Hopework: Health Care Providers Caring for Cancer Patients Facing End of Life

by

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B.S.W., University of Victoria, 1979

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

MASTER OF SOCIAL WORK

In the School of Social Work

University of Victoria

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ABSTRACT

A grounded theory study (Charmaz, 2006) explored health care providers' (HCPs) hope processes (hopework) caring for cancer patients facing end of life. A critical social work perspective was used to investigate experiences of nurses, doctors and social workers and counsellors in their work with psychosocial and emotional end of life issues.

Health care providers' engaged in a core process of hopework as they faced the ambiguous and uncertain terrain of *end of life care*. They searched for realistic hope by shifting their professional and personal hopes. This core process was achieved by meaning-based actions that enabled HCPs to *tolerate tragic circumstances* and to *build emotional scaffolding* to sustain themselves.

The findings indicate that HCPs engage in a parallel process of hopework with their patients to achieve 'realistic hopes'. Although concepts of hopework are not easily defined, the processes of hope need to be addressed in the professional training of HCPs to optimize patient care and to prevent damage to patients' vulnerable hopes.

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Acknowledgments

I would like to acknowledge members of my thesis committee for their support through my thesis writing process. Pat McKenzie provided me with encouragement and vision of the value of the clinical work that I do that is translatable to research and back into practice. Anne Bruce's thoughtful, grounded questions and discussions guided the spirit of my work. My thesis supervisor, Susan Strega offered me solid guidance, supportive yet critical feedback and deep encouragement in my process of learning and understanding about research. I thank Susan for her commitment, hard work and dedication to being an exceptional teacher and for the many discussions we had about hopework. I have been extremely blessed with the extraordinary support of these mentors.

I also want to give due recognition to my colleagues in the oncology field particularly those who participated in my study, as this study rekindled further my appreciation of the extraordinary human beings who share my work with cancer patients. I felt 'heartful' and fortunate to be working with such caring and committed colleagues.

Finally, I thank the members of the CIHR-funded Victoria Palliative Research NET (New Emerging Teams) project on Overcoming Barriers to Communication through End-of-Life and Palliative Transitions, particularly, Drs. Peter Kirk and Frances Lau for providing financial support for this amazing opportunity for me to return to academia after years of practice to research my passion about hope. The opportunity to network, discuss and learn with other members of the research team and sub-committees have been invaluable and deeply appreciated experience.

Dedication

I dedicate this work to all those who have contributed to my hopework: my mother who came to this country with hopes and dreams for herself and her children. My amazing family who accommodated my academic pursuits with good-natured support: Larry who picked up the other half of the parenting role when I was not available and went on 'dates' with others when I was too busy working on my thesis. Erin who I had the greatest pleasure of being a fellow student with at the University of Victoria and who inspired me to remember what it was like to study hard and reminded me that "your grades don't matter, mom". Lauren forgave my absence at soccer matches and softball games and gave me lovely back-rubs during longs hours on the computer and even the occasional home-cooked meal.

I thank friends and extended family for putting our relationships 'on hold' during this thesis process which I am eager to resume with pleasure.

I need to recognize above all the profound lessons that cancer patients and their families have taught me over the years about their hopes and dreams. It is for them that I have written this thesis.

I see hope as the very heart of healing. For those who have hope, it may help some to live longer and it will help all to live better.... For a [person] to effectively impart real hope, he has to believe in it himself.

– *Medical oncologist in The Anatomy of Hope (Groopman, 2004, p. 214 & 209)*

The significance of hope at end of life care

The concept of hope has played a significant part of my work as a social worker practicing in an oncology setting for the past 19 years. This experience has given me a unique perspective on the importance of hope to cancer patients facing end of life issues. As I provided support and counselled patients who faced a poor prognosis, I noted how often they commented on their sense of hopelessness: "the doctors gave me no hope"; "they took my hope away"; "I have no hope". Yet, there were also patients who, when given the bad news seemed hopeful and able to face their uncertain futures with equanimity. Somehow, these patients were able to acknowledge the reality of their diagnosis but remain hopeful because they understood that there *were possibilities* for the future for them. I have observed patients' hopes to be influenced by the health care relationship. If health care providers do not themselves have hope for patients, they are, arguably complicit in patients' hopelessness.

In my research, I aspired to better understand the social processes of hope of health professionals, deemed by various authors (Jevne & Nekolaichuk, 2003; Schecter, 1999; Zilberfein & Hurwitz, 2003) to be a vital process for HCPs to address the hopes of dying patients. A review of the literature suggests that current hope research tends to focus on the hopes of patients facing a serious illness. Very few studies explore the hope of health care providers (HCPs) who care for people facing end of life.

This research addresses curiosities arising from my psychosocial oncology practice: What are the hopes of health care providers? How do HCPs sustain their hopes? How can HCPs better understand their own hopes? How does this sustained hope impact HCPs in their relationship with patients facing end of life? This study explores the hope experiences of nurses, doctors and social workers/counselors working in the field of oncology practice.

Adopting a critical social work perspective

This study uniquely examines the hopework of various health care disciplines from a critical social work perspective. This viewpoint acknowledges possibilities and freedom from adherence to mainstream assumptions found in the medical discourse. It recognizes that society, relationships and individuals change as they interact with each other and that understanding the processes of change in relationships between people in their lifeworlds is fundamental to understanding why people believe, value and do what they do. "...Critical social work seeks opportunities to uncover the possibility for alternative and better social forms... [and] fosters self directed emancipatory practice for both individual and social transformation" (Pozzuto, Angell & Dezendorf, 2005, p. 25) The deep stories of HCPs in this study not only revealed their relationships with their patients, but reflect a bigger picture of how society shapes beliefs, values and views of ourselves. We understand more about the 'invisible' powers or discourses which permeate our professional practices in health care through examining micro- relationships between HCPs and their patients.

This critical perspective does not privilege professional knowledge by ignoring patients' experiences. This study was borne from recognizing and honouring patients' struggles with their hopes as they are overshadowed by the constrained hopes of many HCPs. This study attempts to provide insight as to how HCPs can better understand their own hopes, in order that they do not cause further distress to palliative patients by undermining patient hopes beyond the news of their poor prognosis. By offering this critical social work perspective to other disciplinary practices, I 'open up the space' for discussion of how we can better address patients' hopework. The prospect of improved care for people at end of life is a cause profoundly worthy of further exploration and discussion.

The biomedical culture of care

The power of Western medical discourse is deeply embedded and represents 'sedimented layers of accumulated knowledge and practice' (Chambon, 1999:54) [1] that is unchallenged and invisible to our everyday experiences. Health professionals' desire to ease suffering is affected by unquestioned practices and constrained awareness of the ways they may view health and healing. Hierarchal power differences are intrinsic to the Western medical model of practice and deeply embedded in the training of health professionals. This hierarchy is presumed to be 'natural'. Those who train in medicine develop knowledge of a 'distinctive lifeworld' as they enter into a reality

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[1] This was Chambon's description of Foucault's term, "archaeology" (Chambon, 1999:54)

system which requires specialized ways of seeing, writing and speaking (Good, 1994, p. 71). Indeed, Foucault drew attention to the importance of critically studying practices by analyzing how the institution imprints and embodies a 'historical manifestation of the self' within individuals:

> *In thinking of the mechanisms of power, I am thinking of its capillary form of existence, the point where power reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives (Foucault 1980:39, quoted by Chambon, 1999, p. 59).*

Training in medicine is indoctrination into an elite, self-defined group, where the very grain of individuals is imbued with specialized ways of knowing and viewing the world.

Medical students for example, are trained to construct people as *objects* of medical attention (Good, 1994). In this medical realm, the focus of care revolves around the story of the disease rather than the story of the person. Western society, as a whole, has adopted this biomedical model of health care and has unconsciously embraced the hierarchal standards of the medical culture. Doctors are not trained to spend the time and energy necessary to understand patients' reactions to their diagnosis, or why they make the choices that they do (The, 2002, p. 226). The patients' psychosocial well-being is not considered important in this medical framework.

Patients' deep stories are lost amidst the focus on the disease and the search for treatment. Their needs are often fragmented to satisfy the predominant goals to provide treatment with efficacy, efficiency and effectiveness. At times, patient care is conveniently compartmentalized for the benefit of the disciplinary interests of health care providers who work in the system. The specialized disciplinary expertise of HCPs can further fragment patient care. For example, in the cancer centres patients may encounter oncologists and nurses who specialize within different areas of practice.

Patients who don't accept the 'truth' about their diagnosis or treatment and/or refuse to comply with prescribed treatment are often pathologized or medicalised by health professionals. The hope literature revealed a medicalised view of hope; patients' hopelessness is assumed to be in need of intervention and treatment. Hope therapy is in danger of becoming totalized (Foote & Frank, 1999) within the biomedical realm as assumptions are made that everyone needs hope treatment. That is, professionals are required to perform 'hopework' for all cancer patients prophylacticly to prevent hopelessness and depression.

My research on hope focuses on the meaning of hope to HCPs, in their relationship to, and with their patients. This *meaning-focused* approach impacts on the social relations that HCPs have with their patients. Hope is significantly acknowledged in this research as a psychosocial process and hope is recognized as unique to each person as a form of resistance to the pervasiveness of the medical discourse.

My complicity as a HCP

As in many settings, the social worker participates in regulating and controlling behaviours that threaten the status quo of the system. It is our role to assess and intervene in circumstances where patients are unwilling or unable to participate in their prescribed treatment. I recognize my own complicity in perpetuating institutional practices that consider the needs of the client secondary to that of the institution. For example, I have been culpable in neglecting to educate all patients about their rights to voice their preferences in regards to the timing of treatment, in deference to the needs of the clinic and other patients. I rationalized that the system would not be able to function if all patients exercised their rights for the timing of their treatment. On the other hand, facilitating a patient's journey through the system may meet the needs of the treatment protocol more than it addresses the needs of the patient. Patients, for example, are informed of their choice regarding their treatment timing if it reduces their stress and helps them to cope with treatment. My role as a social worker involves encouraging compliance to treatment and to provide 'adjustment' therapy to those who have difficulty conforming to expectations. We are all vulnerable to the hegemonic power of the medical discourse whether we are health care providers or patients.

