participation in this study at the site and I decided to engage a skilled transcriptionist. In doing so, I could focus on maintaining the momentum around focus group participation. I did ensure that I listened to all audio recordings of data collected while reading the transcriptions, ensuring the transcriptionist did not omit any data.
Through a “…process …of mulling” (Wolcott, 1994 in Thorne, 2008, p.163) I was better situated to process the data as I probed through, critically asking ‘what does this mean’? By comparing the pieces of data within and between group sessions I was able to uncover the commonalities and patterns of the human experience (Thorne, 2008). Within data analysis it is traditional to develop coding26 as an initial step to developing data into patterns and so on. Traditional grounded theorists27 have developed advanced coding in order to “arrive at theory about basic social processes” (Liehr, LoBondo-Wood & Cameron, 2009, p. 172). However, with such in depth development of data there is a risk of losing the voice of the subject(s) (Dr. W. Hall lecture notes Jan 2010). The key to coding in an interpretive descriptive study is to keep the codes very broad, focusing less on “words and expressions” but paying attention to “ideas and themes” (Thorne, 2008 p. 145).

Using broad codes, data was analysed further based on whether it was offered in reference to the “consequence” it had to the situation or whether it revealed an emotional response that was a central theme (Thorne, 2008, p. 146). Thorne (2008) offers alternatives to rigid coding to analyse data collected. Using notations, memos and journaling as a researcher I was able to resist labelling data with codes but, rather, I flagged ideas and themes, sorting them into 'like' piles as I moved back and forth and identified what seemed similar with phrases taken from the study data. Each time I

26 Thorne, 2008 suggests that coding is essentially the “…initial basket into which the laundry is being sorted…” (p. 144).

27 Grounded Theory, developed by Glaser and Strauss (1967), is considered an efficient qualitative research methodology as it develops theory from data to themes, categories and constructs in social settings.
returned to the data I looked at it from a different angle to see what grabbed my attention so it was not lost (p. 147). My flagging system was completed by physically cutting up the pages of copied transcription; a process offered by Burnard (1991) that allowed me to return to the groups of words, comments and thoughts to re-sort where the similarities lay and to develop themes. Using a tactile approach to sorting the data helped me as a neophyte researcher to make sense of the patterns that were emerging. This technique helped me to clarify the thoughts and ideas around what I was seeing in the data. All memos and analysis were saved to my personal computer. The sections of transcripts that were cut were then saved in folders. Each theme had its own folder which allowed me to return to the folder and reflect upon whether the information was relevant to that theme. Once analysis was completed the folders were filed in the locked cupboard at the palliative care office on site at Community Hospital.

Joint broad coding and frequent meetings with my thesis chairperson assisted in the review and discussion of the coding process. Although I am a novice researcher, with the guidance of my thesis committee I was able to engage in making sense of the data even while still collecting data and so I was able to “consider and modif[y]” (Thorne, 2008 p. 165) in order to conceive the final findings that I will present in Chapter 4. All direct participant quotations and indirect references will be identified in Chapter 4 as ‘P’ followed by the numerical order the participants’ comments were received e.g. P1; P5 etc.

3.6 OBTAINING ETHICAL APPROVAL

Newell and Burnard use a simple statement suggesting that as ethics is the basis to health care, similarly ethics must be the basis in health care research (Newell &
Burnard, 2006). Research that involves human participants is subject to the ethics principles as set out by Tri-Council Policy Statement (TCPS) (Tri-Council 2010). This agreement sets out the obligations that must be met by a researcher when engaging human participants in research studies. Ethical approval was sought and obtained by me from the health organization Research Ethics Board (REB) and from that of University of British Columbia (UBC). The study was non-invasive and clinical involving human participants. To satisfy these principals I proposed to both REBs that consent would be gained from each participant once the purpose and outline of study was explained to the participant.

Explanation of participants’ right to exit the study at any time was given and guarantee that no harm was expected was included in the agreement form. Participants were advised that all information would be held in secure confidence. If a participant wished to be interviewed in private versus in a focus group setting that option was available. Consent also depended upon participant understanding and agreement with the fact that each participant had the right to pass on a question and/or halt the recording of information at any time.

Confidentiality was maintained in different ways. First, each participant in a focus group setting was responsible for a signed agreement to their confidence and not to share any information outside of the interview setting. In the same way the signed confidentiality agreement assured that the substance of the focus group details would not be reported outside the group. This signed confidentiality form is also bolstered by, but not dependent on, the code of ethics guiding the practice of each HCP included in the study. For any person handling or privy to data in my study a research assistant...
confidentiality form was completed. This form required a signature indicating the individual would not share any information to which s/he is exposed. This applied to the focus group assistant; a school colleague who also had the role of transcriptionist.

3.7 CHAPTER SUMMARY

In this chapter I have discussed the theoretical perspective of relational ethics and the research methodology of interpretive description as I applied them to this research. The data collection methods considered for this study--focus group interviews in addition to reliance on journaling and field notes--were essential components of interpretive descriptive inquiry. From a relational ethics perspective, HCPs are obliged to engage with the patient and family and to look beyond the surface. Health care practitioners’ involvement with patients and families requires “ongoing inquiry and deliberation…” (Hartrick, Doane & Varcoe, 2013, p. 156). Holding focus group sessions allowed me to explore the complexities of end of life conversations and to also explore the nature of how HCPs interpret a companion card for effective communication with patients and families.

Semi-structured interviews for focus groups offered the emic perspective of HCPs both new to and familiar with the companion card. Additionally, personal journaling and reflexivity enriched my analysis of how HCPs have taken up goals of care conversations with patients and families who are facing end of life.

Using Thorne’s (2008) practicalities for situating myself as a researcher in the setting helped me to address the strengths and challenges I encountered in this study. This research study met ethical standards for research involving human subjects at both
university and health care organisation research ethics review boards. Key elements in the ethics review included ensuring confidentiality of all participants by removing identifiers, name and specific professional title. Further, the ethics review included ensuring that all participants were offered informed consent prior to participating in this study and sharing the insights with participants and the organisation once completed.
Chapter 4 – GOC companion card & GOC discussions: Findings and interpretation

4.1 INTRODUCTION

In this chapter I offer details of what was discovered when the researcher and the participants came together to co-create their understandings of the phenomena being studied. My job as clinician-student researcher was to make sense of the complex interplay between shared realities and subjective experiences that informed the participants. Lincoln and Guba (1985) and Thorne et al. (2004) concur that “no pre-existing knowledge could possibly encompass the multiple realities that are likely to be encountered; rather, theory must emerge or be grounded in the data” (Thorne et al. 2004, p.5). Taking this into consideration I realised that as a clinician-student researcher I could offer some interpretations on what I had discovered.

As participants discussed their responses to the companion card and their experiences with goals of care discussions, I constructed a tapestry of influences on goals of care discussions at Community Hospital. Ethical and moral issues surfaced through data analysis, highlighting the challenges, struggles and obstacles that HCPs experience when involved in GOC discussions; a consensus also supported in those works by Larson and Tobin (2000), Rodney (2013), and Weeks et al. (2012). Participants explained that struggles surrounding GOC discussions are not unique to the experience of HCPs, as they interpret that patients and families also struggle. Their interpretations of patients’ and families’ struggles are echoed in the literature (Garland, Bruce & Stajduhar, 2013; Weiner & Roth, 2006). The participants acknowledged that
patients and families living with life limiting illnesses are ill equipped for our health care system and have little preparation for the expectations of HCPs, not knowing to come forth with information about what they understand of their illness and what is important to them. Such concern is also echoed in literature (Storch, Starzomski & Rodney, 2013).

In this chapter themes and sub themes are analyzed and described from focus group sessions using Interpretive Description methodology and a relational ethical perspective as described in Chapter 3. First, I draw on the experiences the participants shared with me based on their experiences with goals of care conversations at the end of life for patients and families living with life limiting illnesses and their responses to the GOC companion card. I introduce a series of three themes that relate to the experiences of HCPs with discussions around goals of care. These themes are the big struggle, responsibility, and building relationships. Participants also described their responses to the GOC companion card, which will be presented in the section following the themes mentioned above. I have analysed their descriptions of their experiences related to this card into three categories within the theme utility: physical, emotional and professional.

As I move through the various themes, I will differentiate between those participants who have used the GOC companion card in their practice and those who have not, as those with actual versus theoretical experience. Additionally, I will also identify the professional discipline to which a participant identifies when it is appropriate to identify disciplinary similarities and differences. In terms of this study, this means that the contextual and constructed (Thorne et al. 2004) realities of each participant will inform and ultimately re-shape my a priori knowledge of the field and create a different
understanding of using a GOC companion card in discussions with patients and families. In this way it is my intention to remain true to ID analysis in the hope to “... lead the eventual reader toward a kind of knowing that was not possible prior to (this) study” (Thorne, 2008, p.163). Such knowing can also inform the wider health care community.

4.2 DISCUSSING GOALS OF CARE: THE CLINICIANS’ EXPERIENCES

In this study I gathered together accounts of discussing goals of care practice, and I analysed and synthesised the accounts to look for broad themes from three focus group sessions. From the broad themes developed from the initial three sessions I planned for a fourth session to confirm and or revise my initial findings. As previously stated, the majority of participants were not familiar with the use of the GOC companion card and as such unable to offer a broad picture of the actual utility of the card. However, each participant was given a GOC companion card to hold and review during all focus groups sessions. What the participants did speak of was their subjective experience of working in the clinical setting where the term ‘goals of care’ is used. What emerged was a group of individual practitioners talking about their own practice and their own experiences. All the thoughtful comments that were offered had some shared similarity and yet also had unique elements.

Participants’ descriptions of their individual experiences are organised based on Thorne’s (2008) suggestions to proceed in a sequential manner using inductive reasoning. My understanding of the three sequential experiences they shared with me is as: ‘the big struggle’, ‘responsibility’, and ‘building relationships’. Subthemes within each category emerged through the process, which helped to develop each category and are
discussed under each heading. A table of themes and subthemes is provided (see Table 3) below to reflect the development of the themes.

Table 3-Table of themes and subthemes: clinicians' experiences discussing goals of care

<table>
<thead>
<tr>
<th>The Big Struggle</th>
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<tr>
<td>Pushing</td>
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<tr>
<td>Huge Societal Issue</td>
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<tr>
<td>Being Morbid</td>
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<tr>
<td>End of Life: Specific vs Generic Term</td>
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<tr>
<td>Reaching a Turning Point</td>
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<td>Stepping Away</td>
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<th>Responsibility</th>
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<td>It's the Right Thing To Do</td>
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<tr>
<td>But It's Not a Task</td>
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<tr>
<td>Not Knowing Where to Start</td>
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<tr>
<th>Building Relationships</th>
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<td>Patient Centred Care</td>
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<td>Multiple Conversations</td>
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<td>Hearing the Lived Experience</td>
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<td>• Acting as Experts</td>
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<td>• Making Assumptions</td>
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<td>• Forgetting to Touch Base with Patient and Family</td>
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4.2.1 The Big Struggle

My analysis of the data collected indicated that providing person centred care is challenging at this health care setting. As participants talked of their experiences with patients and families as individuals or as a member of a multi-disciplinary group they used words and phrases that resonated as the big struggle.
A subtheme within the big struggle was called “pushing”, a term used by participants themselves. From the participants’ perspectives patients, families, HCPs and even the organisation were “pushing” for something. The efforts in “pushing” were “varied” according to P17 dependant on the age of the patient and or dependant on whether the illness situation is one that is chronic in nature. Indeed, according to P10, the organisation has “pushed the envelope” because of developments and availability of advances in technology to the point that the person’s lived experience is not attended to. The following excerpt will help explain this point:

In fact, umm although there are great devices, we’re part of an organization that really pushes the envelope with development and technology we have something called an L-VAD that is like dialysis for the heart that keeps people going on and bridges them to transplant. But, the thing is that what we don’t understand sometimes …when you offer someone prolonged life versus maybe a quality of life … a person’s lived experience is a key factor as well. (P10).

The above comment was interpreted as a description of a HCP who struggled with the competing priorities between quality of life and quantity of life and how the organisation might attract a patient and or family to desire life prolongation because of the availability of new technical developments rather than recommending less aggressive treatments. This participant, a social worker, struggled with the potential for coercion of vulnerable patients and families into accepting interventions and treatments that might not offer overall quality of life. The concept of HCPs assisting patients and families to make realistic decisions that help patients achieve a good death (in place of a potential bad death from choosing interventions and treatments that are overly aggressive) is addressed in Krau’s (2002) commentary on Norton and Bowers’ 2001 study with nurses and physicians. These works highlight the need for nurses and physicians to support patients and families to understand the differences between
interventions to improve quality of life in a society that has expectations for technology that potentially sustains life.

As the discussions continued that were organised around “pushing”, it emerged that the big struggle is one experience that runs the gamut from individual to societal. At the individual level some participants perceived that patients and or their families were asking for interventions and treatments that are not considered “medically appropriate” (P9). Medically appropriate interventions, according to the literature I have reviewed, and in my opinion, are those that are offered by HCPs to patients and families, guided by evidence informed, best practice guidelines and based on patients’ and families’ goals of care. This participant’s comment highlighted for me the challenges that are experienced in clinical settings when goals of care are not addressed during an acute care hospital admission. Furthermore, the big struggle is one that applies to the infrastructure of the setting; the practices, systems and processes through which such a vision is achieved at this health care setting. My interpretation of this comment that the registered nurse made was that she was struggling to bring about valuable change to a compromised system. The participants demonstrated that patients and families are seeking medically inappropriate interventions when they are not offered opportunities to discuss and consider whether they are amenable to the variety of interventions, treatments and care that are available.