Contextualizing the research

The communication of 'bad news' by HCPs is inherently challenging and encompasses a need for compassion, sensitivity, wisdom, courage and caring. Ann-Mei The (2002) described the oncologist as the "author of hope" and other professionals as "collaborators" in the process of truth-telling (p. 202). In her ethnographic study, she immersed herself in the palliative experiences of lung cancer patients and their families. HCPs need to convey their empathy to patients through the way they observe, listen and speak to patients. Failure to deliver bad news in a sensitive way can cause irrevocable suffering amongst palliative patients who are in the greatest need of support and care. These qualities are not ‘natural’ for health care providers. Practitioners hone these qualities and skills over time through experience (Arora, 2003; Butler, 2005; Fallowfield & Jenkins, 2004). Findings from the current study supported this premise.

Hope in the context of health care

The narratives of hope differ for the health care professional and for the patient. HCPs often view hope in the context of medical efficiency and cure, whereas patients often view hope from the standpoint of quality of life (Eliott & Olver, 2002; Groopman, 2004). Despite the differences in hope narratives, health care providers in my experience, consistently hope against hope and greatly desire for palliative patients’ successful treatment outcomes in the light of poor prognoses. HCPs ‘hope for the best’ that the cancer has not spread; they hope for curative disease and for the patient’s longevity. However, if hope is paramount to a patient’s quality of life, as suggested by numerous writers, (MacLeod & Carter, 1999; Pilkington, 1999; Post-White et al., 1996) how can an incurable prognosis be conveyed by HCPs without communicating a sense of futility to the patient? Maintaining hope has been correlated to physiological well-being (Brooksbank & Cassell, 2005; Udelman, 1986) and quality of life. If a patient's hope process is critical to their survival, what kind of hopework do HCPs need to do for themselves so they can encourage patients' hopework?

What do we 'know' about hope?

Our understanding about the social processes of hope between HCPs and patients rests on our awareness about the current discourses on hope and how it is socially constructed in our society. Patients undergo a hoping process as they adjust to their prognosis (Hagerty et al., 2005; Jevne & Nekolaichuck, 2003; Parker-Olver, 2002). The meaning of hope is socially constructed, and unique to an individual's social experience:

> *Patients know the enticement of possibility in the pain of uncertainty. Many know the mystery of believing against seemingly insurmountable odds. Others lean more to the rational assessments based on visible evidence. Yet others are nourished and sustained through a difficult time by valued relationships. The need for conceptual clarity or purity is rarely a need for the patient. For patients, hope is a lived experience. It is known by its absence as profoundly as by its presence. It is an essential thread woven into the fabric of living with illness. It cannot be x-rayed or injected but a day without it is very difficult (Jevne & Nekolaichuk, 2003, p. 192).*

Health care providers co-construct their hopes along with their patients. The process of hoping is dynamic and changes with perception of 'reality' (Callan, 1989). In colloquial terms, hope "is those things that make us want to be part of life regardless of our circumstances" (D.J. Larsen, personal communication, May 3, 2006).[2] Saleeby (1996) defined hope as a kind of rhetoric that "preserves the possibility and promise" of patients (p. 298).

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[2] Denise J. Larsen, Clinical Psychologist, Director of Research Programs at the Hope Foundation of Alberta, Department of Educational Psychology, University of Alberta. Quoted at: *Naming &*

Hope is relational

Health care providers influence patients' hopes in the context of the relationships they establish with patients. Koopmeiners et al. (1997) explored healthcare professionals' influence on patients' hopes by interviewing palliative cancer patients. Respondents indicated that doctors (75%), nurses (63%), chaplains (28%) and social workers (19%) were instrumental in contributing to their hopefulness by "being present, giving information and demonstrating caring behaviors" (Koopmeiners et al., 1997, p. 1509). Although Koopmeiners' (1997) study indicated that patients were encouraged and felt more hopeful when HCPs were warm, friendly and polite, smiled and remembered patients' names, the *underlying beliefs, values, opinions or emotions that underpinned the hopes of HCPs for the survival of patients were not addressed.*

My study examines the internal hopework (hoping processes) by HCPs that enables them to optimize the external hopework that impacts the hope of their patients. Interviews with HCPs in my study reveal how individuals constructed their personal hopes. The HCPs' personal views on hope illuminate how their hopes are communicated to patients helping patients to construct and maintain their hopes. Patients' vulnerable hopes rests within the health care relationship, (Benzein & Saveman, 1998; Miller, 1984; Penson, 2000) reliant on the imagination of the HCP (Simpson, 2004) and the ability of patients to envision possibilities for future prospects. HCPs are challenged to use hope 'audaciously'

Claiming Spirituality: the invisible ingredient in health & healing conference sponsored by Providence Health Care. May 3, 2006. Vancouver, B.C.

rather than being held back by conventional beliefs (Edey, 2006, personal communication).[3]

What is hopework?

The phrase, "hope work" appears in the research by Perakyla (1991), a sociologist who conducted an ethnographic study of health care professionals working with dying patients in Finnish hospitals. She noted HCPs shaping and defining patients' hopes and identities as they interacted with palliative patients and their families. The patients and their families were observed to be particularly vulnerable to opinions of the HCPs as to how hopeful they 'should' be about their medical situation. Hope was constructed in the conversations that took place between the HCPs and patients. The health care professionals in this study conveyed patients' hopes to be curative, palliative or in need of dismantling in anticipation of death. Perakyla (1991) defined hope work as:

> *… an interactional process whereby the medical identities of the patient and the staff are explicated and specified in terms of hopefulness of the situation. Conversation is the most important tool in hope work, and hope work is an important part of the doctors' and other staff members' jobs as well as an essential component in the work of patients and relatives (Perakyla, 1991, p. 417).*

Herth (1990), a nurse researcher, viewed HCPs' hope work as an intervention process whereby HCPs addressed patients' concerns about the quality and meaning of life. The context of hope work by both authors focused on the relationship and dialogue between HCPs and the patient or family.

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[3] Dr. Wendy Edey, Clinical psychologist, Director of counselling, Hope Foundation of Alberta, adjunct faculty, University of Alberta, Department of Educational Psychology.

In the context of this current study, I elaborate and define the phrase "hopework" to include the HCPs' inner hope processes and how they construct and make meaning of their hopes in their work with palliative patients. This internal aspect of the hope process was not readily apparent in Perakyla's (1991) or Herth's (1990) relational views of hopework. Simpson (2004) recognized the internal dimensions of hope work and noted that internal and external resources are used to do hope work. She identified actions of hope work to include 'self-reflection, spiritual and emotional components' (p. 442). I adapted Simpson's (2004) concepts of hope work for the following definition for this study:

> *Hopework – (def.) a process of constructing hope in terms of hopefulness of the situation which can be an internal process of working on one's hope, or an external process of encouraging the hope of others . Internal and external resources are used to do hopework within an interpersonal or intrapersonal context. (adapted from Simpson, 2004, p. 431).*

In my experience, the ability of health care professionals to practice self-reflection to understand their own hopes and to personally explore the meaning of life and death enables them to better understand and be able to address the hopes of dying patients.

Situating myself in the research

Research outcomes inevitably reflect a perspective mediated by my own experience and knowledge, which I need to concede, in order to be accountable to this research that I undertake (Clarke, 2005, p. 15). My psychosocial oncology experience inspired this subject and shaped the direction of my research. Over the years, palliative patients' intimate and tragic stories of despair and loss of hope have been shared in a sacred space of privileged confidence in sessions within my counselling office. Their hopes are often diminished by the doubts of health care providers whose belief in statistics limited their confidence in patients' abilities to survive their illness. HCPs often viewed 'truth' within the narrow confines of their biomedical perspective of the world. Their limited beliefs in healing possibilities hindered their hope for patients.

Patients frequently succumb to the truth of the bad news without questioning the authority of medicine. Their fears, lack of knowledge, helplessness and inability to fathom alternative narratives, made them susceptible to the explanations produced by their health care providers (Perakyla, 1991). I learned early in my practice, however, that some patients *did heal* and recover in spite of the dire predictions of doctors. It was not uncommon, or unheard of, to encounter cases of remission or recovery 'against odds' in the cancer clinic. Unfortunately, these hopeful stories were often invisible, untold and uninvestigated. Within the current medical culture the focus on patients' 'sick-being' prevails over stories about well-being.

My own narratives or stories of hope continued to grow over the years and contribute to my own hopework. Patients have been the greatest inspiration in teaching me about hope. Gina[4], who died several years ago, joined the young cancer patients' support group that I facilitated. She had metastatic stomach cancer. Her stomach was removed and she had multiple chemotherapy treatments. Gina was married and had two active pre-teen children. She was 32 years old. She came in every few weeks to see me. According to Gina,

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[4] All names and identifying information has been changed to protect confidentiality and anonymity.

everyone expected her to die. She recounted to me how surprised her doctor always seemed to be when she attended her routine follow-up appointments. "He'd look at me, looking surprised that I'm not dead, yet", she'd remark. Her husband expected her to die and focused his time and energy preparing for the worst instead of being engaged in the best in their relationship. Gina, however, had *audacious* hopes and dreams. She desired to learn to skate. She always wanted to build a doll house. Gina yearned to go to Portugal to see her homeland. Sadly, Gina perceived that I was the only person who believed and listened to her hopes. People in her life gave her the impression that she let people down; she felt guilty that she did not die as expected. She felt frustrated that people did not uphold their own hopes for her, or support her hopes. As I journeyed with Gina's hopework --- she joyfully took skating lessons, built a delightful doll house, visited family in Portugal and connected with her roots. She eventually died with few people who knew her emotional pain and her lonely hopes and dreams. She was anointed with hopelessness by the medical profession and doomed in the eyes of friends and family.

The everyday stories of hope and hopelessness are innumerable. HCPs need to honour the hopework of patients by allowing, accepting and understanding their *audacious* hopes. This is only possible if HCPs can understand hopework and learn to hope audaciously themselves. My personal story of hope began with my own diagnosis of a possible malignant spinal tumour several years ago (see Appendix A). Although I was supported by sensitive and caring colleagues, I encountered those who believed that I had a life-threatening diagnosis. These well-intentioned HCPs believed that it was their job to 'tell the truth' so I could prepare for the worst. I recognized their unwillingness and inability to support my hopes. My suspected life-threatening diagnosis fortunately, was a benign tumour which could have resulted in serious health consequences. These deeply personal 'insider' perspectives in the cancer context, along with my clinical oncology experience, provide me with a unique perspective and impetus to challenge the 'realities' presented to cancer patients, and to explore hopework as a life-sustaining process.

SUMMARY

This study acknowledges and honours patients' hopes by exploring ways in which health care professionals can better understand their own hopes and how these hopes can impact on how they attend to palliative patients without causing further distress beyond the news of their poor prognosis. If hope is paramount to the quality of a patients' life, how can an incurable prognosis be conveyed by HCPs without communicating a sense of futility to the patient? Maintaining hope has been correlated to physiological well-being and quality of life. If the hope process of patients is important for their survival, what kind of hoping processes do HCPs engage within themselves before they can encourage patients' hope?

Can health care providers recognize the unique hopes based on the narrative of patients that differ from their own? Do they in fact recognize what their own hope narratives are? Despite widespread agreement that the attitudes and beliefs of HCPs invariably influence patients' views of their prognosis, *how* HCPs maintain their hopefulness within themselves remains largely unexamined. The current study investigates what health care providers do to cope personally and professionally in their interactions with patients with poor prognosis. The research explores underlying beliefs, values, opinions or emotions that underpinned HCPs' hopes about patients' survival.

Chapter two includes a cursory review of the hope literature. As the grounded theory method eschews doing a literature search prior to data collection (Strauss & Corbin, 1990), the review of relevant, core literature enabled me to narrow my study of hope as a relational process and to contextualize my intention to focus on the hopework of HCPs rather than patients. As research progressed, literature was investigated to further illuminate the data. Discussion about this literature has been integrated into the body of the report where it is helpful in clarifying concepts. Included in the Relevant Literature chapter is a critical discussion of issues that surfaced from the core literature. The topics include: a) *Hope doing and hope being*, b) *The multiple realities of hope*, c) *Medicalisation of Hope*, d) *Collaborative views on hope.*

Chapter three covers the study's Research Design. A grounded theory approach was used for this research, incorporating Charmaz' (1990; 2006) co-constructionist approach and adapted concepts of situational analysis (Clarke, 2005) to the grounded theory methodology. Interviews were conducted with nurses, doctors and social worker/counselors recruited from a cancer centre. Data from a previous pilot study was incorporated into the current study. The

Methodologies section includes a discussion about the complexities of my role as an insider researcher in this study.

Chapter four reviews the findings of the research. The study data is grounded within the experience of HCPs as they revealed personal and professional views about their work with patients facing end of life. Health care providers' actions and viewpoints indicated that they engaged in a process of modulating and shifting their hopes with reality as they tried to live with the ambiguities and uncertainties of end of life care.

In the final chapter, Discussion & Conclusion, HCPs' hopework practices are examined as problem-solving and meaning-based coping processes. Personal and professional factors were found to impact hope processes. The relational aspect of hopework was identified as a condition or source by which hopework can be nurtured in HCPs. The findings of hopework are discussed regarding implications for practice and future research at the conclusion of this chapter.

INTRODUCTION

Grounded theorists dissuade researchers from conducting a literature review until the study has been completed (Charmaz, 2006; Strauss & Corbin, 1990). The primary concern is that the researcher can become 'captive' to existing literature (Strauss & Corbin, 1990) which may influence and deter originality and creativity in data analysis of the current research. I conducted a cursory review of the literature which Strauss and Corbin (1990) would have defined as 'technical literature'. The literature reviewed served the purpose of identifying and narrowing the focus of the research from the broad topic of hope, to examining 'hope as a social process of health care providers who provide end of life care to cancer patients'. The review of literature confirmed that there were no studies that specifically addressed *how* interdisciplinary health care providers in oncology sustained their personal hoping processes in their work with patients with poor prognosis.

A second review of the literature was conducted during and after the fieldwork. Emergent themes and categories stemming from the collected data guided the selection of more references to clarify theoretical concepts. This dialogue between the literature and the research further enhanced the conceptual richness that emerged from the study (Strauss & Corbin, 1990, p. 55). Some of the secondary writings from this phase of the literature review have been woven into the discussions in subsequent chapters to illuminate discussion about the topic of hopework.

Purpose of literature review

How do health care professionals sustain their own hopes in light of what is perceived to be a 'hopeless' palliative situation? What kind of hopework do they need to engage in, within themselves in these circumstances and how does this impact on their relationship with the patient? My study began to address these questions by doing a review of hope literature: conceptual frameworks, clinical reviews, opinions and research. The specific purpose of this review was to locate my research in the context of the existing body of knowledge of the hope of health care providers working with patients facing end of life. The literature selected focused on the topics of: a) the importance of hope at end of life; b) theoretical frameworks of hope in the health care context; c) exploring the social processes or relational aspect of hope, and finally, d) the hopework of health care providers who work with cancer patients facing end of life --- with a specific interest in exploring the contributions made by the social work discipline.

Literature review process

Internet academic data bases, including Academic Search Elite, Wiley Interscience, Web of Science, PsychINFO, and EBSCO Host, were used in the search. Articles were identified using key words such as 'hope', 'end of life', 'palliative', and 'communication'. Subsequent to this initial foray into the literature, further key words were added such as 'social work + hope + end of life'. Authors or articles that were cited frequently in literature were identified as seminal articles that provide foundational concepts related to the topic (Callan, 1989; Dufault & Martocchio, 1989; Farran, Herth & Popovich, 1995; Jevne & Nekolaichuk, 2003; Nowotny, 1991; Snyder et al., 2005; Udelman, 1986). Although some articles dated back to the 1980s (Callan, 1989; Dufault Martocchio, 1989; Udelman, 1986) their important contributions to knowledge about hope warranted their inclusion in this review. More than half (23) of the 32 articles that were initially reviewed addressed hope in the context of health, cancer, and end of life. The remainder addressed the psychological and theoretical processes of hope.

CONCEPTS OF HOPE IN THE LITERATURE

> *Hope…is the ballast that keeps us steady, that recognizes where along the path are the dangers and pitfalls that can throw us off; hope tempers fear so we can recognize dangers and then bypass or endure them… (Groopman,2004, p. 199)*

Hope and quality of life

The concept of hope was considered of significance and value in relation to improved health in the diverse literature reviewed. Stress researcher Donna Udelman's (1986) primary research on the correlation between hope and the immune system provided a backdrop for subsequent studies of psychoneuro-immunology that laid the groundwork for how hopeful emotions contribute to physiological health. Psychologists Cheavens et al. (2005) reviewed research on the psychological and physiological benefits of hope and concluded that higher hope decreased pain and stress (p. 123-124). The clinical experience of a hope researcher who developed a hope measurement scale defines the importance of hope:

> *Hope is essential if people are to cope successfully with and adapt to situations they encounter throughout life. Without hope, the events of today become meaningless. Without hope, patients and their families cannot cope with the crisis of illness (Nowotny, 1991, p. 118).*

Patients' hope processes contribute to their physiological wellbeing and hope is considered to be critical for their survival. This viewpoint has been expressed by a cross section of writers from the nursing field (Moadel, 1999; Nowotny, 1991), psychology, (Cheavens et. al., 2005; Scheier & Carver, 2001) and less so from the field of medicine (Macleod & Carter, 1999). Patients facing a potentially terminal illness such as cancer often struggle to sustain their hopes in light of overwhelming circumstances.

Hope as a science

According to Jaklin Eliott's (2005) comprehensive historical overview of the construct of hope, "hope reached a critical mass, and [became] a self-sustaining industry" (p. 27) in the twentieth century. She pointed out that hope became a science with 'truth claims' within the medical discourse. Medicine, which she viewed to include the nursing profession, assumed dominance in discussion about the topic of hope in her review of the history of hope literature.

Within this medicalised conceptualization of hope, health care professionals strongly believe that it is necessary to provide support for patients' hopes and provide interventions to patients, by doing hope work or 'hope therapy'

(Farran, Herth & Popovitch, 1995). For example, nursing researchers, Farran et al. (1995) published *Hope & Hopelessness: Critical Clinical Constructs,* which offered nurses, chaplains and social workers a handbook on the application of hope interventions, which included using hope/hopelessness assessment scales.

Hope as therapy

Intervening and treating patients' hopes dominated discussions in the literature sampled (Benzein, 1998; Eliott & Olver, 2002; Farran et al., 1995; Peterson, 2004; Scheier & Carver, 2001). For example, Ronna Jevne,[5] a psychologist and well-known hope researcher, focused on the practical application of hope theory and intervention strategies to enhance hope for those who experience despair. There were numerous articles that drew attention to the health care providers' role in *instilling, sustaining, engendering, fostering, restoring, enhancing and conveying hope to* patients. These articles assume the presence of hope in the *relationship* between the health care provider and the patient, which supports my exploration of the relational aspect of hopework.

Eliott & Olver (2002) noted that hope was engendered in the interactions between doctors and patients. Furthermore, patients' hopes were primarily influenced by their interaction with doctors. Nurses, clergy, and social workers were less influential to patients' hopes, but still had an impact on their hopes (Flemming, 1997). Patients were hopeful when they encountered a positive

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[5] Jevne is a Professor Emerita in the Department of Educational Psychology at the University of Alberta and founding member of the Hope Foundation of Alberta.

attitude from the health care provider (Benzein & Saveman, 1998). These articles highlight the importance of health care providers' ability to sustain a hopeful orientation in the presence of hopeless situations (Jevne & Nekolaichuk, 2003, p. 197). The literature trail becomes undefined and threadbare at this juncture of research as to *how* health care providers (HCPs) are expected to sustain their own hopes while providing care for people who are dying.

Elusiveness of Hope definition

Despite increasing research into examining hope, the definition of hope eludes consensus amongst hope researchers (Eliott, 2005, p. 27). Perhaps the oft-quoted definition offered by nurse researchers Duffault & Martocchio offers the most inclusive hope definition, as it acknowledges its multifaceted and multidimensional qualities:

> *...hope is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person is, realistically possible and personally significant. (Dufault & Martocchio, 1989, p. 380)*

This study focuses on exploring the relational dimension of hope, that is, the hope processes that transpire *within* the health care provider and how these internal processes of hope impact on the relationship with patients facing end of life. The inner psychodynamic process of hope, or hopework, has a powerful impact on relationships. Health providers' internal hopework can change, for better or worse, patients' perception and understanding of their condition. This causes patients to reflect on their physical and psychological pain and suffering and can ultimately impact on their desire to live or die.