P7 named this phenomenon a “huge societal issue” and this became another subheading of the big struggle:

When you think about some cultures like some Buddhists right, they’re preparing for death from birth. So I mean a lot of it is our medical culture
(other participants agreeing) our family culture … it’s so much more complicated than our little goals of care in a medical setting. I mean it’s a huge societal issue. (P7).

The “it” that P7 refers to above is the big struggle from my interpretation of the data. Society has determined that death and dying are taboo subjects and, as such, the practice within health care has been to ignore illness as life threatening and instead focus on life prolongation as was highlighted in Chapter 1 (Larson & Tobin, 2000; Storch, Starzomski & Rodney, 2013; Weeks, 2012; Weeks et al., 2012; Zapka, Hennessy, Carter & Amella, 2006). And so it came about that another subtheme “being morbid” emerged as the Big Struggle theme developed from what some participants shared.

One participant, a social worker at the setting, self-referenced her own attempts to discuss goals of care with her parents in a non-acute setting. Because of her experience with her parents, who expressed disapproval that such a suggestion was made, I considered the social worker had been deterred. Exploring as to whether this participant reintroduced this conversation with her parents once more is unknown to me and not a focus of this study, however it adds to the perception that the public is not prepared and or ready to engage in such conversations. Interestingly, one participant, a registered nurse, shared that discussing goals of care might place undue burden on the patient, as evidenced by this statement:

When is it appropriate? Like when am I actually going to be asking these questions to the patients you know at what point… do these need to come up? You know people come into the hospital at all different levels of care and you know half the time we don’t know what’s going on until they get the results back a week later … at what point are you bringing this up without worrying a patient, without putting them in a situation where they think things are worse than they are or causing doubt in their minds? Things like that, you know. When is it most appropriate to start talking to them …? (P18).
During my analysis process this resonated for me as to how some participants struggled to understand the meaning of goals of care. For me, the nurse who made this statement viewed a goals of care discussion as delivering bad news and not as it had been intended when the GOC companion card was in development.

The big struggle continued as another participant equated discussing goals of care with a patient as sending a message that death was close. I noted the participant was one who was previously unfamiliar with the GOC companion card and spoke from a theoretical, not practical perspective. The participant indicated that she understood the GOC companion card would be handed to the patient and or family member and this action would be cause for alarm. In doing so, I thought the participant would miss the opportunity to attend to the quality of the nurse patient relationship if this intention was followed through in practice. In my perspective, discussing goals of care provides a HCP with the opportunity to engage in relational ethics. Indeed, the GOC companion card was intended as a resource to guide and not to replace the conversation between HCP and patient and or family..

One participant identified her experience with physicians who might not avoid the actual conversation but does not demonstrate comfort in having such discussions with patients and families. In this participant’s opinion a physician can mislead a patient and family by vacillating, and ultimately avoiding the issues. Because of this experience the participant saw the GOC companion card as a vehicle to practice a change in behaviour:

I think it’s really helpful. I think it would be really helpful that you know if…you know for people who might be new or not comfortable to have some
sort of guidance in their mind about how they might direct a conversation … I mean like I know a couple of physicians whose never felt comfortable about you know this … the person is actively dying and then what I would hear is that when their pain was better controlled; the symptoms were managed; he would say they’re getting better (laughing) and so, and in his mind it is better but they’re not getting better, they’re still actively dying but then it was his struggle with finding the words …. (P17).

Such struggles with being judged as, or considering oneself morbid is driven by western society’s fixation on the need for life prolongation and this is supported in literature by references in Chapter 1. What participants did not discuss was whether individually or collectively they are distressed with the results in patient care when fear of being morbid outweighs a need to discuss goals of care with patients and families. This was interesting to me because I know from my own clinical practice how distressing the results of not discussing goals of care can be for nurses in particular.

Participants demonstrated a big struggle with nomenclature surrounding the definition of the term “goals of care”. Few participants understood “what are the goals of care?” as a means to assess any patient and family’s appreciation for “what are we doing here”? I attributed this to the fact that those who demonstrated understanding of the term goals of care, had either previously used the GOC companion card when meeting with patient and families and/or were part of the EOL council that developed the card. Previous clinical experience was highlighted as those participants discussed the importance of getting the patients’ perspective of the illness situation and broaching discussions such as whom should be involved in decisions; how little or how much information patients were looking for and what was important for HCPs to know about the patient and his/her beliefs and values. Such differences in comprehension of the language represented another aspect of the big struggle as I interpreted their divergent
terminology for goals of care as an *end of life specific versus a generic* term and for many participants, goals of care are discussed when *reaching a turning point*.

Hearing from one participant, a registered nurse, that discussing goals of care was a non-threatening experience for both patient and HCP, that can take place on day one of admission to hospital, demonstrated degrees of comfort among participants in being able to discuss goals of care, as demonstrated here with the following quote:

“That first day when they sit down with you *(other participants agreeing)* and you ask them…what they would like?” (P13).

Indeed, in a recent article Cox-North, Doorenbos, Shannon, Scott and Curtis (2013) indicate that nurses must be responsible for ensuring that goals of care discussions take place with patients as part of routine care delivery. Furthermore, the authors hold nurses responsible for facilitating discussions between patients and their primary care providers, yet it seems from the information that some participants offered that such routine care delivery poses many challenges. Some participants at the focus group sessions expressed that they did not see themselves as agents who could influence discussing goals of care. Indeed discussing goals of care would motivate a participant to “run the other direction” (P20). For participants who saw goals of care as a term reserved for use when a patient’s condition was deteriorating, those experienced in discussing goals of care were eager to explain their personal perspectives. One participant, a seasoned registered nurse with many years of relational experience responded to a less experienced participant as a means to help others understand the meaning of goals of care and in the words of Bergum (2013) to “…improve the human condition” (p. 128). This participant stated:
“… we use the phrase goals of care meetings to imply more of a formal process” (P11).

But wouldn’t you say that to a healthy 20-year-old? What are you hoping for? I mean that’s just a human interest question. I just…do wonder if people are using this as clinicians do people think that they always have to have the answer? Like to, you know somebody says I’m hoping for a complete recovery. Well…you know I’m hoping for whatever somebody’s hoping for. I may in the back of my mind not think it’s probably…possible, but it doesn’t mean at that moment I’m gonna say: look you know what you may be hoping for that, it’s not gonna happen. It’s just curiosity about what are you hoping for. (P7).

The diversity of perspectives is indicative of whether HCPs engage in goals of care in chronic illness situations upstream--early on and throughout the trajectory of care--or whether they separate patients and families into groups based on what is happening in the moment for the patient. One participant provided the following demarcations that illustrate my point above:

…there seems to be a distinct difference between the groups of people. Like they’re all, they’re all old but like you know one group is either palliative now or in a long-term care home and kind of going in that direction and then there’s the other groups of people are usually…relatively functional and haven’t quite hit that stage yet. Like there seems to be a bit of a distinction, which is maybe why those terms become so separated. (P18).

Yet it might be that familiarity with discussing goals of care within the organisation might begin to turn the HCPs’ attention further upstream. One participant, a physiotherapist who claims that she has discussed goals of care over the past three years at the setting commented on how her perception changed as she became more aware of the need to look at the patient and family situation as a whole versus as a separate illness event:

I think probably for me…umm…it certainly changed like … you are talking about chronic illness you know, to me palliative … we always think it’s like cancer, death, whatever right? And, and most of the patients we are seeing on [geriatric rehabilitation ward] they have a lot of chronic illnesses that the
trajectory is [declining]. It would have never occurred to me to have
discussions with these people right...about end of life. Because you know,
they come in for their acute exacerbation and then they're gone, but...you
know it’s not a bad idea the next time they come in or even now to have the
discussion. ‘Cause it’s going to just progressively get [worse] and while
they’re still cognitively intact enough to make the decisions, like it would
have never occurred to me to discuss that kind of thing with people... you
know now it's just almost everybody on our unit we should be having goals
of care conversations cause they’re all coming in on the downward trajectory
right now” (P4).

The participants who had not used a GOC companion card in the past were
struggling while anticipating the big struggle. As suggested by Weekes (2012), this
perceived inability to discuss how illness manifests over time influenced some
participants’ avoidance of giving and receiving important information about illness
trajectories. This avoidance of the big struggle prompted some participants to stepping
away as explained below; a perspective also found in Thorne et al (2010). This
participant said:

“Let me start with I have no experience with it 'cause I’m a pharmacist, so I
try to avoid it (laughter). So basically it's like ... okay I'm going to step away
now and find out what the ultimate agreement is …” (P20).

Again, in this situation I noted that no participant took the opportunity to talk
about distress that is experienced when a HCP does not engage with a patient in
discussing goals of care that can often result in a patient receiving extensive
lifesaving actions that might be considered death prolonging. I considered this
might be due to the level of familiarity within the group membership and a
preference to not say something that could be viewed as inflammatory by another

Paradoxically, as HCPs step away patients and families react with “do
something” when illness situations worsen. Indeed, according to the participant who
claimed she was unsuccessful with engaging her parents in goals of care discussion,
there is a burden with making decisions on behalf of others; knowing that HCPs do not relish a situation where those with medical and health care system knowledge are perceived by patients and families as being most appropriate to intervene. Moreover, patients and families who are unaware of the seriousness of their health situation because they have not heard clearly about what to expect as an illness progresses are often those who turn pleading to HCPs to *do something* if they are unaware that cure is impossible. This distress experienced by participants informs this interpretation of what contributes to the *big struggle*:

“Then I think there are some confusing messages that we give, right … I struggle the most with that piece, you know, what we do versus what we say doesn’t always you know make sense to patients and families” (P16).

This subtheme of *‘doing something’* was acknowledged by other participants who were sensitive to the *big struggle* that some HCPs experience:

I’m new here, and I think it’s relatively uncomfortable. It’s a topic that you’re trying to come from a medical standpoint and explain to them medically what’s going on but at the same time you want to be compassionate about what’s happening with them and I think it’s a bit of a…struggle to find a balance often especially when you know the family is also trying to understand, whether the end of life is near or trying to make decisions around that. It’s a bit of a complex environment in those meetings trying to figure out what they’ve come to terms with what they haven’t, what they need to know, what they don’t and cause I think there’s a bit of a barrier to that just medical staff versus the family (P18).

Yet this separation of medical issues from the whole person view of a patient caused me to question whether the participant saw the development of a quality relationship as an ethical practice issue. In Bergum (2013), the author states “the moral community includes each of us as responsible for our actions in relation to the people we care for, educate, supervise, or work with in partnership. In each interaction a relational ethic can flourish” (pp. 128-129). In no way do I propose that
some participants’ intentions were to dismiss the need for quality patient centred relationships experience. What I understood from the example offered above was how it is sometimes accepted that attention to the quality of relationships is seen as a bonus in health care settings. In situations where a patient and family are living with life limiting illness it is still common place for patients and families to not understand the progression of the illness situation and how it will impact the overall lived experience. This lack of understanding is illustrated by the following quote:

So many times the family are not prepared. Umm you know, the patient comes in with certain complications of the chronic illnesses. So the focus is either how to treat the complication or how to prevent the complication, they might hear about stages, but they might not really be prepared that the stages are coming forth or they are not willing to accept stages that are coming forth. Like … dementia they may think that it only affect the brain and they do not have a clue about how it affects the brain … the physical abilities… (P6).

Adding to the Big Struggle were the ‘conflicts’ that participants discussed. This subtheme of conflicts was introduced and developed from contributions of those participants who had no previous experience with using a GOC companion card to establish a patient’s and or family’s goals of care. For those participants unfamiliar with using a framework such as the GOC companion card to assess patient and or family understanding of the illness situation the participants were conflicted with interpreting what a patient was hoping for, as indicated by the following:

What is challenging is trying to understand what the family…wants and what the person want but I often see conflicts in the teams, how a team member interpreted what it would be that person [might] want and what would be good for that person. Sometimes there [are] conflicts among team members … among nurses or different disciplines that we might see things from our own perspective and it makes it really hard if we have different opinions and different…ways to look at things and then it impacts how we intervene or how we care for that person right, so…umm often things like that will create conflicts in the team. (P16).
From the perspective offered above, I interpret that individual HCPs, and not the patient and family, are actually at the centre of decision making. Yet engaging the patient and family in establishing goals of care based on values, beliefs and personality of the patient is central to respectful professional ethics and how we, as HCPs, relate to patient-family relationships. This ethical perspective is a component of the theory that informed this study. Therefore comments from participants showing how difficult it is to enact a relational ethical perspective were troubling for me as a clinician and a researcher. I will explain how I tried to come to terms with this discomfort in Chapter 5.

In addition to the conflicts expressed above, some participants expressed that they were conflicted in situations where a patient could not speak for him/herself, often due to cognitive impairment. In cases such as these the participants appeared to have opened floodgates for potential complex discussions. Not knowing if a family member is representing the wishes of a cognitively impaired patient or speaking for what the individual themselves might want adds yet more challenges to the big struggle. The following excerpt from one participant is offered here to illustrate this point:

I find that it’s extremely challenging when patients who may have dementia or not able to speak for themselves it just totally complicates things … and family dynamics and family members might not have agreement about, so you’re trying to understand what would be the best for that person …. (P6).