THEORETICAL PERSPECTIVES ON HOPE

Nurses prominently contributed to the literature pertaining to theoretical concepts of hope (Parse, 1999; Farran et al., 1995; Dufault & Martocchio, 1989), and are leaders in investigations in the 'science' of hope. Nurses' frontline exposure in providing palliative care to dying patients makes concepts of hope an understandable area of interest and concern to the nursing profession. Articles were categorized to broadly to reflect the main theme. Some articles reflected more than one perspective, or were co-authored by multi-disciplines.

From a disciplinary viewpoint, it was interesting to note that clinicians' hopes were theorized primarily by social work practitioners (see Table 1 in Appendix B). Considering the limited contribution of the social work profession to the overall hope literature, it is significant that social workers like myself consider the clinicians' hope worthy of investigation and discussion. I attribute this interest in the clinicians' hope to the social work profession's value of self reflexivity in practice. The following theoretical perspectives from the literature provide scaffolding for the current research.

Hoping as a process

The concept of hope can be construed in many forms. It can be perceived as an emotion, a feeling, a future orientation, a spiritual value and undefined:

HOPE is the thing with feathers
That perches in the soul
And sings the tune without words
And never stops - - at all.

Emily Dickinson

The following research provides a theoretical 'backdrop' on *hope as a process* to support my focus on health care providers' hopework.

Nurse researchers Dufault & Martocchio (1989) defined hope based on their qualitative study of cancer patients. Their observations identified two spheres of hope: *generalized* hoping--- an overall feeling of hope which is not attached to anything tangible, and *particularized* hoping, which is attached to a particular object of hope (Dufault & Martocchio, 1989, p. 380). The hope processes were theorized to be influenced by the hoping person's sensations and emotions (*affective*), perception of hope (*cognitive*), actions as a result of hope (*behavioural*), hope in relationships with others (*affiliative*), hope in the context of past, present and future (*temporal*) and hope in the context in which hoping persons situate themselves (*contextual*) (Dufault & Martocchio, 1989).

Farran, Herth & Popovich's (1995) work further examined hope as a process that can be experiential, spiritual, rational and relational. *The Clinical Constructs of Hope and Hopelessness* was based on their collective years of nursing in end of life care situations. Their contribution to the hope literature defined four central attributes of the hope as being: an experiential process (*pain of hope*), a spiritual or transcendent process (*soul of hope*), rational thought process *(mind of hope)*, and finally, the area I wish to explore, the relational process, which they termed *the heart of hope* (Farran et al., 1995, p. 6).

In Farran et al.'s extensive review of the literature, they were only able to identify two studies pertaining to the hope of health care professionals: a grounded theory study by Owen (1989) who reviewed the experiences of six oncology nurses in the U.S. and their work with cancer patients, and a Finnish ethnographic study by Perakyla (1991) who observed the hope work done by health care professionals in the context of three seriously ill patient populations. Additional comprehensive literature reviews conducted by Macleod and Carter (1999) and most recently, Eliott (2005) confirmed the paucity of studies about the hope processes, or the *hopework* of health care providers. The primary focus in the health care literature remains focused on patients' hopes rather than on the hope of health care providers. It is my intention to view health providers' hopes within the relational perspectives identified by the previous authors.

Relational view of hope

Psychologists developed a theoretical conceptualization of hope within the relational context (Snyder, Cheavens & Michaels, 2005; Averill & Sundararajan, 2005; Eliott & Olver, 2002; Clayton & Butow, 2005). Hope was identified as a process rather than just being an emotion (Snyder et al. 2005). Hope was theorized to have a purpose or goal and a sense of agency. This 'pathways thinking' hope theory has been embraced in current hope intervention practices whereby health care professionals encourage patients to identify hope goals to aspire to (Benzein, 1998; Elliot & Olver, 2002). This concept of the hope process assumes the belief that HCPs should participate in "shaping realistic hopes" (Clayton & Butow, 2005, p. 1973) and guide patients in their cancer care.

A relational viewpoint of hope as being co-constituted with others in a relationship was presented by Parse's (1999) nursing theory. Her human-becoming theory viewed patients' quality of life as unique to their experience as human beings. In her view, the patient and what they deemed important and meaningful in their care, should guide nursing practice. Her human becoming approach used a dialogic approach to *do with* patients and work with their hopes. This is different from the conventional bio-medical approach and the bio-psycho-social-spiritual approach of 'doing to' patients (Cody, 2007). In this patient-centred approach, she views people from a holistic and relational framework and acknowledged that meaning and reality can only be defined uniquely by the person who is affected by the experience. Parse's recognition of individuals' unique constructs of hope was further expounded upon by other authors who viewed hope as a social construction (Saleeby, 1996, Parker-Oliver, 2002). According to Parker-Oliver (2002), hope is entrenched in meaning. As long as there is meaning, hope will exist (Parker-Oliver, 2002, p. 116).

Hopework of the health care professional

Clinicians' hope processes were discussed peripherally in the literature despite health care providers' significant impact on patient's hopework in the health care setting (Benzein & Saveman, 1998; Eliott & Olver, 2002; Miller, 1989; Jevne & Nekolaichuk, 2003; Penson, 2000). According to hope researchers, Jevne & Nekolaichuk (2003), there is a *"need for caregivers to examine their own hope --- hope work is not something that professionals do to patients. Both the health care provider and patient are key to harnessing the power of hope*" (p. 197). Links and Kramer (1994) noted that health care providers' attitudes had a more significant impact on patients than the bad news itself. Cancer patients felt more hopeful from their interactions with "confident, collaborative, and supportive" health care professionals (Hagerty et. al., 2005, p. 1284). This begs the question of how HCPs engage with their own hopework in the literature.

Some insight exists, particularly amongst hospice doctors, about the need for health care providers to be more aware of the significance of hope in healing and to be more self- reflective in their approach to engendering hope in palliative patients (MacLeod & Carter, 1999). Brookbank & Cassell (2005) expressed in their opinion paper that health care providers can better understand their own hopes as they consider the hopes, desires and expectations of their patients (p. 239). This reference to the HCPs' practice of self-reflection and understanding as to how their own hopes impact on patients' hope in the context of their relationship, recurs in the literature contributed by social workers.

Social work perspectives in reviewed literature

There is a dearth of literature on hope from a social work perspective, particularly within the dimension of health care and end of life. David Callan (1989) focused on the social processes of hope and clinical interventions during the late 1980's. He offered a rare social work perspective which seemed to remain the solitary social work contribution in the area of palliative care until almost a decade later. Callan based his clinical opinions on Viktor Frankl's meaning focused therapy and advocated raising the visibility of hope in clinical practice. He identified hope as a clinical issue in counselling patients. The article focused on the clinicians' role in helping patients gain insight into how they might live through the ambiguities of life-threatening experiences such as cancer (Callan, 1989, p. 45).

Since Callan's article, the literature suggests that social workers tended to write about clinicians' hopes, rather than about patients' hopes. Social worker Ann Schecter (1999), for example, interviewed three non- medical social workers on how they were able to sustain their hope in work fraught with adversity and challenge. Parker-Oliver's clinical opinion (2002) provided a conceptual framework for social workers to define hope for themselves; however, she ultimately focused on interventions for patients rather than for the health care provider. Zilberfein & Hurwitz (2003) emphasized through case examples how clinicians can build emotional tolerance through self-examination, in order to support dying patients.

Further investigation into social work data bases revealed an opinion paper by Itzhaky & Lipschitz-Elhawi (2004) whose literature review confirmed that social workers' hopes have not been studied. Their opinion paper focused on ways to encourage the hope of social workers of terminally ill patients. They believed that therapists' reactions to patients' helplessness impacts on the patients' ability to overcome their sense of hopelessness (Itzhaky & Lipschitz-

Elhawi, 2004, p. 46). More recently, a collaborative commentary by Larsen, Edey & Lemay (2005) (social work, psychology and nursing) addressed the need for health care providers to work with their own hopes (p. 517).

Notably, the literature authored by social workers generally relies on clinical opinion (Callan, 1989; Itzhaky & Lipschitz-Elhawi, 2004; Parker-Oliver, 2002), casework experiences (Zilberfein & Hurwitz, 2003), and patient narratives in the field (Schecter, 1999) to illuminate their understanding of the hope process. Although this observation may be skewed by the few articles authored by social workers found in this review. Five out of the seven articles that was ultimately reviewed, written by social workers were clinical opinions or theoretical concepts of social workers based on case experiences (Parker-Oliver, 2002; Monroe, 2003; Saleeby, 1996; Zilberfein & Hurwitz, 2003; Callan, 1989), and only two were qualitative research studies, based on narrative interviews and grounded theory respectively (Shechter, 1999; Ridgway, 2004). In comparison, six of the twelve articles by nurses were based on primary qualitative research, using techniques such as hermeneutics (Benzein, 1998), interview (Miller, 1989; Thorne et al., 2006), surveys (McNeal, 1997; Moadel, 1999) and participant observation (Dufault & Martocchio, 1989).

This practice-generated knowledge is common in the social work profession, complements research-generated knowledge, and respects the *many ways of knowing* that stem from bringing forth practice wisdom from clients' lived experiences (Hartman, 1994; Reid, 1994). In comparison, health professionals (nurses and doctors) whose roles seem strongly defined within the context of the medical structures in which they work used more research-generated knowledge in the discussions on hope, as evidenced in the literature reviewed.

Summary & discussion of literature review

In spite of the proliferation of research on the topic of hope in the past 20 years (Eliott, 2005), there appears to be limited research about health care providers' hopes and how this impacts on their relationship with dying patients. Consequently, this topic warrants further exploration. Furthermore, a social work perspective on hope in the palliative care setting was rare.

One could argue that social work perspectives on hope could and would be better represented in the health care literature if social workers engaged in more research in this area. Social workers need to value the potential that research can provide in substantiating their practice wisdom and in giving voice to their depth of knowledge and understanding about the human experience. This voice is ever important in the cacophony of other viewpoints offered within the medical discourse. This current research is an example of such an endeavour.