In light of the participants focusing on their subjective experience with the *Big Struggle* it was logical to move into the descriptions of the *Responsibility* that shaped their individual and collective experiences with discussing goals of care.
4.2.2 Responsibility

Alongside the big struggle the theme of responsibility emerged from the discussions among participants within and between focus group sessions. Taking time for reflection and “evolving interpretations” (Thorne, 2008 p. 109) assisted me in making sense of the data. As a result of this reflexivity my data analysis uncovered participants' stories of their feelings of responsibility to do what is in the best interests of the patient. A sub theme that contributed to this grouping is obligation and specifically, the "job of the living" (P8).

Participants in this study appreciated the need for goals of care conversations to take place with patients and families because it is the “right thing to do” (P2). In general, the participants collectively expressed that HCPs have an obligation to meet the needs of patients and families in health care settings and to provide care based on what is in the best interest of the patient, yet this ethical obligation, as P7 advocated, should not be considered “a task”. Similar ethical considerations and the related concept of informed consent were discussed in Chapter 1 (Storch, Starzomski and Rodney, 2013; CHAMP, 2009; Weeks et al., 2012) and are consistent with P7’s stance.

One physician participant, who was familiar with the companion card and who explains that she has incorporated it in clinical practice to help guide conversations, discussed her responsibility and obligation to medical trainees to introduce the concept of goals of care :

I was thinking that it would be really good tool to use for medical education … I'm just thinking of the (medical) residents I work with at [Large Hospital].
It’s a little bit more challenging in the CTU\textsuperscript{28} environment to introduce something such as goals of care. Here at [Community Hospital] we have more one-on-one training … and there’s also a lot of great mentors in the team that they work with so I feel like it’s a little bit easier for them (medical residents) to grasp the goals of care philosophy or approach when they’re working within the culture but … in a place like CTU I wonder how many medical residents I work with would actually feel comfortable even addressing one little box (on GOC Companion Card) … I just feel like it’s an essential skill to be able to know what a goals of care conversation is and it might not be one of the core essential internal medicine skills that … they need to do in order to graduate but I think it’s a really practical one.(P 11).

While the physician considered that she has a responsibility to support learners to understand and become proficient with discussing goals of care with patients and families, another participant saw the larger scale responsibility of all HCPs.

Responsibility is “the job of the living” (P8) across the spectrum of HCPs individual to organisational, as described by the participants. The responsibility comes from the perception that HCPs are obliged to support patients and families in making informed decisions regarding health care, a perspective also found in Legare (2010) and Larson and Tobin (2000), and that was also introduced in Chapter 1. One participant further clarified the responsibility to enable patients to make informed decisions, adding the responsibility included:

“…getting to know the patients and families, their preferences … also I think providers have responsibility like helping the family understand … the options …the impacts and … to help family make informed decisions” (P16)

Similarly, another participant added finding “…the true person…” (P6).

In the realm of responsibility, nurses were identified by some participants as being more responsible than other HCPs on the team to engage a patient in goals of care discussions. This perceived responsibility is in contrast with others’ perception that

\textsuperscript{28} CTU is an acronym for clinical teaching unit; any medical ward at an acute care university training hospital.
discussing goals of care is the responsibility of the physician on the team. I interpreted the conflicting opinions as an indication that discussing goals of care is confused at times with delivering diagnosis, or ‘bad news’. One participant, a registered nurse, offered that nurses are the “…people who spend … the most time with the [patient, and] the person who becomes the patient’s strongest advocate” (P9). Furthermore, this participant considered that if nurses embraced this responsibility the result likely would be that they would feel “…empowered or [feel] like they were a little bit more comfortable bringing up you know…the topic it might help them be a stronger advocate for the patient” (P9). Regardless of whether the participants apparently saw goals of care being a responsibility of physician or nurse to discuss with patient and family, I did not find the participants had experienced the responsibility as a shared one. The organisation supports interdisciplinary team care to meet the specific needs of patients and family in their care; however, the responsibility of discussing goals of care seems to fall outside a team care approach from the experiences that participants shared. The interprofessional approach to discussing goals of care was discussed as a theoretical, not actual, experience. In the following excerpt a participant unfamiliar with the GOC companion card considers that HCPs’ responsibility is not to tell each patient what to do specifically but to offer the benefit of medical knowledge and experience in order for the patient to make informed decisions:

… part of our responsibility, not to tell them what to do, but we’re here as medical professionals and they have the right to ask us you know: what do you think we should do? What’s your professional opinion? And I think telling them what to do is not the answer but I think it’s fair for them to have a team that can give them a strong opinion or at least background to understand what a good direction might be because that’s part of our job is to be that support for them in that way (P18).
Not only did participants feel responsible to advocate for patients and families, but there is a degree of responsibility imposed on employees of the organisation, as each HCP is expected to engage in conversations around patient preferences for medical treatments:

“… The idea ... within [organisation, is] that anybody can be having these conversations” (P4).

Yet despite an apparent collective consensus on what was the right thing to do, from participants’ account of their experiences without use of a GOC companion card, other explicit and latent patterns emerged. Because the companion card is used by so few at Community Hospital, participants suggested that these conversations could improve with more use of the companion card. The subtheme that emerged from participant data related to the need for the companion card is identified as ‘not knowing where to start’.

Participants’ reasons for ‘not doing it well’ are far reaching. Issues regarding their feelings of being unprepared surfaced as another influential factor with regards to not doing it well. As I introduced in Chapter 1, this was a finding of research and other literature at the turn of the millennium and yet over a decade later it would seem that HCPs remain unprepared.

The sharing of stories illuminated participants’ fears of “saying the wrong thing” (P1). For participants who have never used the companion card, GOC discussions are anxiety provoking. One participant stated that she has been improving her goals of care conversation technique over her career. She has experience with the framework used on the companion card and had input into this card’s development.
I have to say when I first started doing them, actually it was in the community, my sensation was incredible anxiety and I was quite fearful, very nervous and I was just really lucky the first few times I got people who already had plans in place I mean they had their no CPR so they were very kind to me. But it did take me quite some time to get, to get the tempo umm and get over my own anxiety to discuss somebody else’s anxiety. (P7).

Based on the fact that all participants are not new to their particular areas of health care there were varying stages of readiness and also ability to relate to patients and families around goals of care. Some claimed that they were paralysed by not knowing where to start. Regardless of whether participants had previous experience with the GOC companion card it was suggested that the tool could potentially help inexperienced practitioners transition from novice to expert. This finding will be discussed in more detail in the next section on the utility of the GOC. The physician participant’s consideration of introducing the companion card to medical residents has been offered in the preceding theme the big struggle, however as I develop this not knowing where to start subtheme, I will weave in some excerpts that bring the voices of participants to the reader.

Despite the differences in disciplinary groups and differences in times and places where participants gained their basic professional education there was a general consensus that professional schools lacked in preparing individual participants for discussing goals of care with patients and families. One participant, a registered nurse who graduated less than five years ago offered that she “… didn’t feel like nursing school very well prepared (her) for those conversations”. Her sentiment was supported by others at the same focus group. Furthermore, this nurse also considered that communication in general was not given the attention it required. The perspective
shared by this participant and supported by others in the focus group is also found in literature offered in Chapter 2.

Other participants referred to the experiences of novices, and how those novices with less experience in clinical settings required more tools and resources to support and enhance practice. In particular, participants could identify a comfortable starting point on the GOC companion card for themselves, to help get discussions underway.

“In terms in being a relatively new clinician I think it’s really nice because sort of sometimes you don’t know where to start in these sorts of conversations. So there’s some really concrete kind of questions and things that you could say to the family, even if you’re someone who doesn’t have a lot of background or training in talking about goals of care” (P12).

I was struck by one comment offered by a registered nurse participant. In her opinion those involved in direct patient care are often not aware of what goals of care are established and what information a patient and or family member has received. This is “anxiety provoking” for that individual care provider because patients:

…are seeking guidance. Like they don’t know where to go, they don’t know what to make of it and they’re coming to you for guidance but…sometimes as a bedside clinician you don’t necessarily have a full context of what’s going on or a structure with which to sort of provide guidance either (P19).

While there is a message about the lack of safety in practicing without all the information required, what is also interesting to me was the participant’s perspective that an immediate answer has to be given. Given my experience at this clinical setting I am aware that this nurse is novice; that is, she graduated from nursing school less than five years ago. Her comment therefore demonstrated to me the pressure among some novice nurses to have all the answers and it caused me to wonder whether getting answers outweighed building relationships.
4.2.3 Building relationships

Generally, within the different focus groups session, participants from all professions appreciated that discussions between patient and HCP are dependent on relationship building. Many participants considered that discussing goals of care is a component of building helpful relationship. How participants view **building relationships** as it relates to goals of care discussions using the GOC companion card as a framework is offered below.

As previously introduced, P7 commented that a goals of care conversation is not “a task” and the following statements from P7 articulate how this framework brings meaning for her in relationship development:

I think for me, I think I use it as…I sort of think that we’re all here in relationship. And for me in my discussions with families it’s kind of about building a relationship. I don’t know that I always say “goals of care” sometimes I do to patients and families it’s more about what are we all doing here anyway? And what are you hoping for? What is our relationship? What are we all doing here?

My interpretation of what we are all doing here is named as a focus on **patient centred care** and this was fundamental to **building a relationship**.

Some participants who had not used the GOC companion card in the past perceived that incorporating this card in practice would lend to focusing on **patient**

29 **centred care**. They explained that being **patient centred** facilitates conversations between patient, family and HCPs in order for HCPs to “…understand what [patients] would like … [because it] is really important for informed decisions [to be made]” (P15). For those who could only theorise on how using the GOC companion

29 Patient centred care is also understood as person centred care.
card in clinical settings because they had not had an opportunity to use the resource in the past, it was seen as a reference tool to “…remind yourself… how [to] practice with patients… [which] is great in terms of providing great patient care”, as one social worker participant suggested. In using the GOC companion card as a framework for interactions with patients, this social worker saw the emphasis became less about “fixing” the particular illness issue and encouraged “patient involvement in the process” (P 10). This theme of engaging with a patient at the place where patient centred goals can be addressed was supported by the participants over and again. For some participants discussing goals of care from a patient centred perspective was seen as an opportunity for concrete discussions because the people involved were more likely to understand “their diagnosis… and what that entails so that they could understand at what point they [can] ask for whatever interventions [are] available” (P17).

For other participants who were involved in the development of the GOC companion card, discussing goals of care involved having discussions earlier in illness trajectory so that patients had the opportunity to make decisions for themselves versus depending on others to decide for them. This statement from P5 supports this interpretation:

When I start talking to them, a lot of [patients with] chronic illness coming in, may be three times, four times [we start] talking about placement versus going home. Then leading towards… thinking about goals of care …even from that day forward. It’s more like, you know what? You could make decisions what you want to do now while you still have the brains to do it. Later on you might not so…why don’t [you] start thinking about it and it’s just more like on a more…upbeat note versus oh it’s going to be the end of the world and you won’t have a choice and so on and so forth. And so [being patient centred] it’s like willing to open my mouth … hey; you need to think
about this. So make your decisions about what you want now versus down the road when you have no choice”.

Yet being person centred is also challenging at Community Hospital. For example, one nurse participant voiced his concerns at how not discussing goals of care with a patient and family can result in misuse of time and other resources in health care settings:

I’m just thinking … you get a patient and you have to run a whole gamut of tests and investigations and so forth and you spend x amount of days, hours doing all this stuff… All these tests and the patient says you know I didn’t really want to have all these tests and … in terms of workload, it terms of resources… you know five minutes just to start talking about it in the beginning it’s, it’s amazing how you could have changed it…. (P11: of course) not just for the benefit of the system itself but umm for the patient who went through all this stuff that didn’t necessarily want to or just wants say this is the diagnosis okay got it and now I don’t want to do anything. You know that would have made a change. (P13)

This nurse’s statement echoes not only the distress at the misuse of health care and human resources but there is clearly intense dismay with how the patient is affected by not discussing goals of care. This participant was not involved in the development of the GOC companion card but was motivated to use it in practice.

For those participants familiar with patient centred goals of care conversations the goal was expressed as being about having *multiple conversations*. Multiple conversations were beneficial in terms of improving HCPs’ confidence; moving from novice to expert over time as P7 recognised with her use of this resource in the past. Additionally, P7 was well practiced in discussing goals of care, and commented how the conversation ideally takes place at admission and throughout the hospitalisation.

“And if we have a few of them over time then it’s not so frightening when it’s sort of goals of care means… end of life care. I mean… from the beginning when you’re admitted what’s the goal of care and again what’s the goal of
care umm I mean this is, I think this is a great framework from the beginning” (P7).

Participants also recognise that patients and families can only absorb so much information at one time and therefore the need for multiple conversations arises in order to ensure that patients and families receive all the information they desire and need in order to make informed choices. The following excerpts from participants highlight these points:

Sometimes families or the patient who’s ever there receiving all of this information are overwhelmed when they hear it for the first time (other participants agreeing) and actually need to be able to come back again umm after they’ve processed, really asked questions. Not everybody can process at the same rate. And it may take more than one, two; it may take several meetings in different venues for to support and help them get to where they want to be. (P8).

Another participant expressed:

I mean sometimes we have to have multiple goals of care meetings. Sometimes we will have goals of care meeting in hospital and then if the patient’s from a nursing home back at the nursing home that team will have another goals of care meeting and if they come back into hospital we’ll have another meeting, sometimes, it’s a process. Not just one meeting. (P9).

In the latter statement the participant is referring to the need for multiple conversations across the health care continuum. Community Hospital receives many patients from long term care facilities who are all living with life limiting illness approaching end of life. It was suggested that those GOC discussions that have been less challenging in Community Hospital are those that are a continuation of prior conversations. That is, when patients and families have taken the time and been offered the opportunity to consider what is important to them have less difficulty accepting approaching end of life. Given the understanding among developers of GOC companion card that goals of care involve more than diagnosis
based on personality, values and life experiences, the need to continue discussing goals of care at all health care settings can ensure the person as a whole is the focus of care. Specifically, one participant offered:

… [in] my experience the goals of care of meetings that have gone the smoothest have actually been when there’s been already a lot of discussion (P9: absolutely) … (P13: mmm-hmm). And so, I think whenever, looking at this puzzle, whenever there’s a discussion [around] one of these pieces that’s a goals of care meeting (P11).

Through conversations participants acknowledged that HCPs have an opportunity to be patient centred by hearing the lived experience, which was succinctly stated by one participant involved in GOC companion card development who spoke of inviting patients and families to “… come [and] share your story with us” (P7). Another participant who helped develop the GOC companion spoke of the importance of knowing the needs of “…the true person”, and to expand our focus beyond the medical issues to discover what “…is important to them…what they want to accomplish [and] who they want around them” (P 8).

Moreover, discussing goals of care can help HCPs understand how to improve the medical care of a patient. One participant discussed how goals of care discussions will reveal beliefs and values that a patient and or family members hold that might interfere with best clinical practice, particularly with managing distressing symptoms at end of life. For this nurse, the framework offered in the GOC companion card could be helpful in the following common scenario:

…you have a guide line on some kind of questions that you can try to investigate why? Why they are thinking this way? Is there a specific goal related to the decision-making? Because sometimes people tend to base (decisions) on their own values or their own way of thinking. I have experienced a person who is suffering at end of life … has to have some
hydromorphone and then the family and the family definitely say that no. So it would be ... it’s not ethical, like the nurse feels that, the family has made a very unethical decision on that. But you can see that the family is very caring to the patient and you kind of question why they have made such a decision. So after umm an interview we’re able to explore that it is something related to a very bad experience that the family has encountered previously related to hydromorphone so that is how it affected their beliefs on it. So, I think this [GOC companion card] provides very good guidelines… (P6).

HCPs can lose focus on the patient and family lived experience when delivering information and performing tasks gets in the way of understanding what is important to the individual and their family. As HCPs attend to their daily duties they meet many patients and families, all of whom have varied experiences in the health care setting. One participant, a social worker, reflected on how important it is for her and her colleagues to pay attention to the fact that discussing goals of care might be common place for HCPs, yet this is not the case for each patient and family. To this end discussing goals of care should be attended to delicately each time.

However, as I introduced in the theme Responsibility, discussing goals of care is not always done well. I attribute this to an interpretation that a GOC companion card can be responsible for building relationships, making that relational process look overly simple. Alongside participants’ descriptions of their experiences over time at Community Hospital, they described situations where even those who are frequently engaged in conversations with patients and families abandon rather than attend to patient centred communication.

Some participants in the focus groups I conducted conveyed an ‘us versus them’ approach, explaining that there are times that patients and families “just don’t get it”. I struggled with expressions of this type and needed a significant amount of time and
reflection\(^{30}\) to understand the meaning. Guided by the authors Kleinman and Copp (1993), who identify the importance of emotions in research fieldwork, I acknowledged my distress with a participant discussing patient provider interactions, and paid attention to this emotion. Ignoring the emotion, the authors caution, will impede the analytic process.

What my emotional response prompted me to consider was that the GOC companion card is a tool to prompt discussions in any health care settings and cannot be seen as a replacement for communication skills use. Participants’ accounts of HCPs *acting as experts, forgetting to touch base with family and making assumptions* are incongruent with those practices that were covered by the umbrella theme of *building relationships*. In Chapter 1 I reviewed various reference materials identifying that these types of behaviours reduce the quality of patient care at the end of life (Larson & Tobin, 2000; Providence Health Care, 2004; Thorne et al., 2010; Weeks, 2012; Weeks et al., 2012).

HCPs can quickly alienate patients and families and distract themselves from acting on behalf of the patients’ best interest as soon as they take on the *expert* role. Acting as an expert implies a power differential between HCP and patient and family. As one social worker noted, HCPs enter into discussions with patients and families many times a day or week. And as they enter into those conversations it is often the perspective of the HCP that they are coming with all the information; thus acting in the role of expert. From the perspective of this social worker participant who was paying

\[^{30}\text{My thesis supervisor suggested that I review a research reference on acknowledging my emotions as I engaged in the iterative process of data analysis (personal communication Dr. Rodney, March 2013).}\]

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attention to the likely power differences I appreciated how some HCPs can be cognisant of relational ethics and avoid those negative ‘expert’ activities that participants chronicled. Included in this list of expert activities, which distracts from HCPs doing the right thing, were the occasions when HCPs use jargon\textsuperscript{31} that only some HCPs understand, and when HCPs “forget to touch base” (P 16) with patient and family, “make assumptions” (P 15) about their understanding of the situation, and subsequently fail to provide appropriate health literacy at the patient and family level of comprehension (P 3). The following excerpt helps explain this concept:

…we don’t always do it well and …care providers often tend to be coming from a lens like we are experts and we know what’s going on and we don’t do really well trying to understanding where the patient’s situations is… I’m thinking of nurses and physicians and we don’t often…invest enough time trying to understand things from the perspective of the patients and families (P16).

Language and choice of words used in discussions with patients and families can be harmful. Personally, I have heard HCPs telling patients and families that there is “nothing more that can be done” and “we will withdraw care” which gives patients and families an impression that the HCPs will abandon the patient. One participant who is familiar with the GOC companion card echoed this concern when she discussed how HCPs must “…mak[e] sure that your language is (agreement from another participant) clear that you’re going to be providing care it’s just that the goal of the care will be different. Sometimes families feel like if somebody is palliative then it’s like hands off, but that’s very much not the case” (P3).

\textsuperscript{31} Jargon is medical terminology that is not in plain language
Adding to the opinion that HCPs need to attend closely to how conversations take place with patients and families, others recognised that colleagues have a responsibility to improve their skills. I was given the impression that the HCPs the participants referred to were not involved in the focus groups setting as I did not notice any signs of discomfort among participants. One participant voiced her frustration about those who need to improve communication skills and suggested that using the GOC companion card would achieve this objective. What was not discussed was how other HCPs at a patient/family meeting situation might intervene to discuss patient and family understanding of the illness situation and broaching goals of care.

What is most challenging I find is when you have a group of people that could benefit from doing something like this goals of care practicing, like this goals of care companion, but still in the team not everybody...participates or not everybody uses this goals of care module you could say. And that sometimes is really frustrating cause you know how much it would benefit the patient and the family, you know they want to talk about it sometimes especially it’s been their fifth, their family’s fifth admission into hospital” (P10).

What P10 referred to as identified in the above statement is the missed opportunity to help patients and families improve health literacy.

Attending to health literacy was introduced in Chapter 1 (Bowen, 2000) as a requirement for all HCPs in order to remove barriers to health care access. Avoiding the use of jargon is one way that HCPs can improve health literacy. One participant made the following statement describing what she experiences when she has witnessed conversations that are full of jargon:

I know as a nurse when I talk to patients and families I very rarely use any medical terms at all. And when I am in family meetings hearing people using medical terms I can often see families completely glazing over. Umm so I think (using the GOC companion) would be great cause then you’ve even
got a little interpreter on your card, you know. Because we think of risks and benefits, but …I don’t know that (patients and families) use that vocabulary (P7).

Returning to what participants described as contributing to building relationships, sharing information (the companion card) with patients and families emerged as important in being transparent in the health care interactions. Sharing the GOC companion card with patients and families was not the intention of the developers and, as such, this was a recommendation from the research participants I was not expecting. However, there is empirical evidence to support that when patients are provided prompts for their health care providers there are positive outcomes for patients (Au, 2012). There was consensus between group participants that if patients and families had access to the GOC companion card better relationships would be forged to meet the need for patient centred care. In the opinion of some participants, displaying the GOC companion card in a prominent place at Community Hospital would help HCPs to point to what information would be sought in order to get to understand the needs of each patient and family.

Indeed, some participants discussed that if patients and families had a hard copy of the GOC companion card they could prepare for meetings and have time to consider what questions they might have. One participant shared that discussing goals of care is possibly not what patients and family expect from HCPs and so they would benefit from some prior preparation.

I think that if people knew…Oh you know what we’re booking a meeting for two o’clock on Tuesday these are some ideas of things that we’re probably going to be talking about. It gives people the chance to prepare like “whoa”…umm you know, this … conversation is more umm is probably deeper than sometimes I think families expect and that they need time to process (P7).
Sharing the GOC companion card with patients and families would foster confidence that indeed the HCPs have a plan in place for how they discuss issues with patients and families. One participant discussed sharing the GOC companion card as a means to demonstrating;

That the team is actually working all together in this different piece of puzzle and so instead of these nebulas”. Furthermore the patient and family would “realize that underlying it all there is umm kind of this approach and we want to keep them and their loved ones in the centre of it (P11).

I was struck by one participant’s explanation that patients and families might benefit from having viewed the GOC companion card to acknowledge the fact that HCPs were not exerting power by selecting to whom certain interventions and treatments might be offered. The participant suggested that:

Families think that we’re giving up or we’re not doing as much for their loved one and you know sometimes to be honest they think ‘oh is it because of age’…they may even take it personal[ly]” (P 10).

She added to this notion that using the GOC companion card would help eliminate the discomfort that patients and families might have with discussing death and dying; once more reinforcing that the GOC companion card could somehow complement how HCPs approach conversations about death and dying with others.

Potentially sharing (the GOC companion card) with patient and family would advance building relationships in the opinion of participants because patients and families could have time to consider “what I want to talk to my attending team32 about” (P7). HCPs, patients and families could all be on the same page when discussing goals of care. One participant saw patient and family understanding of

32 Attending team is the group of HCPs caring for the patient in Community Hospital.
the GOC companion card components as being key to offering a “cohesive…message”. In order to deliver this cohesive message the patient and family need to see the HCPs acting as a team “it’s not just one person saying it to them…they hear it from a whole team (other participants agreeing in background) I think you know it’s easier for them” (P9).

Discussing goals of care and using the visual image of the GOC companion card was also viewed as a means for building relationships within the team, which was also considered a step towards delivering exceptional patient centred care. One participant had this statement to offer:

“I think when everybody’s on board that it honestly is probably one of the best things for patients and families but also for staff as well because it’s so hard when not everybody is on the same page and …that can be very challenging” (P10).

I found that some participants viewed having goals of care conversations as a key component of a high functioning health care team. Those participants who spoke of situations when goals of care conversations did not take place were also those who spoke of distress in delivering patient centred care. In a health care setting where goals of care are discussed regularly and as part of routine care, that setting was seen as contributing to better outcomes for patients and families but also as generating better satisfaction among HCPs. They explained that knowing that your colleagues are well equipped to address specific patient and family needs ensures trust among HCPs.

*Being on the same page* also influences *providing credibility* to patients and families. I would extend this subtheme to encompass the issue of trust as indicated in
Chapter 1 and supported by literature (Heyland, Groll, Rocker, Dodek, et al., 2005; King & Quill, 2006; Larson & Tobin, 2000). One participant considered that patients and families can sense if a team is a unified team, and one indication of a unified team is the delivery of a consistent and clear message. In this participant's opinion a unified team demonstrates to patients and families that they are capable of delivering “good care” (P 13). However, one participant spoke of situations where she had been asked by patients and families “do the team actually talk to each other?” (P16) and this was understandably demoralising for that participant.

Demonstrating cohesion by delivering consistent messages and regularly discussing goals of care with patients and families has been taken up and incorporated into clinical practice by some research study participants. Some participants considered there was a culture of care at Community Hospital which was considered a component of building relationships. The culture of care was attributed to the work of the EOL Council in 2010, which drew its membership from various disciplines and practice areas throughout Community Hospital. The EOL Council promoted a palliative approach to care at Community Hospital and approach was demonstrated by the palliative care team at this site since 2006. The philosophy of care demonstrated the focus on “quality of life versus quantity of life” (P 9) which “fits very well in our current climate and how we care for our patients; it’s very much multi-disciplinary” (P11).

One last subtheme of practice makes perfect completed the theme of building relationships in this data analysis. During the four focus group sessions, participants described actions and intentions that required regular attention in order
to discuss goals of care with confidence. For one physician using the GOC companion card had “changed [her] practice” (P 11), both practically and how she viewed her position within the team. Using the GOC companion card over time has required her to share goals of care discussions with her multidisciplinary colleagues. She no longer feels the pressure to complete the entire conversation in one sitting. Additionally, she sees discussing goals of care as “process” and “it’s a team approach and… sometimes it’s just not the right time and that’s okay. I like to think a [I have a] … more …mature approach to it than I did when I first started” (P11).

Although P9 was unfamiliar with using a GOC companion card in practice she agreed in theory that indeed practice makes perfect:

I think practice in this type of sense makes you much better, much more comfortable cause it’s not an easy conversation to have with anybody. So I think it definitely you feel, with time and having to do them a couple of times you get a bit more comfortable and how you phrase things and the words you pick, umm how to talk to the family (P9).