As expected, all the articles written about hope by nurses were in the context of end of life and cancer, whereas three of the articles written by social workers were more 'global' in nature, addressing hope in the context of working with adversity and challenge (Shechter, 1999), hope and resilience (Saleeby, 1996), and hope and mental health recovery (Ridgway, 2004). The wisdom that emerged from these articles written outside the realm of palliative care was completely relevant to end of life care practices. The transferability of these life skills and wisdom about social processes and relationships in social work practice supports the potential of shared practice wisdom and knowledge translation between disciplines and areas of practice.

MacLeod & Carter (1999) aptly observed that physicians have not integrated knowledge about the value of hope into their practices, despite supporting evidence as to its value. The lack of articles in the sampled literature reflecting physician perspectives on hopework juxtaposes research which reveals that patients' hopes are strongly linked to their relationship with their doctors (Thorne et al. 2005; Hagerty et al. 2005; Clayton et al. 2005). This reiterates the need for health care professionals to be mindful of their own hopework in order to address patients' hopes. Patients would benefit from physicians' ability to attune to their own hope processes and awareness of how their hopes significantly impact on the patients they care for.

CRITICAL SOCIAL WORK PERSPECTIVES ON HOPE LITERATURE

The review of the literature on hope identified the following themes: 1) Hope doing & hope being; 2) The multiple realities of hope; 3) Medicalisation of hope and 4) Collaborative views on hope. The following discussions address concerns from a critical social work perspective concerning the current discourse about hope in the literature.

Hope doing & hope being

Much of the hope literature pertaining to end of life care focused on health care providers directing hope interventions towards patients (Eliott, 2005; Farran, et al. 1995; Macleod & Carter, 1999).[6] The literature assumes an obligatory sense of responsibility by HCPs to only intervene in the hoping process for palliative patients whose hopes had been 'lost', 'destroyed' (Thorne et al., 2006) and 'killed' (Ridgway, 2004). In the nursing literature there was a particularly strong element of ownership and responsibility to help patients maintain their hopes. This observation was echoed by Eliott (2005), who noticed a marked increase in articles that instructed medical staff, particularly nurses, to modify patients' hopes (p. 37). Benzein et al. from Sweden emphatically stated: "hope is a nursing role"; they considered nursing actions and treatment as means of fostering hope. Hope was perceived as doing to patients and based on professional duties, rather than being client-centred. Penson (2000) who represented a U.K. hospice nursing viewpoint, demonstrated this 'doing' stance by insisting that nurses inspire hope through their attitude and behaviour. A

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[6] See Appendix C for an overview of hope interventions in the reviewed literature.

clinical opinion offered by physician authors adopted the following stance, assuming the singular knowledge that:

> *[Patients] require our strength and our sustenance to maintain a future vision of themselves…and the expectation that in the future they will not lose themselves to the depredations of sickness (Brooksbank & Cassell, 2005, p. 239.)*

Some of the interventions discussed seemed formulaic, or prescriptive in tone. For example, Nowotny's (1991) hope assessment scale regards hope as a 'true vital sign' that used goal and task-oriented strategies to help patients cope with loss of hope. Numerous hope assessment scales (Gottschalk, 1993; Herth,1989; Snyder, 1991) suggest an approach to hope that is congruent with the positivist, scientifically orientated, biomedical model of health care (Farran, Herth & Popovich, 1995).

In contrast to the foregoing focus on patients' hopes, the social work literature focused on health care providers' examination of their own process in working with palliative patients. This literature delved into clinicians' hopework as they worked with clients facing challenging, life-altering circumstances. The focus on the self-reflexivity of the HCP acknowledged how patients' hope can be shaped in the relationship between the patient and HCP. This practice of self-reflection enabled health care providers to explore their personal views, limitations, biases and feelings about their own hopes and how their hope processes impact on their relationship with their patients.

Social workers, like their colleagues in other disciplines, perceive that they have a role in doing hopework with patients' hopes. Yet, the literature noted that rather than 'doing for' or 'fixing' patients' hopes, their hopework focused on supporting the patients' *process* of hope. The social worker's role in this context was identified as: 'holding' and creating a safe space for patients to find ways of maintaining their hope and remain engaged in life (Zilberfein, 2003, p. 318). Acknowledging the clients' process and providing 'scaffolding' to enable patients to cope (Ridgway, 2004; Zilberfein & Hurwitz, 2003) was an important part of the hope intervention. This suggests that the practitioner is less invested in being responsible for the *outcome* that befalls the client, but remains available to provide meaningful support to them. This viewpoint, reflected in the literature, is supported by the findings of the current study.

The multiple realities of hope

An important aspect of this literature review was to acknowledge the 'spaces in-between' or the silences in literature pertaining to the topic of hope in end of life care. This discussion draws attention to what has not been represented in the literature. Foucault pointed out that representation is:

> *That which can be cast in a quantifiable and scientifically rigorous form. Usually, the attempt is made to define it [positivity] in terms of mathematic: either by trying to bring it as near to mathematics as possible, by drawing up an inventory of everything in the sciences of man that is mathematicizable, and suppose that everything that is not susceptible of such a formalization has not yet attained to scientific (Shawver, 1999, p. 363).*

There are many valuable and important issues about hopework that may not be 'mathematicizable' yet warrant further attention and discussion, because they *do* exist. For example, cultural differences and differences in beliefs regarding hope are poorly represented in the literature and not easily susceptible to formulization. A study on the disclosure of poor prognosis determined that English-speaking cultures often prefer ‘realism’ in their prognosis, whereas other cultures may not (Hagerty et al., 2005, p. 1285). This perspective assumes that other cultures share the same concept of realism as the dominant culture, while ignoring *difference* and the existence of multiple realities and truths (Hick, Fook & Pozzuto, 2005). Averill & Sundararajan (2005), however, provided some insight into the theoretical differences between Eastern and Western concepts of hope.

The authors found that Westerners tend to base their hopes on finding solutions and coped by *outwardly* doing and setting goals, whereas Easterners (ie. Chinese and Koreans) directed their attention to *inward* coping and “self-cultivation of optimism” (p. 136). This differing cultural perspective strongly impacts and affects not only the way in which HCPs view patients, but also the way in which we as researchers and practitioners construct hope. Consequently, the hope interventions formulated by professionals (Snyder et al., 2005; Scheier & Carver, 2001; Clayton & Butow, 2005; Benzein & Saveman, 1998; Nowotny, 1991) closely reflect the Western concept of ‘doing’ and goal-setting and may be incompatible to the needs of clients outside of the dominant Western socio-cultural discourse. This has practice implications for our increasingly diverse and heterogeneous population of patients facing end of life issues.

From a personal perspective, as a person with epistemic origins based on non-mainstream cultural values and beliefs, these cultural issues have a significant impact in my practice of hopework. My ability to see hope in an 'ambiguous' way enhances my ability to maintain a critical perspective of hopework and hope at end of life care. Although I did not elaborate on the ethnic and cultural background of the HCPs in my study, some members of cultural minorities were interviewed. At one point during an interview, a HCP respondent commented to me, in recognition of our mutual Asian heritage: "*because of where we are from, there is a sense of acceptance [of dying for patients].*" This comment referenced to the sense of 'inward coping' and self-cultivation of hope that Averill & Sundararajan, (2005) described so well in their study. It was a different way of managing hope than is normally conceptualized in Western discourse. I affirmed this comment made by the health care provider interviewed, acutely aware that I knew what the comment was about. I pondered over what to do with this piece of data visible to me only because of who I am and what I represented to the health care professional at the time of the interview. It would have been convenient to ignore this information that reflected the existence of difference viewpoints on hope, other than the one represented within the Western, mostly medical discourse on hope.

Nowotny (1991) and Farran et al.(1995), who authored foundational studies on the topic of hope, acknowledged their Judeo-Christian perspectives on hope. Whether or not succeeding authors choose to divulge their beliefs and values, and whether or not they recognize the importance of taking a critical stance, their ontological viewpoints will have a bearing on subsequent perspectives on the topic of hope. Generally, the literature revealed an adherence to the mainstream discourse of health, healing and understanding of hope. It is paramount that health care providers recognize that hope processes are unique to what is important to the patient, by taking a patient-centred approach. The patient-centred approach taken by Parse (1999), or the inherent client-centred approach in social work practice, ensures that the 'hope-doing to others' approach that prevails in the hope literature, meets the unique needs of the patients we care for, rather than serving our own purposes.

Medicalisation of hope

Patients' hopes are often unacknowledged and peripherally regarded because the concept of hope is difficult to define and not viewed as a resource to be valued. If hope is recognized as an important construct, it is often medicalized and pathologized. It seems that having *too much hope* or *too little hope* can be 'problematic'.

The construct of hope has been subsumed within the realm of medical discourse, as evidenced by increasing interest in the study, assessment, measurement, and intervention of patients' hopes (Eliott, 2005, p. 38). Interventions to engender, foster, restore, maintain, instill, and enhance hope imply that hope is missing or in need of adjustment and treatment. There is, however, a silence around the complicity of HCPs' role in diminishing patient's hopes. The medical focus of looking at hope from a deficit viewpoint or "pathology paradigm" (Ridgway, 2005, p. 289) obscures the HCPs' ability to recognize that loss of hope can be prevented through improving the HCPs' understanding of hope processes.

The biomedical culture of valuing evidence predominates in the mainstream culture and impacts the hopes of HCPs' and patients alike. For example, in the medical discourse, numbers represent a powerful means of foretelling life events, and health care professionals are the interpreters ascribing meaning to these events, within the framework of *their* reality. Health care providers and patients attribute different meanings to the numbers used in discussions about prognoses (Thorne, Hislop, Kuo & Armstrong, 2006). The study by Thorne et al. (2006) demonstrates the powerful need for the human spirit to find hope within their perception of reality:

> *…the underlying effort on the part of all of the patients--- to develop, retain, and sustain hope. Whether that hope specifically referred to disease survival or to some other desired aspect…., numerical information was powerfully associated in the patient's accounts with the desire to be hopeful and to have that hopefulness supported through reference to grounded, credible , and "reality-based" possibilities (Thorne & Hislop et al., 2006, p. 327).*

This study revealed how numbers are potent in creating, sustaining and destroying hope in the hands of the health care professional (Thorne et al., 2006) p. 333). To the authors' credit, they recognized the competing truth claims that patients face in making meaning of their prognosis. They identified the importance of the health care relationship as a means of engaging patients in a dialogue about their hopework (Thorne et al., 2006, p. 334).

Health care providers ascribe meaning to life events for patients by framing these meanings according to their biomedical perspectives. These events are significantly marked by our scientific ability to measure, screen and prognosticate the physical, the psychological, the state of our spiritual condition and hope. We have expectations that the complexities of hope are quantifiable, measurable and treatable. We assume that we can *know* what hope is about and identify 'truth claims' about it. The medicalisation of hope itself remains invisible to those who work within the biomedical discourse. Much of the literature on hope is based on the biomedical paradigm.

An interesting ethical issue emerges as to whether hope should be 'prescribed' (Jevne & Nekolaichuk, 2003; Eliott & Olver, 2002). If the clinical use of hope is deemed valuable, should psychosocial treatment be routinized for all patients diagnosed with life-threatening illnesses? Who benefits from this promotion of the self-regulation of hope? A social worker offers what appears to be a medicalizing viewpoint of hope:

> *Hope instilling practice will empower people individually and collectively, both inside and outside the mental health system. It will help people build their resource base and personal assets; it will provide effective programming; and, it will put self-management tools in the hands of consumers. (Ridgway, 2005, p. 288)*

Health care providers are challenged to accept hope in its messy, undefined, unpredictable and mysterious state of being without feeling the need to fix or improve---what is *just right* for the hoping individual. This post-structuralist viewpoint supports an inclusiveness and receptivity to 'difference' and avoids assumptions that we can impose our values and knowledge on others by reifying hope.

Collaborative views on hope

An overview of the hope literature by the various health disciplines illustrated the breadth and magnitude of how themes of hope permeate health, illness and dying. Intrapsychic and internal dialogues of patients' hopes were defined mainly by psychologists and to a lesser extent, other disciplines (Nunn, 2005; Snyder et al. 2005; Averill & Sundararajan, 2005). The interpersonal and social processes of hope addressed by social workers, add further insight to understanding how hope is socially constructed (Saleeby, 1996; Parker-Oliver, 2002; Schecter, 1999). The nursing perspective explicated further, our theoretical understanding of hope and the development of hope interventions. The sparse literature representing doctors' perception of hope and the hopes of their patients leaves plenty of room for further exploration. Unfortunately, the lack of dialogue between disciplines to collaborate their various perspectives on hope, forestalls incorporating hopework into the practice arena (Macleod & Carter, 1999).

Elliot (ed., 2005) recently published a collection of interdisciplinary views on hope by well known hope researchers, who were amongst the authors reviewed for this study. This unique compilation of interdisciplinary perspectives signified a beginning for this process of sharing views on the processes of hope. A social work perspective was noticeably absent from this collection of writings. Even as the social work profession embodies hopework through envisioning possibilities and positive change for their clients, there is currently little written by social workers on the topic of hope, even *within* social work literature. There is certainly great potential for social workers to elaborate and share their practice wisdom with their interdisciplinary counterparts.

Ridgway suggests, in her dissertation on hope in the area of mental health, that a new paradigm of knowledge is needed to integrate models of hope towards a holistic ecological model (Ridgway, 2005, p. 279). This suggestion is particularly applicable in the area of health and end of life care, where a holistic view of the patient encompasses body, mind and spirit within their social world. There is much potential for disciplines to engage in sharing their perspectives on how the needs of the hoping patient can be best met.

Patient-centered care, rather than discipline- focused research, will encourage and strengthen interdisciplinary teamwork. Hopework is not about which profession has the right version of hope, or the best assessment framework for hope, but about what matters to the patient, and the meaning they ascribe to their situation. *Meaning-making* becomes deeply and critically important for dying patients. Collaboration across disciplinary 'silos' of knowledge would ultimately provide opportunity for improving care to palliative patients. Social workers' client-centered focus and global perspective of the needs of patients in the context of the health care system (Monroe, 2003) allows them to contribute their views on hopework in a way unique to the discipline and thereby be of value in sharing with other disciplinary practices.

RESEARCH PARADIGM

Introduction

A grounded theory approach was undertaken to explore the psychosocial processes of hope amongst health care providers (HCP). Adaptations of the original GT methods (Strauss & Corbin, 1990) by grounded theorists such as Charmaz (1990; 2006) and Clarke (2005) were consulted in this process. The social constructionist approach (Charmaz, 1990) that considered participants' construction of their reality, experiences, values and priorities was used in my exploration of HCPs' experiences. This approach acknowledges the multiple realities of how participants construct and view their world. This study focuses on how HCPs construct their experiences of hope in their work caring for cancer patients facing end of life.

My dual identity as a researcher and clinician in the place of study necessitates that I adopt a reflexive stance in my research. Constructivist grounded theory acknowledges the co-construction of data that stem from the relationship between researcher and the participants (Charmaz, 2006, p. 131) to enrich the research process, rather than being problematic. This constructivist stance broadens the view of how reality is constructed; 'facts' and 'truths' can be linked to values held by individuals' beliefs and broader discourses.

Clarke (2005) further elaborates on this broader perspective of 'social worlds/arenas/discourses' from a post-structuralist viewpoint. She employs her situational analysis methods to acknowledge the "ecological relationships" of the studied phenomena (p. 10). She views data from the micro relations viewpoint as it interfaces with issues at the macro level - the personal is connected to the political (Clarke, 2005, p. 10). In the context of my research, Clarke's (2005) situational analysis approach allowed me to map the individual hope experience of HCPs in relation to how it interfaces the broader medical discourse. This analytical framework enabled me to map out how research conducted at the micro patient care level can potentially impact on macro-level medical structures and biomedical viewpoints. Clarke's (2005) methodological approach to extends data analysis to social worlds and arenas (p. 48) is similar to the systems approach used in capturing the 'big picture' in social work assessment practices. The use of this 'mind map' provides a framework for conducting research which acknowledges the pervasiveness of the medical discourse in my attempts to conduct research 'that makes a difference' for patients and HCPs.

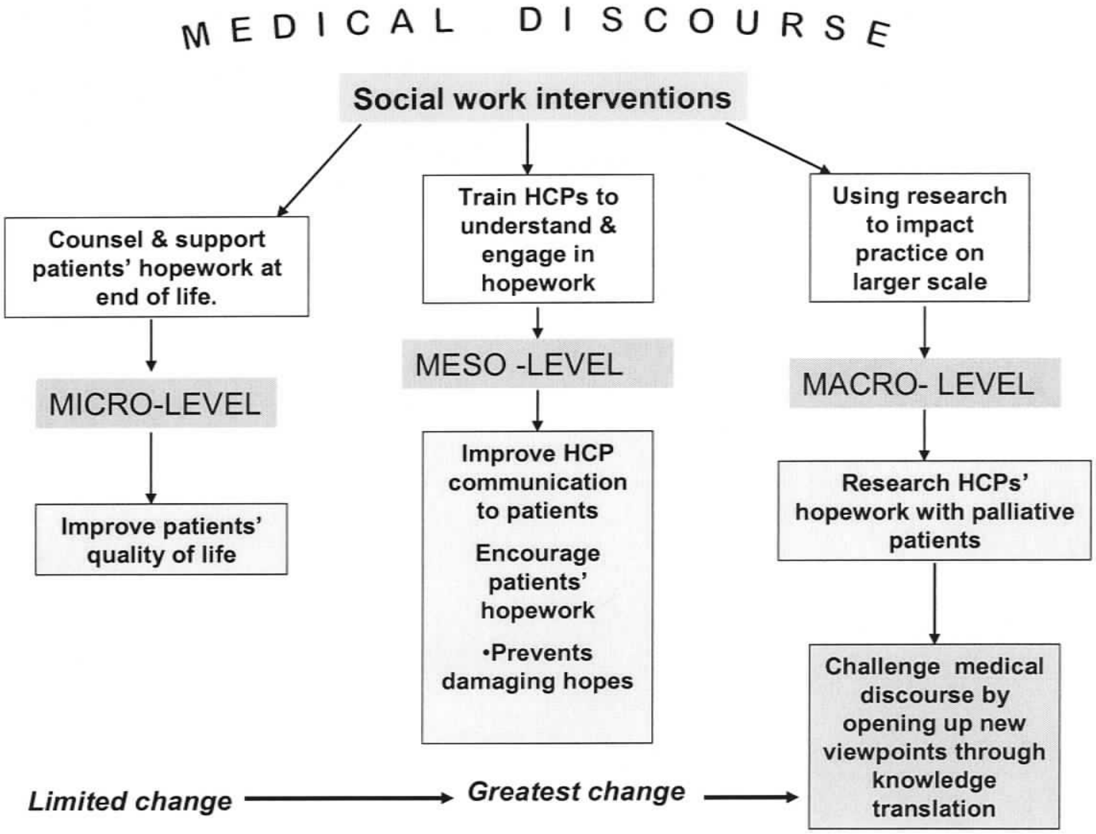

Figure 1: 'Mind map' of analyzing social work intervention on hope

METHODOLOGY

Sample selection

In this grounded theory study, HCPs were selected to best inform and contribute to theory development regarding the concept of hopework (Ritchie & Lewis, 2003). The individuals selected were representative of HCPs working with palliative patients in an oncology setting to represent the fullest range of factors. Physicians, nurses and social workers/counselors were equally represented in the sample group for this study. Respondents were selected to represent a range of experiences from each professional group to allow the researcher to gain a broad perspective on HCPs' perception of their work with patients facing end of life.