Participants’ combined positive experiences with using the GOC companion card in goals of care discussions were tempered with the consensus on the difficulties and challenges inherent in those discussions. They also expressed that they understood how easy it was to get caught up in clinical demands, putting the conversations on hold until the urgency of a health crisis forced the situation. Participants stated that they considered the GOC an important practice tool, and many planned to incorporate it into individual practice. Moreover, many participants also discussed the potential utility of the GOC companion card in furthering patient centred care if the card could be shared with patients and family.
4.3 THE UTILITY OF THE GOC COMPANION CARD

In the methodology section I introduced that just three participants were familiar with the GOC companion card. For those who were not familiar with it, their first introduction was at the time that posters were circulated advertising the research study. During all focus group sessions each participant had a hard copy version of the GOC companion card to hold, look at and review as discussions were underway.

Participants reported an overall satisfaction with the GOC companion card and those clinicians who had never used it stated that they were willing and eager to incorporate it into future practice. At first I was willing to accept this as a “finding”, however my thesis committee urged me to ask myself the reason for this. As Thorne (2008) suggests “…that which we consider ‘findings’ is not simply reporting the first credible set of patterns that emerges from (the) sorting process. Rather, findings reflect an interpretive manoeuvre within which you consider what the pieces might mean, individually and in relations to one another … or schemes might illuminate about those relationships …” (p. 163). Moving back to the collected data I explored why they were willing to incorporate this resource into clinical practice. From this reflexive activity, three categories emerged for me. The discussions about the utility of GOC companion card fell into categories related to its physical and emotional attributes and influence on professional practice.

4.3.1 Physical attributes

The card was described as “easy to use”, “portable” and “clean”, “common sense” and “concrete” by many participants over the four focus group sessions. In
comparison to other education materials used at the site, participants explained that the 
card was welcomed as it was easy to use, readable and could be placed on a clipboard;
visually cuing a HCP in discussion with patient and family. Clinicians who had not used 
the companion card told me that they are bombarded with written material and practice 
guidelines and thus physically the companion card was considered useful. One 
participant commented on how some adult learners are visual and as such the clinicians 
could look at any part of the card and find a comfortable starting place.

I mean aesthetically, if I was to see this and I was going to use it for that day. For example: clean, simple, not overwhelming, very simple ... the way I work is, you, I always start to the top left when I start an algorithm. And algorithms have their own place and calling process. But here I'm sort of looking at it as and as I was listening to everyone, where would I start initially? I could have picked at any point in time here, there, but even if I started over in the left or to the bottom right, it's simple to and it's easy to see that whatever fits down in the left bottom is affected or it can be I mean it's everything is sort of related, everything comes together. So, even if I started at a different stage it's not critical, it's not too bad. And I could, go over here and it would be easy, and I wouldn't fall out of place during a conversation, it's easy to pick up ... there's not too much information, I mean and that's a good thing. I mean it's simple, basic stuff ... and the prompts at the back are pretty good (P13).

In addition to “prompting” HCPs during goals of care discussions, the card was 
described as a “framework” (P3; P9; P15; P20), “guideline” (P1; P2; P6; P10; P15; P17), 
and “tool” (P1; P8; P4) to assist clinicians who had and had not used it in the past 
regarding what questions to ask patient and family.

I think it’s a, it’s a good tool in terms of a... having the different pieces 
needed in terms of creating the framework for a discussion with the family or 
an individual about their care. These things seem quite common sense but I 
think that often times in acute care, it can be sort of... forgotten. A so it’s 
really good to have them sort of laid out ... so that we can be reminded to 
reflect on the different pieces of them. I certainly think it’s helpful for directing 
a meeting which I think is probably my most common experience in terms of 
goals of care, would be ... meetings with families (P3).
As P3 indicated above, using the companion can help “direct the meeting” and provide context in difficult discussions with patient and families. Some participants emphasised that using the companion card might help indicate stopping points with aggressive therapies and would be especially helpful for the families who want “to do everything” (P11). This echoes the suggestions that… brought forward in chapter one of this work. Indeed, P7 suggested the companion card is “like a mini advanced care plan”.

In this way the GOC companion is viewed as a sign post to direct discussions with patients and families as described in the themes of responsibility, building relationships and turning point. In fact, some clinicians suggested the GOC companion should be the framework used for any clinician entering into a resuscitation conversation with a patient. Indeed, they claimed that it might eliminate those “bad discussions” they heard during clinical practice as illustrated here:

...you kind of over hear these conversations that go: “Okay so if things go bad do you want us to do everything or not?” (Laughter from the group) And...you know not the most effective, so kind of re-focusing (and) coming at the DNR\textsuperscript{33} forms from a goals of care perspective. Like you said it’s simple, they can go through it, it gives them something concrete (P12).

The visual image of a puzzle on the companion card was also discussed. Some participants saw the puzzle as an indication that the complete picture might not be finished in one sitting:

Sometimes families or the patient who’s ever there receiving all of this information are overwhelmed when they hear it for the first time (other participants agreeing) and actually need to be able to come back again after

\textsuperscript{33} DNR also known as DNAR is the acronym for Do Not (Attempt) Resuscitation – cardio pulmonary resuscitation.
they’ve processed, really asked questions. Not everybody can process at the same rate. And it may take more than one, two, it may take several meetings in different venues for to support and help them get to where they want to be (P8).

Many participants identified goals of care conversations as a process and discussed how talking with patients and families about goals of care can take more than one discussion, which is supported in literature I identified in chapter one (CHAMP, 2009; Ferrell, 2012). P11, who has used the companion card many times in the past, offered that discussing goals of care is “not sequential”, which is consistent with what the puzzle pieces emphasises, while P9 and P6 offered that in comparison to other resource materials that offer hierarchical images of process, the companion card was considered superior.

I really like the goals of care companion card because first of all it’s not…sequential so you can see that different pieces of this card can happen at different times during the patient’s stay and kind of piece it together so, it’s not something that you start with and then you work through the steps but it kind of more…organic in that the nurse might have a conversation with a family member and realize that their goals of care for the patient are different from the patient’s goals of care and that can be brought up to a team (P11).

Those clinicians who had used the card in the past to discuss goals of care with patient and families found there was a decreasing reliance on the card over time. This was because the pieces to the puzzle were easy to remember once rehearsed a few times.

“So I use it but I don’t … always bring it up and …look at it but I think it’s because I had some extra training from the previous palliative care nurse team and I feel like that’s very much ingrained in how we do things” (P11).

Even those with no previous experience working with the companion card felt it was a quick study and therefore considered the companion card a much needed support for inexperienced or ill prepared clinicians.
This would be easy to integrate … initiate … to use and I don’t think one would require this afterwards to refer back to cause it’s very simple. I mean, you sort of identify and look at visually. One way for me, that I learn is to look at the picture and that’s pretty clear. You guys have made it part picture-puzzle. You’ve taken that, the aspect of it not just hearing it but reading it and now I can visually see it and I know it’s a puzzle and it’s easy to follow through (P13).

4.3.2 Emotional attributes

Regardless of personal experiences with using the companion card, during goals of care discussions participants agreed they would feel better supported to engage in discussions with patient and family. Furthermore they claimed that they felt that having those discussions facilitated better care and improved their emotional preparation for end of life with patients with chronic illnesses. This phenomena that discussing patient and family goals of care equates with quality end of life care is well documented in literature, as I introduced in chapter one (CHAMP, 2009; Collins, Parks, & Winter, 2006; Larson, & Tobin, 2000; Providence Health Care, 2004; Storch, Starzomski & Rodney, 2013).

The companion card was viewed by participants who had never used the card as a support for any clinician who felt that his/her skills in discussing goals of care were not strong. They offered that such a clinician would be encouraged to engage in goals of care discussions because s/he could find a concrete place to begin a conversation, as indicated with the following excerpts:

I think the different pieces on this goals of care (card) help the different disciplines in their discussions. (Be)cause we each all have our strengths and it reminds us that there is all, there’s many parts to this discussion with families (P2).

And:
I think it’s really nice because sometimes you don’t know where to start in these sort of conversations. So there’s some really concrete kind of questions and things that you could say to the family, even if you’re someone who doesn’t have a lot of background or training in talking about goals of care. So, like you said you could have it on your clipboard and you can look at it, so I think … it has been useful as a relatively new clinician as a place to start (P12).

Indeed, some clinicians acknowledged their fears, previous discomforts and avoidance of end of life conversations but stated that their feelings have improved since the support of a Palliative Outreach and Consult Team was introduced at the site. Since goals of care might best be considered a team approach in participants’ opinions, they felt that knowing that others on the interdisciplinary team might be better matched to one aspect or another on the card was reassuring. As I delved into the data I heard the participants describe the GOC companion card itself as a potential ‘member of the team’, supporting clinicians to provide their best end of life care.

Goals of care discussions in general provided some clinicians with very positive experiences, including those participants who were new to the companion card. Some participants remarked on the sense of personal fulfillment and “reward(s)” that come with being involved in discussions with patients and families. Despite the fact that those conversations “are difficult and never easy” (P3), clinicians discussed how they enact the roles of “help(er)” (P1) and be a source of support for patients and families:

For me I think it helps me feel that I’m supporting somebody who’s in a dilemma given that their loved one is at a place where they have to make some important decisions. It’s very confusing for them and I feel when I’m having this conversation with them that I’m helping them to make decisions. Not actually giving them, making the decisions for them, but kind of assisting them to make the decision. So it makes me feel…I’m, I’m being supportive to somebody (P1).
If the conversation happens naturally though which it might, it might do when like you say you’re putting patients to bed or what have you, it’s good to have like a kind of framework or a lens with which although you’re just sitting with the patient and actively listening and it is spontaneous it’s still nice to have in …your mind an idea of … the direction that the conversation go in and the questions you that might ask. So it’s nice to have some sort of like framework for that I think (P19).

The outcome for the patient was described as a “dignified death” which was also rewarding for the clinician, as told by P2 in the following quote:

So I think part of the, for me the rewarding part is umm we’re hopefully ending the suffering of this patient by all the different interventions that are potentially possible even though overall there will be no benefit. And that their end of life is dignified and the family …has that memory of that patient forever (P2).

Poignant accounts were shared in two separate focus groups of participants’ use of this card in their personal lives. For P12 the GOC companion prepared her family for discussions with HCP when her grandmother had an illness crisis.

(t)he day before my mom flew off to be with my grandmother who’s nearing the end of her life. So I actually gave her the card and I said talk to the team, these are some questions to ask grandma and talk to the team about when you’re making decisions about, you know, does she want to stay in the hospital, does she want to be at home and these are some things to think about (P12).

Similarly, P1’s experiences working with a palliative care team at the site who modelled the use of a GOC companion framework prepared her when her mother was dying. She was able to draw on her clinical experiences with this framework to talk with her dying mother ensuring that her wishes were well understood.
4.3.3 Influence on professional practice

Participants who used the card discussed how using the GOC framework improved their relationships with patients and families and, overall, improved their professional performance. The following quotation supports this statement:

“And it helps … us as a team to remind us … we need to be refocused to include that … because I think you’re respecting… respecting the needs of … the patient and the family or … whoever else they’ve chosen to involve to support them” (P8).

During the focus group discussions some participants who had not used the companion card before discussed how they planned to use the GOC in the future. For these participants who considered themselves as not being “good at this” or who were reticent to engage in discussions in the past, using the GOC companion card would improve their communication skills. These participants were satisfied that using the GOC companion card would encourage them to participate in end of life discussions, thereby ensuring that patients’ goals of care could be met.

Discussing GOC ensures that various members of a health care team would engage with patient and family either to help gather formation and bring that information to HCP daily team discussions, as recognised by the following:

As a (team member) in order to prepare for a goals of care meeting I talk to everyone here. Because there’s bits of pieces of the puzzle that I’m not able to address and I think a physician (is) often expected to lead the meeting or at least help facilitate the meeting, and so it’s really important for me to talk to…the members of the team and … I find they have very valuable things to say that maybe I have not had a chance to…talk to the patient myself or when I did talk to them they didn’t bring that piece up (P11).

Participants considered that if multiple HCPs were engaged in discussing goals of care for those with life limiting illnesses the process would be “normalised”. In this
way goals of care discussions would be valued by HCPs as usual care for patients and families throughout the health care system.

It is a great framework and ... I think that by doing that we help normalize it in our community in ... this particular site. So we all have an appreciation whether you go from one unit or a different floor to another they all understand ... the conversation (P17).

From the information participants shared with me I developed an understanding of knowledge of a collaborative approach to patient and family care without synthesis and completely incorporating it into daily practice at Community Hospital. Most participants acknowledged the physician as the person most responsible for discussing goals of care with patients and families, although nurses were seen as spending the majority of time with patients and families. Others had not engaged in any conversations about goals of care in the past; considering it outside of the professional scope of practice34. Furthermore, if goals of care were not discussed with patient and family it was because the physician had not initiated the conversation. Participants indicated to me that if all HCPs were engaged with patients and families and discussing goals of care there would be culture change at this site; a culture of care that is well supported in literature (Legare, 2010; Larson & Tobin, 2000). Based on my clinical experience, this culture change to a more collaborative approach to goals of care discussion is dependent on the individual HCP’s willingness to relate to other disciplines to provide optimal patient care.

34 “A profession’s scope of practice encompasses the activities its practitioners are educated and authorized to perform” (Canadian Nurses Association, 2011 web page).
In one participant’s opinion, the companion card represented a refreshing approach to patient care:

And what does this mean in terms of me working with the patient? It takes it away from the factory mode; get a patient in, strip them, give them clothes, put a band on them, stick them in the room, treat them, come back next day put on a smile pretend everything’s okay, come back. This (card) makes you…get personal with the patient …this makes it a little bit more real … being in a personal mode (P13).

I see this as impacting the organisation as a whole and not just the individual HCP. Clinicians who experience a sense of meaning within a role will be more satisfied in their “… practice and how (they) work together with families and patients … in terms of providing great patient care” (P10). This sense of fulfillment is recommended in nursing leadership literature for its impact on retention and recruitment of staff (Perry, 2009). However, reliance on the card alone begs the question of whether a clinician can truly engage relationally with a patient with over-reliance on a communication tool. Engaging with a patient involves using communication skills of empathy respect and clarity to establish relational dialogue (Thorne, et al. 2010), which comes from a desire to provide ethical care and thus cannot be engaged with simple reliance on the card alone.

With plans to use the GOC companion card and the ongoing support of the palliative care outreach team, participants described a potential to practice at full professional scope. Yet the appropriate use of the card and modelling patient centred care will require leadership within Community Hospital.

As I have indicated earlier in this thesis, holding end of life discussions are often avoided because of the time they require. However, one participant saw the card as
potentially helping to organize time to hold more in-depth conversations with patients and families to understand the “big picture”. In addition to supporting clinicians to practice to full scope in environments where time limits are many, the companion card was also seen as a tool to potentially assist with HCP collaboration in care delivery and more seamless care. The following excerpt demonstrates this perception:

I mean it’s the things that are not said, that are not discussed, when things are assumed where you start getting problems. Having a place where the team can come together…prepared or not prepared but to have a place where, like an open forum, to discuss things and to make sure we are all on the same path. Again not just for the patient but in terms of resources, in terms of the system it gets bogged down and we had this patient and we kept him for three weeks. If we had that conversation a while back ago we could’ve…moved things a little bit faster (P13).

4.4 CHAPTER SUMMARY

Interpretive Description is an inductive approach. Moving beyond the purely descriptive, this approach requires that the practitioner-researcher interpret the meanings emerging from descriptive account in order to render a full understanding of the clinical phenomenon. In this chapter I have used the words of participants to describe the similarities and distinctions between HCPs’ shared experiences, and I have suggested how their experiences relate to the literature I reviewed at the outset of this thesis. Participants’ experiences were similar in many areas, including not knowing where to start or how to have goals of care conversations at the care setting. Additionally some participants discussed their experiences and challenges working alongside team members who have not developed communication skills specifically surrounding goals of care discussions. In terms of discussing goals of care, most participants struggled with the language involved, as some identified the need to discuss goals of care only in situations of a deteriorating health, and some had
concerns about the stigma associated with discussing end of life issues. Goals of care
discussions lacked a formal framework and in some cases HCPs failed to discuss
illnesses and quality of life issues with patients and families because of pressures to
focus on the medical aspects of the person alone. Participants’ ‘big struggle’
experiences in this study points to a focus on medicalization more so than a focus on
building a relationship with patient and family in order to see the whole person and to
understand the lived experience. Distinctions did emerge in terms of the background of
the participants; whether they had been involved in the development of the companion
card and or subsequently had used it with support from the palliative outreach team at
the site to improve practice. Those experienced HCPs were practiced at incorporating
the GOC companion card framework into their goals of care conversations with patients
and families, and some had become so familiar with the framework they no longer relied
on having the companion card physically ‘with them’ at such discussions.

Overwhelmingly, participants explained the lack of preparedness in their
professional education for the emotional work involved in discussing goals of care with
patients and families. Most participants adopted the behaviours modeled by other;
learning “on the job”. In goals of care discussion work the willingness of individuals to
participate--and inter-team expectation of involvement--was dictated by their disciplinary
differences, with physicians and nurses identified as more responsible for discussing
goals of care with patients and families than others. In general, participants left the
focus group sessions suggesting that they believed could engage in conversations with
patients and families if the GOC companion card was incorporated into clinical practice.
In facilitating goals of care conversations with patients and families, as is indicated by participants’ input, HCPs can and will get a sense of the bigger picture if indeed they address any gaps in patient and family health literacy before offering a smorgasbord of medical technology for all patients and families at end of life. In having goals of care conversations at end of life HCPs are likely to ask first, versus act first. This argument is congruent with Bergum's position that when we practice with caring, respect and thoughtfulness we are working from a relational ethic perspective (Bergum, 2013).
Chapter 5 – Summary and closure

5.1 OVERVIEW

In this concluding chapter I offer a final summary of HCPs’ experiences discussing goals of care using a communication companion that have emerged from this study, and how the findings relate to current literature on preparation for discussing goals of care. I will organise this chapter commencing with the study strengths and limitations and moving into sections as proposed by Thorne (2008) in her text. Those sections are identifying what is important, deciding how to interpret, extending interpretation, drawing conclusions and considering implications. I will close the chapter with my conclusions.

5.1.1 Strengths and limitations of the study

Exploring the emic perspective of HCPs as they relate to and take up a conversation companion card has been a considerable undertaking. Synthesising the working practice and related issues of HCPs’ use of a conversational resource for a variety of HCPs leaves the research potentially open to simplification. The rich and complex work of goals of care discussions could not be addressed in detailed consideration because many participants could only hypothesise on the utility of a GOC companion card, which leaves this research open to criticism. In order to address the study from its strengths and limitations, I will offer my opinions in terms of its credibility, transferability, dependability and confirmability.
In terms of establishing trustworthiness in the study, *credibility* was achieved by inviting participants from the previous three focus groups to a final focus group session to comment on my analysis of the data, and also from self-involvement in the data collection and analysis processes in order to remain close to the data. Furthermore, credibility is exhibited by the congruence between research question and methodology and theoretical framework throughout this study, which I articulated in Chapter 3.

In terms of the *transferability* it could be argued that the study does represent the whole population of HCPs at Community Hospital working with patients and families living with life limiting illnesses. This is illustrated by the fact that 21 HCPs from seven different disciplines agreed to participate. Nonetheless, although many participants at Community Hospital are not engaged in formal patient/family meetings, all participants have a responsibility to share information within the health care team, and this informs goals of care discussions.

In terms of *dependability*, detailed consideration was given to the research methodology, procedures and methods during the course of the study. Every aspect of the study was discussed with my research chairperson. Constraints to dependability are synonymous with qualitative research. Much of the data that was collected offered other avenues to explore, however, some of this data did not answer the research questions asked and therefore is not included in this discussion.

In terms of *confirmability* the subjective nature of qualitative research affords the researcher the opportunity to capture the nuances and subtleties of the phenomenon being studied. Constraints to credibility in this study centred on the assumptions that I brought to the research having worked as an palliative care nurse at the setting in the...
past and also being involved in the EOLC. Acknowledging my familiarity with the setting encouraged me to continually question the assumptions I made throughout this research process.

5.1.2 Identifying what is important

In Chapter 1 I introduced that the study purpose was to understand how HCPs interpret the use of the GOC companion card for effective end of life communication with patient and families and to understand HCPs’ experiences as they engage in complex goals of care discussions in the clinical arena. HCPs at Community Hospital have first-hand experience being involved in goals of care conversations with patients and their families and, indeed, HCPs’ involvement in such conversations is supported in literature (Legare, 2010; Larson & Tobin, 2000). Therefore gaining the perspectives of HCP representatives, including those who typically are not engaged in formal patient/family meetings, was important in order to appreciate the complexities involved in this subject matter. Goals of care discussions influence advance care planning when a competent adult identifies preferences for potential future medical interventions and delineates quality of life considerations based on lived experience, personality and health literacy (Collaboration for Homecare Advances in Management and Practice (CHAMP), 2009; Collins et al., 2006; Larson, & Tobin, 2000; Norton & Bowers, 2001; Pekmezaris, 2011; Providence Health Care, 2004; Storch et al., 2013). When HCPs facilitate conversations based on patient and family centred goals of care, quality end of life care is promoted (Curtis et al., 2005; Heyland et al., 2005; Jacobson, 2009; King & Quill, 2006; Larson & Tobin, 2000). End of life care is incorporated under the palliative
care umbrella, and is an important constituent of whole person care, which is central to all health care.

As I indicated at the outset of this thesis, patients and families are negatively impacted when goals of care are not addressed and/or where therapeutic communication is not valued in clinical practice settings (Curtis et al., 2005; Garland, Bruce & Stajduhar, 2013; Providence Health Care, 2004; Ury et al., 2003; Weeks, 2012; Weeks et al., 2012; Weiner & Roth, 2006). Therefore discovering the emic perspective of what HCPs experience when participating in these conversations and, more specifically, how the participants at Community Hospital experienced the use of the GOC companion card as a resource, was my motivation for pursuing this study. The GOC companion card was developed at Community Hospital and it was important to gain the participants' perspectives of their experiences to assist in understanding how, as a communication resource, it could support health care providers. Drawing on empirical and theoretical knowledge I undertook a systematic review of the literature to locate an extant body of knowledge to answer the research study questions.

5.1.3 Deciding how to interpret

In Chapter 2 I reviewed the literature to situate the research study. Thorne suggests that the researcher must return to the literature to think through the findings, reintroducing the original pieces to “deepen the meaning” (2008, p. 197). Additionally, she suggests that the researcher explore and consult new literature to add new angles to what was already found. My review of the literature led me to decide on the methodology to inform this research study. In Chapter 3 I discussed qualitative methodology and the reasons why Interpretive Description complemented exploring the
experiences of HCPs engaging with patients and families regarding goals of care and end of life care.

Twenty-one participants consented to sharing their experiences in four focus group sessions. Employing ID methodology and a relational ethical perspective the health care providers’ experiences using a communication companion and their experiences with discussing goals of care were analysed and four themes emerged. These themes included the big struggle; responsibility; building relationships; physical, emotional attributes of the GOC companion and influence on professional practice as they relate to discussing goals of care and the utility of the GOC companion card.

Themes of big struggle and responsibility and building relationships, seemed in alignment with clinicians’ experiences in discussing goals of care with patient and family. The physical and emotional responses to the GOC companion card and the professional influence of the card on the participants demonstrated how clinicians took up the companion card at this site.

In the process of the big struggle, participants described individual, organisational and societal influences on engaging in goals of care conversations with patients and families living with life limiting illnesses. Some participants lacked the confidence to discuss goal of care for various reasons related to not knowing where to start, not knowing when the timing was right, not having the professional training, and fear of saying the wrong thing. Such concepts are in keeping with the work of Hartrick Doane and Varcoe (2013), who discuss how establishing meaningful relationships with patients and families are influenced by more than a desire to be a responsible health
care provider. Being compelled to do the right thing can have a paradoxical effect of “...spark[ing] the flight response” (p 156). Some participants assumed that others such as social workers were “good at that sort of thing” (P18); an assumption that one discipline is somehow immune to the situational and interpersonal challenges that others face in making connections with patients and families in health care settings. The big struggle extended throughout an organisation where biomedical information was valued and often patients and families were not involved in decision making. Additionally HCPs did not inquire about patient and family preferences and individual quality of life indicators. Despite the espoused mission of the organisation for shared decision making and collaborative practice, participants’ accounts shed light on practices that did not fit with the mission statement. Some clinicians were troubled when they witnessed encounters where HCPs gave mixed messages to patients and families speaking of “getting better” (P17) rather than discussing the bigger picture of a patient with a chronic illness on a downward trajectory over time. HCPs’ perceived failure to recognise and/or to discuss the big picture created distressing situations. Not including patients and families in conversations to explain the nature of illness and how it develops and its potential impact on a patient and family’s life over time erodes patient and family trust in care providers in situations when aggressive treatment is well indicated to be discontinued. When patients and families do not have this information the participants agreed that medically inappropriate and unnecessary tests, investigations and treatments are imposed on the patient (Azoulay et al., 2009; Bottrell, et al., 2001; Mack et al., 2012; Rodney, 2013).
In a society that is death denying (Weeks, 2012), HCPs who fail to incorporate discussing goals of care at time of diagnosis and other health care interactions fuel the notion that goals of care conversations are equivalent to delivering bad news. This is particularly the case when such discussions are only offered at a ‘turning point’. The participants in my study were united in the belief that discussing goals of care was the responsibility of HCPs, and offered that HCPs are obliged to start these discussions. This expectation is supported by Au et al. (2003) and many other commentators I have cited in this thesis. Many participants contemplated the HCPs’ broad responsibility to see the person beyond the medical issues and considered how personality and situations in life influence both how and what patients and family deem important. This consideration might be incongruent with an organisation that offers advanced techniques and interventions (such as the LVAD example offered by participant P 10) to those people experiencing severe illness situations. There was consensus among some participants that if patients were more or better informed about the consequences of sophisticated technology, the organisation might find a reduction in volume of specialised interventions. Indeed, it became apparent that participants were certain that goals of care must be discussed with patients and families based on the harm and benefits of interventions and how those goals might be impacted. Such a patient centred approach would, in the opinions of the participants, satisfy truly informed consent. When specifically related to end of life goals of care, HCPs can provide informed consent on realistic, expected outcomes of specific aggressive interventions and treatments (Weeks et al, 2012).
5.1.4 Extending interpretation

According to Thorne (2008), the Interpretive Description process is incomplete until attention is paid to the work of “thoughtful examination, reflection and reinterpretation within the context of what else is known about the phenomenon” (p. 193). This study largely confirms what is known about goals of care conversation experiences of health care professionals as they relate to patients and families with life limiting illnesses. It also largely confirms what little is known of HCPs’ responses to communication resources, thus adding findings that extend current knowledge and understanding. Overall, my findings are consistent with previous studies and extend knowledge by detailing the areas of the communication processes and challenges in discussing goals of care. As well, my findings point to risks to therapeutic relations in over-eager adoption of communication tools.