An initial pilot study that I conducted on the psychosocial experience of cancer clinic social workers/counselors working with palliative patients (Wong, 2005) provided a basis for further investigation of other HCPs' experience. Data from the pilot study suggested potential theories about HCPs' hope processes. The data collected from the pilot study was included in the current research with permission from the original participants. The diversity of individual characteristics of the respondents in this study elicited important and relevant information to be elicited from the participants (Ritchie & Lewis, 2003, p. 83). Efforts were made to optimize the sample selection with the greatest diversity of participants in spite of the limited sample size. The following table summarizes respondents' demographic and work information pertinent to this study:

Table 2: Demographics of health care providers in study

	Current study			**Pilot study**
	Physicians	**Nurses**	**Social workers**	**Social workers/ counsellors**
Male	2	-	1	-
Female	1	3	2	3
Age range	30 to 65	30 to 50+	49 to 55+	30 to 55
Years of practice	6 to 34	<5 to 23+	10-25	<2 to 23
Work context (range)	Medical & radiation oncology	Cancer treatment in Cancer clinic & In-patient cancer ward	Psychosocial oncology - private counselling practice	Psychosocial oncology
Work status	3 full-time	3 full-time	1 full-time 2 part-time	3 part-time
TOTAL: 12	3	3	3	3

Physicians, who practiced medical oncology, as well as radiation oncology, were chosen to ensure a representation of different experiences in medical practice. Physicians and nurses were selected for their exposure to patients facing end of life issues in their day to day work. By selecting HCPs working with cancer patients who had poorer prognoses (lung, ovarian, pancreatic and liver cancers), I was ensured that respondents were able to offer insight about working with palliative patients. There were fewer social workers to draw upon and most were engaged in generalist practices; some had higher caseloads of palliative patients than others due to their assigned cancer sites. Most respondents worked with palliative patients on a daily basis. All had exposure to providing care at end stages of cancer, although caring for patients at the end stages of life is not a routine experience for staff at the cancer clinic, as it is an outpatient treatment facility.

When possible, participants not well known to me were selected for this study, in order to minimize expectations from any past relationships with the participants. Although I was well-acquainted with members of the counselling team, a senior oncologist (now retired) and a senior nurse. I was only casually acquainted with the remainder of the respondents and not acquainted at all with one physician and a nurse.

Relationships with doctors, nurses, chaplains and social workers were determined to be the primary health care relationships impacting cancer patients' hopes (Koopmeiners et al., 1997, p. 1509). Palliative patients felt that doctors most influenced their hopes amongst HCPs, followed by the nurses, who addressed patients' day-to-day concerns and were privy to patients' hopes in these interactions (Koopmeiners et al., 1997). Clinic social workers and counselors addressed the psychosocial/spiritual issues of patients' transitions into palliative care and provided support to patients as they coped with life-threatening diagnoses.

Respondents reflected a range of experience in oncology practice from entry level practice (one year) to thirty four years of clinical work. Each discipline was represented by both new and well- experienced practitioners in an attempt to capture differences in clinical experience and training. Data collected on these diverse disciplinary perspectives provided "thick descriptions" (Hartman, 1994) that optimized understanding of HCPs' hope processes.

METHOD

Recruitment

Respondents were informally recruited and identified according to their practices in medicine, nursing and social work and exposure working with patients facing end of life. These initial contacts ‘snow-balled’ into interviews with other HCPs, as respondents suggested others who may be interviewed to diversely represent HCPs. The study was introduced to potential respondents via email with an information/consent form attached that explained my research interests (Appendix D). HCPs were invited to respond by email, or to call my home phone number. The email stressed the voluntary nature of participation in the study; this option was further reiterated during the interview.

Efforts were made to accommodate the HCPs’ schedule, as I was aware of the time constraints they faced. Three HCPs found it convenient to be interviewed at home and one chose to be interviewed in their office at the centre. The remaining HCPs were interviewed in counselling offices affording a quiet comfortable space away from patient treatment areas. The nurses and one doctor were particularly appreciative of being away from the busyness of the clinic.

A different strategy was employed in the recruitment of counselling staff. Several social workers/counsellors were previously interviewed for the pilot study (Wong, 2005). These HCPs granted further permission for their data to be used for the current study. Permission was obtained verbally and another consent form was signed, in order to clarify the parameters of the use of their data in the current study (see Appendix E – Consent form). Two more social workers volunteered to be interviewed following an announcement at a staff meeting. I was the third social worker 'recruited' to be interviewed in this process.

Consent

Each participant was given a combined consent/information form (Appendix D) to review at the beginning of their individual interviews. Participants had a chance to read the consent and study information prior to our initial meeting. Respondents were given a minimum of 24 hours to consider their participation in the study so they would not feel pressured to participate. Only one doctor declined to participate in the research.

Respondents appeared to be 'casual' about their involvement in the study and expressed no concerns about others in the workplace being aware of their participation. Most participants expressed keen interest as to the outcome of the study. People were offered an opportunity to debrief and meet others who participated in the study. This offer was met with only mild interest and I suspect that time constraints were a factor. The HCPs expressed interest in having an in-service meeting where the results of my research on hope would be shared.

Interview data

Interviews were conducted over a four week period. I began by interviewing senior practitioners whom I knew to gain confidence in the process and to test the fluidity of the questions and topics. These individuals helped with the snow ball sampling. All respondents authorized the audiotaping of their interview. Field notes were made following interviews. Observations and notes made after each interview helped in particular, to reconstruct an interview (N3) that had been cut off in the taping of the interview. I transcribed all but three interviews. The hired transcriptionists were required to sign a note of confidentiality for their services.

Interviews adopted a conversational tone, to encourage respondents to be introspective and engage in personal reflection. The interviews were flexible, fluid and sought to pursue, elaborate and illuminate participants' hope experiences (Charmaz, 2006, p. 57). Semi-structured questions and prompts invited participants to talk about their experiences in working with palliative patients. The interview process was optimized by my simultaneous collection and analysis of information pertaining to hopework (Gilgun, 2001). Observations of processes and themes that evolved from the interviews were noted after each interview. At the end of the interview, respondents were invited to further question or comment on the topic or express other concerns related to the topic. The interview process provided a unique opportunity for the HCPs to express their professional and personal views on a topic rarely addressed in their health setting, yet, significant in their work with palliative patients. I surmised that the inquiry and interview process itself may have provided health care providers an opportunity to gain insight about their own hope processes and how they can participate in patients' hopework.

Questions about certain aspects of hoping or coping became more comprehensive as subsequent interviews evolved. Insights gleaned from previous interviews were further investigated in subsequent interviews. This stimulated thoughtful responses from the respondents and further engaged them in active discussion on the topic while they considered information and concepts that emerged in previous interviews. The richness of the data collected, and the emergent theories developed lent profundity to the study. However, given the evolving nature of the process of hope, theoretical saturation was unlikely (Gilgun, 1994, p. 118).

In the self-interview, I engaged in a dialogue with the interview questions and prompts outlined in the interview guide (see Appendix F). I typed responses to the questions and engaged in a Gestalt –like dialogue with the question-asker. I asked questions for clarification and engaged in the interview as both respondent and researcher. The process of self-interview was positive and enlightening: a) I was able to share my practice experience as a clinician; b) I gained insight about the impact of my personal questions on recruited respondents; and c) I was able to adjust and ask better questions. I noted, however during data analysis, that I did not achieve the depth of answers in the self interview as compared to the other interviews. I was not able to deeply delve into my clinical experience through the self-interview process, because I was focused on answering questions without taking the liberty to elaborate or go beyond what I was asked. In hindsight, my self-interview might have been more effective if someone else had interviewed me, thereby encouraging deeper reflection.

Participants from the original pilot study were not re-interviewed, although the transcribed data and accompanying field notes were re-examined anew from the viewpoint of the current study. The initial study focused on the psychosocial experiences of social workers and counselors working with palliative patients. The richness of the data, themes and processes that emerged from this pilot study directly resulted in the impetus for the current study's focus on hopework. An iterative process of comparing information that emerged in the current study with the pilot study optimized the use of interview data from the initial study.

Additional data sources

Grounded theory expands upon conventional ways of gathering data by adopting a philosophy that "everything is data" (Charmaz, 2006, p. xii). I explored data from other sources to gain different perspectives on respondents' actions (Charmaz, 2006, p. 19). This additional data provided a means of triangulating the interview data by adding further insight to the processes observed. Extant texts of health care professionals' anecdotal accounts of their hope experience or other research literature further enhanced the analysis of respondents' interviews as well as contributed to the collected data. For example, data gleaned from interviewed HCPs were validated by extant narratives, such as Groopman's (2004) account of his experience with hope processes as a practicing physician. Likewise, The's (2002) ethnographic research study about terminally ill lung patients' relationships with their HCPs added depth and understanding to the data collected for this study. Such texts and writings deepened my understanding of hopework amongst HCPs and contributed to themes that emerged in the study. A secondary literature review was conducted during and after the process of data collection, cued by themes and processes that emerged from interviews with HCPs. The literature from the literature data base was further reviewed, to reflect the theoretical concepts garnered from the interviews with HCPs.

Strauss and Corbin (1990) valued the knowledge, insight and "theoretical sensitivity" (p. 43) that professional experience brings to the process of gathering and analyzing data. As mentioned earlier, the process of self-interviewing was a means by which I contributed my practice wisdom, as a researcher. This self interview process was inspired by van Heugten (2004) who found the self interview to be a particularly useful technique to address her status as an inside researcher. Insider research issues significantly impacted my research process and warrant the thoughtful discussion in a later section of this chapter.

Conventional data obtained from the narratives and observations from interviews were further elaborated upon by memos that I wrote as I interacted with respondents and the data. Memo-writing appeared in several forms in this study. Initially, memo-writing captured my personal and professional experiences exploring the hope process, in the form of a 'free-writing' thesis journal (Charmaz, 2006). This journal reflected my process of understanding how the construct of hope evolved into the concept of HCPs' hopework.

Memoing methods further took the form of mapping techniques that documented and analyzed data in an iterative manner. For example, I took notes and recorded themes and processes that surfaced for HCPs who participated in two hope-focused workshop/seminars (BCCA Patient & Family Counselling Services, 2007: Edey, 2006) to note participants' questions about hope. Finally, specific memos were attached to coded transcripts and quotations during the data analysis process.

Multiple data sources enabled me to triangulate information derived from the interviews. Varied sources validated enriched, stimulated and expanded views of the data. My analysis and understanding of the complexities of the process of hope is thereby optimized by this inclusive process of data collection.