Ury et al. (2003) consider it an expectation of first year internal medicine residents to have competency to “…effectively communicate with patients and their family members about end of life care issues” (p.530). Furthermore, patients share an expectation that physicians will initiate goals of care conversations in health care settings (Johnston et al., 1995). In clinical practice, as P11 explained, medical residents can be ill equipped to engage effectively in these discussions. In fact, research describes an overwhelming lack of preparedness of medical school graduates in the area of communication preparation (Buss et al., 1998; Kelley et al., 2004; Pekmezaris et al., 2011). This situation has implications for other HCPs when there are expectations for medical team members to initiate goals of care discussions and the conversations do not take place. The power of medicine to influence the clinical milieu can lead to
negative outcomes for patients and families when goals of care are not addressed. This situation complicates the health care setting when clinical expectations are unrealistic and when medical personnel are unprepared to engage in such conversations. The findings from this study confirm that many HCPs believe that the responsibility of discussing goals of care with patients and families lies within the scope of the physician alone. While many participants considered that the GOC Companion Card would be a helpful resource to use to improve and make the transition from novice to expert, such a move within the clinical setting would require a departure from current practice. Such a move requires leadership, support and mentorship in place to ensure that the practice, or the ‘how’ of discussing goals of care, takes place sensitively. Specifically, HCPs must be aware of the importance of building a relationship in order to be therapeutic in goals of care discussions (Felgan, 2005; Hartrick-Doane & Varcoe, 2013).

A growing body of literature illustrates that patients believe that discussing preferences for end of life care is best suited to times of stable health (Au et al., 2012; Johnston et al. 1995; Pfeifer et al., 2003; Weissman, 2004). Yet providers, including experienced providers and specifically physician providers, delay conversations due to a number of factors, including personal discomfort (Curtis et al., 2005; Nelson et al., 2011; Walling et al., 2010; Weiner & Roth, 2006; Weissman, 2004). Regardless of whether preferences have been discussed in times of stable health, at difficult periods--such as times of diagnosis and when health conditions change--the impetus for HCPs to attend to goals of care conversations exists. Overall themes that emerged from the participants of this research study included mixed responses among participants on the timing of goals of care conversations and also around HCPs underestimating patient
readiness for goals of care discussions. Although a significant body of research identifies the physician as the provider most responsible for holding goals of care conversations, nurses’ roles in engaging in goals of care conversations is also presented in literature (Botterell et al., 2001; Brataas, Thorsnes & Hargie, 2010; Hartrick-Doane & Varcoe, 2013). What emerged from this research was that only one nurse, P7, engaged independently in, or initiated a team approach to, holding goals of care conversations. Interestingly P7 was also the palliative care consultant at the setting and demonstrating enhanced communication skills is an expectation of the palliative care consultant.

All four social workers had experience in facilitating meetings to discuss goals of care though there was a range in self-described individual levels of skill and confidence in initiating those discussions. Yet it was perceived by non-social worker participants that social workers had the expertise and were equipped with skills to initiate and hold goals of care conversations. Based on these findings I reflected that other HCPs at Community Hospital were not meeting the obligations expected by the organisation and as such were not aligned with the mission and values of the organisation. For HCPs to adopt the expectations of the organisation would require shifts in practice, and given the contextual challenges in clinical settings such shifts might be challenging for HCPs. Indeed, Hartrick-Doane and Varcoe (2013) question whether nurses in particular are supported to provide care using the relational ethics approach I have subscribed to in this thesis. Specifically, the authors invite nurses to “look beyond the surface of one-to-one encounters” so that nurses might “consider what shapes those encounters …
(to)act more intentionally and direct our actions in ways that foster trust, respect (and) compassion…” (p. 156).

During the focus group data analysis it emerged that there was a lack of consensus among providers as to the role and purpose of goals of care conversations. Some participants viewed goals of care conversations as fundamental to building relationships with patients and families. This approach can be considered a component of Frenkel and Stein’s (1999) 4 ‘habits’ for care providers. Similarly, Roter, Larson, Fischer, Arnold and Tulsy (2000) support focusing on patient centred communication to elicit more than the biomedical information needs of patients. In their study Roter et al. (2000) reviewed the communication dynamics of physician participants. The authors concluded that probing and eliciting patients’ values was central to patient centred care and improved partnership building.

Thorne et al. (2010) and Kunyk and Austin (2011) examine the relational space for nurses to enact their moral agency. It is my interpretation that such relational space impacts this study’s participants’ abilities to provide well supported goals of care discussions. For example, I have pointed to the risks of eager acceptance of a communication companion without considering the relationship development between HCP and patient/family, which could subsequently influence the quality of care that patients receive. In Chapter 2 I presented literature claiming that health care providers are open to, and approve of a variety of methods, resources and interventions to improve their comfort level in discussing goals of care at end of life (Alexander, et al., 2006; Au et al., 2012; Back et al., 2010; Kelley et al., 2004; Paul et al., 2007; Pekmezaris et al., 2011; Skinner et al., 2009;). Based on my analysis, the common
denominator is that participants share a significant burden to improve their expertise in order to exert a positive influence on patient/family care at Community Hospital.

5.1.5 Drawing conclusions

Thorne (2008) inspires the researcher using ID methodology to consider what the outcome of the research study is and, furthermore, to question what has been uncovered that was previously unknown. In this Interpretive Descriptive study I have explored how HCPs interpret the use of the GOC companion card for effective end of life communication with patients and families and their experiences as they engage in complex goals of care discussions in the clinical arena. While participants supported the idea that a companion card should be made available for patients and families and also made visible throughout the hospital setting, they also described their individual fears, anxieties and discomfort with discussing goals of care with patients and family. Some participants considered discussing goals of care as foreshadowing death, which was uncomfortable for them.

In addition to individual experiences the participants also alluded to the role of power in clinical settings. Although not specifically named as power dynamics the concepts that were developed pointed to the role that power plays in relationships at Community Hospital. Power dynamics are at play when providers fail to include patients and families in discussing treatment benefits and harm in the context of patient and family goals of care.

As far as I am aware this study is the first to inquire into the experiences of HCPs in holding goals of care discussions at this site. I have uncovered what was previously
unknown about a multiple disciplinary group of HCPs at a community health care setting in Western Canada. What I have done is acknowledge how the experiences of these HCPs were interpreted and how these experiences are also experienced by others cited in related literature.

What I can conclude is that HCPs may find communication tools such as a communication card helpful for discussing goals of care with patients and family experiencing life limiting illness. However, a resource is in itself not a replacement for the development of relationships with patients and families. Therefore HCPs also require organisational support to mutually enact relational ethics in practice.

I conclude that the findings I presented in Chapter 4 underscore the seriousness of HCPs feeling unprepared for goals of care discussions, and also the seriousness at an organisational level if inadequate communication skills are not addressed. Furthermore, I conclude that there is a need to prompt clinicians and leaders within this organisation—and likely others—to engage in seeking solutions to these pertinent issues.

5.2 CONSIDERING IMPLICATIONS

Thorne's (2008) recommends that research into a clinical phenomenon is made available to practitioners in the field. With this intention I consider that the findings will have value for the HCPs at Community Hospital and the organisation, as well as for providers in other Canadian institutions. Implications of this study are for further research and for "everything else" (Thorne, 2008, p. 206). For the purpose of this masters thesis the "everything else" includes professional practice, education and
policy. In considering the implications for further research I will, as Thorne suggests, return to the original research question to determine how to “articulate the potential role of this study within what could become a much more vigorous, focused, and productive program of research” (2008, p. 207).

My first question of this research study was orientated to the experiences of HCPs using the GOC companion card. The participants considered the GOC companion card as a useful resource to assist practitioners in their discussions with patients and family and were willing to incorporate it into their practice. As I have indicated above, what this study elucidated was that many HCPs were challenged with discussing goals of care with patients and families living with life limiting illnesses. The current literature has privileged physicians’ and nurses’ goals of care and end of life conversations experiences, and little is known of the experiences of other health care professionals such as pharmacists and occupational or physical therapists. As the prevalence of chronic illnesses rises more patients and families will be in need of HCPs who can competently engage in therapeutic communication. Thus, there is a vital need for more research to address all HCPs’ goals of care discussion competency with patients and families in the context of life limiting illnesses.

Participants recommended that the GOC companion should be shared with patients and families to help broker better relationships within the health care setting and to better address patient centred care. Sharing this communication companion would warrant research support to study the introduction of the resource into the clinical setting for patients and families while being mindful of issues such as language, literacy and palliative care awareness. A study could inquire about the utility of the conversation
companion among a population that utilises the services at Community Hospital and possibly within other areas of the organisation and also in similar Canadian settings.

The second question of the research study was oriented to how clinicians experience goals of care conversations at this setting with patients and families with life limiting illnesses. As illustrated in Chapters 3 and 4 there was much discussion on the challenges facing individuals and team members in engaging with patients and families in goals of care discussions. Additionally, participants described how some HCPs miss opportunities to discuss goals of care with patients and family. On my review of many health care organisations’ strategic goals for quality and safe care, prioritisation of goals of care discussions is not recognised. What is recognised within the organisation’s safety and quality care areas of priority are hand hygiene improvements, prevention of urinary tract infections, early reporting of medical errors and medication reconciliation. Given the evidence in literature on the relationship of discussing goals of care to quality care provision I find the absence of goals of care discussions of significance.

We have a moral imperative to protect patients and family from harm including harmful communication. As health care providers we share an ethical obligation to raise the standard of care as a team by improving person centred therapeutic communication. Given this, I would recommend further studies and resources to improve the standard of goals of care discussions with patients and families with life limiting illness, making these discussions the norm and not the exception.

There remains rich data that was collected during these four focus group sessions that have not been explored fully as my focus was on the role of the GOC
companion card at this setting, which points to the need for further research in this area. For example, I acknowledge the emergent evidence of the important role the palliative outreach team has played introducing goals of care conversations to HCPs at this site. The outreach team has adopted a participatory versus and advisory approach at Community Hospital and as such has modelled behaviours, particularly relationship development skills across the health care continuum at Community Hospital. This palliative care model is discussed in the literature (Carstairs, 2010; Hughes, Robinson & Volicer, 2005; Parker, Remington, Nannini & Cifuentes, 2013; Robbins, 1998) and has demonstrated improvement in patient and family care and satisfaction scores. How palliative outreach teams within the organisation influence when and how goals of care conversations takes place is another area that is worth studying.

This study has implications for those working in acute care community hospital settings with similar populations, rendering me in a position to comment on and make recommendations to the health care organisation, my health care colleagues working with patients and families with life limiting illnesses, and specifically those in palliative care. In the following section I will discuss implications for professional practice, education and policy development.

5.2.1 Implications for professional practice

The findings of this study are helpful for HCPs as they raise awareness and provide a more complete understanding for goals of care conversations with patients and families experiencing life limiting illnesses. In particular, the contribution of perspectives of those professionals typically excluded from goals of care discussions. This study has illustrated that the participant HCPs are engaged in emergent practice.
In order to work with their interdisciplinary partners as well as patients and families with life limiting illnesses HCPs have had to adopt and adapt medically focused discussion procedures and develop their own communication processes based on ‘on the job’ learning. Developing practice knowledge specific to this client group needs to continue. Each aspect of the therapeutic person centred communication approach must be revisited and further refined in order to develop a desirable working model.

Those participants engaged in this study who were eager to use the card in their practice might do so; however, professional practice culture will not change without leadership resources engaged in harnessing collective energy to change practice. This is an important issue for health care professionals and those working in palliative care in particular, given that we know clinicians experience discomfort discussing deterioration and how it relates to life limiting illnesses.

5.2.2 Implications for education

The study has highlighted that health care providers may come to the field with little or no previous preparation for discussing goals of care. This raises issues about the generic training currently offered to health care provider students and the prioritising of practical skills over therapeutic communication development. This study has highlighted the need for specialised training in working with patients and families living with life limiting illnesses. This is evidenced by the fact that the HCPs in this study spent much of their time adopting and adapting mainstream medicalized practice. Incorporating therapeutic communication throughout all training programs would assist with influencing how to normalise and consolidate a more relational communication style.
5.2.3 Implications for policy

The findings of this study reinforce the growing awareness that patients and families visit and revisit acute care settings with deterioration related to life limiting illnesses without having the opportunity to consider goals of care and how health care decisions impacts quality of life. Furthermore, these findings are consistent with other evidence that improved health literacy of patients and families living with life limiting illnesses results in less aggressive interventions and treatments.

Discussing goals of care earlier in the disease progression requires involvement of primary health and community care providers, especially among a growing seniors population. British Columbians have endured a decade plus of restructuring of primary and community health care services, which have negatively impacted BC seniors in particular. Funding cuts to programs that impact BC seniors, many of whom make up those living with life limiting illnesses, have been felt in home nursing care (3%), home and community services (14%), residential care (21%) and home support (30%) (Canadian Centre for Policy Alternatives, 2013). Furthermore this report from the Canadian Centre for Policy Alternatives suggests that when support is unavailable in the community the seniors population has little choice other than to seek health care at acute care—the most expensive of all health care settings. With patient involvement in health care decisions less “hospital and physician services” are required (Canadian Centre for Policy Alternatives, 2013).
5.3 CONCLUSION

This thesis is a specific inquiry into the experiences of HCPs involved in goals of care conversations with patients and families. It emerged that for some participants, knowledge about goals of care conversations and the existence of a communication resource was learned as a direct result of participating in this study. Participants enrolled in this study with little delay once study advertisement posters were displayed throughout the setting. Proposed study recruit numbers were exceeded, resulting in four focus group sessions with 21 participants. My interpretation is that such prompt response to the study was related to a series of factors. These factors included the researcher’s previous familiarity with the site; the presence of a palliative care team at the setting; provision of food and the timing of study session; the fact the GOC companion card was developed at this site by a once active End of Life Council; and individual HCP interest in the study questions. I also noted that at the outset of my study the GOC Companion Card appeared to be invisible at the setting despite its development there in 2011.

As I worked with the study participants and the data collected from the focus groups questions arose for me on what more needed to be known about the discussions they shared with me. Participants’ emic perspective provided salient complex and sometimes contradictory insights into how HCPs experience discussions with patients and families.

Fear of GOC discussions is not experienced by HCPs alone, as one participant felt that mentioning ‘goals of care’ to a patient and family would “scare” (P13) them. Others, who have never used the card, admitted that they just don’t know where to start...
or how to start the conversation, and as a result in the past they have avoided these conversations. P7, who has much experience with discussing goals of care with patients and families who are living with serious illnesses, countered that a reason for both the fear and avoidance comes from perceiving that the term goals of care is reserved only for those who are nearing end of life versus applying it in a broader sense as a general term that prompts human inquiry into what any person engaging with a health care setting should be asked.

In conclusion, knowledge gathered from participants’ descriptions of their experiences in my study may be used by HCPs to draw attention to the end of life discussions they engage with in an effort to improve goals of care conversations with patients and families living with life limiting illnesses. Furthermore, the rich information provided in this study can be added to a growing current body of knowledge on HCPs’ engagement with patients and families. Such knowledge can inform future policy development, research and professional practice planning, resource allocation and education to reach a universal goal of best practice in collaborative and relational patient-family centred care.
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Appendices

Appendix A – Goals of Care Companion Card

Goals of Care Conversation

Health care team members must appreciate that not all individuals and families are looking for life prolongation when presented with a life limiting disease/diagnosis. Decisions are made based on:

- General Medical Condition
- Personality
- Life Experiences

The gold standard in Palliative Care is to establish individual and family goals of care. This involves understanding what approach to care would be consistent with the person’s beliefs and values.

Goals of Care Companion

Piecing together a preference for care

| What do the individual and or family understand in regards to the individual’s current illness? | Establish goals of care: balance of risks vs. benefit of therapy to meet the individual’s goals. |
| Who needs to be involved in the decision making process? | Is the individual seeking life prolongation, symptom management or both? |
| Where do the individual and or family wish future treatments to be conducted? Where does the individual wish to die? Do they hope to treat reversible illnesses? | What other hopes do the individual and family have? |
| Establish goals of care at each stage in illness trajectory or when changes occur. |  |
“Goals Of Care”
Research Study

Primary Investigator:
Dr. Patricia (Paddy) Rodney RN, MSN, PhD,
UBC School of Nursing


Health Care Providers are needed for research: Researchers at UBC and [Organisation Name] want to learn more about clinicians’ experiences discussing goals of care at the end of life with patients and families.

Are you

- A direct care provider at [Organisation Name]?
- Involved in decision making discussions with patients and families with life limiting illness (with or without familiarity of the [Organisation Name] Goals of Care Companion Card)?

Join a 45-60 minutes focus group or participate in an individual interview to discuss your response to the Goals of Care Companion Card. The Card is an end of life communication resource developed by a multi-disciplinary group at [Community Hospital]. Your experiences working with families facing end of life situations are welcomed to
help us understand how to better support end of life decision making.

**Participants will receive lunch**

For more information or to enrol, please contact the nurse researcher Catherine (Kate) McNamee-Clark RN, [Organisation Name] Palliative Outreach Consult Team (POCT)

Kate is graduate student at University of British Columbia and one of the developers of the Goals of Care Companion Card at [Community hospital]. The principal researcher for this study is Dr. Patricia (Paddy) Rodney RN, MSN, PhD, UBC School of Nursing at Paddy.Rodney@nursing.ubc.ca or XXXXXXXXXXX
Appendix C - Interview Guide

Goals of Care Companion: The Clinicians’ Experience

The following are examples of questions that will be used during the focus group sessions and individual interview(s) to help elicit the participants’ experience(s) with goals of care discussions and to help them describe the experience of discussing end of life issues with patient and family.

Preamble Statement

As a palliative care clinician I have worked with a group of multiple disciplines in developing a goals of care companion card. It was developed to help guide clinicians in discussions around decision making for those reaching end of life. The following questions will explore your reactions to the Goals of Care Companion Card and how you have taken up the resource.

1. As a palliative care clinician, I have seen the outcomes for patients and families who have and have not discussed goals of care with their health care providers. What I am interested in understanding is what it is like to be a clinician in a goals of care conversation. Can you tell me what you understand by the term “Goals of Care”? Can you tell me what it has been like for all of you to participate in goals of care planning discussions? What kinds of thoughts did you have at first and have they changed over time?

2. Could you start at the beginning and describe for me what was happening for you when you had your first goals of care planning discussions?

3. Could you describe your experiences with patients and families as they make decisions around end of life care?

4. Has participating in goals of care discussions toward end of life affected how you view chronic diseases and introducing palliative care? Can you tell me more about this?

5. How did your preparation for goals of care conversations change over time if they changed? Who was present? How have you introduced these conversations? Who do you feel should be included in these discussions and why?

6. If you are familiar with this goals of care companion card have you used it to help guide discussions on decision making with patients and family?

7. Based on your experience with this topic, what sort of advice would you give me on how our colleagues might approach this same issue?

8. Knowing what you know now about this goals of care companion card, what advice would you give to the developers of the goals of care companion card to improve the resource? What were some helpful and unhelpful things you experienced that you would ask them to think about?
Appendix D – Research Participant Information and Consent Form

Research Participant Information and Consent Form for

Health Care Providers

Study Title:

Using Interpretive Description to explore and evaluate the [Organisation name] Goals of Care Companion Card: The clinicians' experience.

Introduction

My name is Catherine (Kate) McNamee-Clark. I am conducting a study about how health care providers view the usefulness of a goals of care companion card as a communication tool to help guide end of life care conversations with patients and families. Furthermore I am interested in your experiences discussing end of life care with patients and families. I am a student in the Master of Science in Nursing (MSN) program at the University of British Columbia (UBC). I am also one of the developers of the Goals of Care Companion Card.

This research is being carried out to meet the requirements of a graduate thesis. Professionally, I am a registered nurse and have worked in palliative care for 7 years and with the Palliative Outreach Consult Team for 5 years in acute and residential care settings. I have been nursing for a total of 23 years.

I. Research Team

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Dr. Patricia (Paddy) Rodney RN, MSN, PhD (Principal Investigator)

Associate Professor, University of British Columbia (UBC) School of Nursing; Faculty Associate, W. Maurice Young Centre for Applied Ethics, UBC; Research Associate, Providence Health Care Ethics Services.

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Tarnia Taverner RN, MSN, PhD (Co-Investigator)

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Email: Tarnia.Taverner@nursing.ubc.ca

Catherine (Kate) McNamee-Clark, RN, BSN, CHPCN (C) MSN student (Student Investigator)

University of British Columbia School of Nursing

Phone: XXXXXXXXXX

Email: kmcnameeclark@gmail.com

II. Sponsor: Who is funding this study?
There is no funding from any outside agencies for this study. All costs are covered by the student researcher.

**III. Invitation and Study Purpose: Why are we doing this study?**

You are invited to participate in a research study to find out about the perspectives of health care providers involved in goals of care conversations at end of life with patients and families living with life limiting illness.

The purpose of this study is to explore the utility of a goals of care companion card for health care providers as a communication tool to help guide end of life care conversations with patients and families as part of a Masters in Nursing degree thesis work. Information from this study will help us better support health care providers in having difficult conversations with patients and families at end of life. Additionally, information can be used to improve resources, supports and tools for HCPs to ensure helpful communication takes place with patients and families particularly as end of life approaches.

You are invited to take place in this study because you are:

- English speaking
- Able to read English in order to give informed consent
- At least 19 years old
- Providing direct patient care at [Organisation Name] acute care setting.

**IV. Study Procedures: What happens in the study?**
Your participation in this study will consist of one 45 to 60 minute focus group session. Focus group sessions will take place in a meeting room at [Community Hospital]. If you cannot attend a focus group session or would prefer to share your experiences in private, an individual interview will be set up at a time and place of mutual convenience such as at a meeting room at [Community Hospital], or a local coffee shop. Your interview will be tape recorded and the researcher will also take notes during the session. This information will be transcribed with your permission. You will be asked questions about your familiarity with a goals of care companion card and how it has been taken up by you. You will also be asked of your experience with discussing goals of care at end of life with patients and families with life limiting illnesses and how these have affected you. Examples of questions you may be asked include: ‘what is your understanding of the goals of care companion card’ and ‘what it means to you to discuss goals of care with a patient and family’? You may choose not to answer questions that make you feel uncomfortable.

We are also interested in learning about your suggestions for supportive decision making best practices.

**V. Study Results**

The study findings will be presented in University of British Columbia library as a thesis work. Main findings may be presented at Canadian and international conferences and published in academic journal articles. If you wish to receive a copy of the published articles resulting from this study, we will send you a copy, either electronically or in hardcopy by mail.
VI. Potential Risks of the Study

There are no significant risks in taking part in our study. However, we realise that talking about your experiences with discussing goals of care at end of life with patients and families can be emotional. If concerns arise you may contact the study researchers at the phone numbers listed above. The researchers are experienced in discussing end of life issues and can be supportive to you.

VII. Potential Benefits of the Study

You may or may not find any personal benefit from your participation in the study.

There is no direct benefit to you from participating in our study. The information we obtain from you will help us to better understand how discussing goals of care at end of life with patients and families affects health care providers caring for them. This may help us to offer better education support to health care providers caring for patients and families at end of life in the future.

VIII. Confidentiality: How will your privacy be maintained?

All information provided by you and other study participants will be treated with the utmost respect.

The results from the interviews will not contain any information that could identify you. Your identity and participation in the project will be kept a strictly private. The focus group sessions and or interviews will be tape recorded and stored in a locked filing cabinet on site at the hospital. The investigators listed above will have access to these
tapes. Your name will not be recorded on the audio tapes or notes and both tapes and notes will be stored without any identifying information.

Short quotes and interview passages may be used in published reports and presentations on the research, but you will not be identified by name. Pseudonyms (false names) will be substituted for your real name and the names of anyone else mentioned in the interviews.

Your participation in this study is strictly voluntary. You have the right to withdraw from the study at any point. Deciding not to participate will not affect your employment or role in the health care team.

IX. Payment: Will you be paid for your time?

A light lunch will be provided to you in appreciation of your participation.

X. Contact for Information about the Study and Your Rights as a Research Participant

It is very important that your participation is entirely voluntary and based on a clear understanding.

If you have any questions or desire for further information with respect to this study, you may contact Catherine (Kate) McNamee-Clark at kmcnameeclark@gmail.com or by phone at XXXXXXXXXXX. If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.
XI. Participant Consent and Signature

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may withdraw from the study at any time without giving a reason and without any negative impact on your employment. If clarification is required the study researchers would like to recontact you in the future as necessary.

Your signature below indicates that you have received a copy of this consent form for your own records, that you agree to participate in this study and that you agree to be recontacted as necessary.

____________________________________________________________________
Participant Signature

____________________________________________________________________
Printed Name of Participant		Date

XII. Copy of Research Results

Please check here and provide your mailing address or email address if you wish to receive a copy of the results of the study:

____________________________________________________________________

____________________________________________________________________

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Appendix E – Research Assistant Confidentiality Agreement

THE UNIVERSITY OF BRITISH COLUMBIA

Research Assistant Confidentiality Agreement

This study, ‘Using Interpretive Description to explore and evaluate the Providence Health Care Goals of Care Companion Card: The clinicians’ experience’, is being undertaken by Catherine (Kate) McNamee-Clark under the supervision of Dr. Paddy Rodney at University British Columbia.

The study purpose is to understand how health care providers (HCPs) view the usefulness of a Goals of Care Companion Card as a communication tool to help guide end of life care conversations with patients and families. The study will help us to understand health care providers’ experiences discussing end of life care with patients and families and then help us to improve resources, supports and tools for HCPs to ensure effective communication takes place.
Your signature below indicates that you have received a copy of this confidentiality agreement for your own records and that you agree to:

1. Keep all research information confidential by not discussing or sharing the research information in any form or format (e.g. disks, tapes, transcripts) with anyone other than the Principal and or student Investigator(s);
2. Keep all research information in any form or format secure while in your possession;
3. Return all research information in any form or format to the Principal and or student Investigator(s) when the research tasks have been completed;
4. Securely erase or destroy all research information in any form or format regarding this research project after consultation with the Principal or student Investigator(s) (e.g. information sorted on computer hard drive).

Research Assistant:

________________________        __________________________   ________________
(print name)                     (signature)                        (date)

Student Investigator:

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(print name)                     (signature)                        (date)

Questions? Contact Dr. Patricia (Paddy) Rodney RN, MSN, PhD [Principal Investigator] xxxxxxxxxx. If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598