DATA MANAGEMENT

Documents, transcripts, and tapes were redacted so as to contain no information that could identify respondents. Respondents were identified through code names and numbers known only to the researcher. After completing the analysis of data, respondents' identities were given further anonymity by identifying them as:

	Physician	**Nurse**	**Social Workers**	**Pilot study - Social Worker/counselors**
*Numbered order denotes most years in practice (1) to the least to (3)	**P1,P2, P3**	**N1,N2,N3**	**SW1, SW2,SW3**	**SW, C, CM**

*note: quotes in the study will refer to coded identities with reference to the transcribed line

All tapes and transcripts from the interviews are stored in a secured, locked location and computer access is password protected. Tapes will be demagnetized and transcripts shredded/deleted within ten years of completing this research. The data will be used for further analysis and research within this time frame, all of which was made explicit on the consent forms.

Transcripts

The accuracy of transcripts was reviewed by listening to the taped interviews in their entirety. Tapes were also listened to several times when I transcribed the interviews. Significant nuances in the dialogue were noted with attention given to voice inflections and emotional overtones. Twelve transcripts were entered into a qualitative analysis software program, ATLAS.ti 5.0, for data management. I initially began with line-by-line coding and making memos on the first three interviews, without using the software. However, I soon found that the software program accommodated this task more readily and efficiently. In addition, the software program had the advantage of organizing and outputting coded data, memos and quotations within chosen categories for ease of analysis.

The following table lists the focused codes and *in vivo* codes based on quotes by respondents on the topic:

Table 3: Codes & Quotations from Primary Transcripts – ATLAS ti data base

```
                                  PRIMARY DOCUMENTS (TRANSCRIPTS)

CODES (33)                         P1  SW1  SW2   N1  SW3  N2  P3  P2  N3   C  SW  CM
Totals
-----------------------------------------------------------------------------------------
--
Beliefs                             7    3    2    2    9   3   7   0   2   1   1   2     39
Beliefs-professional               12    5    7   19   10   4   9   4   1   5   1   1     78
Challenges-structural               0    2    4    4    8   1   0   5   2   1   1   0     28
Communication skills                8    0    1    2    9   4   2   0   0   0   0   1     27
Coping                              1    3    3    1    6   2   1   2   1   0   2   0     22
Coping-self care                    3    4    1    3    4   3   6   0   1   2   1   2     30
Coping-setting boundaries           7    7    4   15   10   0   6   5   1   1   3   0     59
Coping emotionally                 17   12    9    9   11   2   9  10   4   5   3   2     93
Death exposure                      2    2    2    3    2   1   2   2   1   3   3   2     25
Demographics                        3    2    1    1    0   2   1   1   0   1   1   0     13
Detachment                          4    2    2    2    2   1   2   4   1   0   2   0     22
Difficult cases                     6    5    2    5    7  10   4  14   4   5   2   2     66
Exposure to palliative pts          3    7    4    2    4   2   7   6   5   3   6   5     54
'half full and half empty'          2    1    0    0    0   0   2   2   0   1   0   0      8
HCP Guilt                           3    0    0    0    0   0   0   0   0   0   0   0      3
Helplessness - HCP                  7    1    1    2    2   6   5   3   2   1   0   2     32
HOPE of HCP                         7    1    6    2   10   2  12   2   4   1   1   1     49
HOPE(lessness) of patient           0    0    0    0    0   4   8   9   7   0   1   6     35
Interpersonal relationships         4    0    0    0    0   2   4   4   1   2   0   0     17
Intervention                        9   13    7   12    9  12  11   6   8  15   2   4    108
'people often say to me…'           0    0    0    0    0   0   0   1   0   1   0   0      2
Philosophy -life                    0    5    5    0    5   3  10   0   3   0   0   1     32
Sadness of work                     0    2    1    0    1   1   3   1   0   2   4   0     15
Satisfaction                        7    9    2    3   10   4  11  10   7   4   9   3     79
Self reflection                     6    7    7    0    9   7  14   9  13   5   6   5     88
Spirituality                        0    6    5    1    7   0   3   0   0   0   0   0     22
Team work                           5    6    1    7   14   5   0   6   6   3   8   0     61
'the person is terminally alive'    0    1    1    0    0   0   0   0   0   0   0   0      2
Time constraints                    0    0    0    2    0   0   2   1   3   0   0   0      8
Training & preparation              9    1    3   10   11   3  16  12  12   1   2   4     84
'we kind of work as a team'         0    0    0    0    0   0   0   1   0   0   0   0      1
'you need to just face it…'         3    0    1    0    0   0   0   0   0   0   0   0      4
'you'd kinda be an idiot'           0    0    0    0    0   0   1   0   0   0   0   0      1
-----------------------------------------------------------------------------------------
--
Totals                            135  107   82  107  160  84 158 120  89  63  59  43
1207
```

CODES-PRIMARY-DOCUMENTS-TABLE (CELL=Q-FREQ)
Report created by Super - 25/02/07 10:43:20 AM
HU: [C:\Documents and Settings\Helen\My Documents\THESIS - DATA ANALY...\Hopework of HCP 6Feb2007.hpr5]

Coding

Codes, memos and quotations were retrievable together, or separately. It was possible, therefore, to see all interview quotes or notes pertaining to 'hopework', which was defined as a memo. For example, since HCPs' coping was a focus of the interview, the codes reflected a deeper analysis of the coping behaviour of respondents. There was detailed coding and memoing of the different ways in which the HCPs talked about their experiences of coping.

Although this grounded theory-based software retrieved coding, memoing, and quotations in a comprehensive way, the act of coding and memoing was subject to the interpretation and lens of the researcher. The coded data was not a statistically significant or exhaustive, tally of quotes, memos or codes. However, the coded data represent a remarkable picture of respondents' experiences based on recurrent categories or themes that emerge during interviews. As analysis proceeded, some memos of events, actions and thoughts became established as codes as they evolved to a category of greater importance than originally surmised. For example, 'coping' was a broad code that was further specified into the categories of *Coping – setting boundaries* and *Coping –self care*. Memo writing on coping further refined definitions of the coping process, which I labeled *Coping by doing, Coping by reframing*. Memoing helped to engage in further analysis and to think about the coded categories.

DATA ANALYSIS

My data analysis process was influenced by the perspectives of several grounded theorists (Charmaz, 2006; Clarke, 2005; Kirby & McKenna, 1989; Ritchie & Lewis, 2003) who adapted or expanded interpretations of analytic processes originally formulated by Glaser and Strauss (1967) and Strauss & Corbin (1990). From the beginning, the data was understood to represent a 'micro' view of the larger discourse on hope within the medicalized discourse in health care (Clarke, 2005). Also, I knew that my process of observing and analyzing HCPs' hopework rested on a co-constructed viewpoint based on my social reality as a researcher/health care provider and the perception of reality by the people that I interviewed (Charmaz, 2006); this perspective may not represent the multiple ways of viewing the 'truth' out there. Likewise, my analysis adopted the expectation that researcher and respondents are of equal knowing of each other (Kirby and McKenna, 1989). Lastly, I adhered to the perspective acknowledging the 'silences', 'spaces in between' and in noticing what is different and what may be missing during my process of analysis (Clarke, 2005; Ritchie & Lewis, 2003).

Using situational analysis

As a clinician, I routinely used the problem-solving method of mapping relationships and processes in my work with patients to enable me to visualize and contextualize the patients' world. Clark (2005) advocates the use of this familiar technique which she refers to as 'situational mapping', to allow ideas, concepts, discourses, symbols, debates and cultural issues to be documented visually for ease of analysis. Situational maps enabled me to contextualize the elements found in an individual's interpersonal relationships (micro-level) within the framework of their social world (meso-level), thereby linking individual human actions to the conditions in the broader context of major discourses in society which she viewed as macro-level practices (Clarke, 2005, p. 96).

The mapping process helped me to narrow my research topic to explore the relationship between individuals' hope issues (micro-level) and larger world views of how the biomedical discourse (macro-level) has constrained and medicalized hope in the health care context. This analytical framework will be of further use to organize thoughts and discussions about the implications of findings in this study. (Refer to Figure 1: Mind map, p. 46)

Acknowledging intersubjectivity in research

Kirby and McKennas' (1989) perspective of research from the margins stressed the importance of intersubjectivity in research, "an authentic dialogue between all research participants in the research process in which all are respected as equally knowing subjects" (p. 28). In the medical system, uneven, hierarchal social relations exist and not all health care providers are equally-knowing subjects. Some are deemed by Western society to 'know more' than others, and are valued more. Doctors epitomize this unquestioned 'reality' (Becker, 1970, p. 211). The nature of this reality is taken for granted and is apolitical, a non-issue simply because doctors rank at the top of the "hierarchy of credibility" within the medical system (Becker, 1970, p. 207). This lack of equality was inherent in the medical system in which my interviews took place. Spaces in the data needed to be critically acknowledged and carefully considered in the data analysis process. For example, the data indicated fewer expressions of satisfaction by nurses. This study result is possibly explained by information gleaned from interviews that a reorganization of the nursing responsibilities had occurred several weeks prior to my interviews. This seems to have impacted on nurses' responses to the study questions. Analysis that acknowledged the context in which respondents expressed their views brought an awareness of power differences and inequalities amongst the respondents interviewed.

Being aware of inclusive analysis

Data that did not support my presuppositions, as well as the data that did, was included in the analysis. Inclusive reporting and explanation of atypical themes captures the diversity and breadth of the experiences represented in the research (Ritchie & Lewis, 2003, p. 290). Clarke (2005) challenged researchers to be "radical" by representing heterogeneity and difference, rather than to default to binary concepts that permeated conventional research (p. 21). The process of analysis enabled me to identify 'messy' data that did not fit into categories, and to identify information different from what I had expected. As a clinician, I had some pre-conceived notions of what I might have expected to be the outcome of the research. The interviews certainly indicated that things are often not as they seemed. This encouraged my attentiveness to process rather than outcome.

Clarke (2005) spoke to the importance of stepping outside of the "politics of representation" by recognizing our positionality as researchers (p. 127). Unspoken, unrepresented, invisible points of view remain unacknowledged and unexamined (Clarke, 2005, p. 127). In terms of my investigation, the reification and medicalisation of the concept of hope is just such an unspoken viewpoint. By stepping 'outside of the box' I was more aware of what was and was not included in my investigation of the hope process. Hopework, itself, has been largely unacknowledged and silent.

Adapting grounded theory analytical techniques

Grounded theory provided a unique, detailed methodical framework for the analytical process, which included line-by-line coding of transcripts (focused coding), conceptualizing the relationship between codes (theoretical coding) and combing through data to find overlooked data in order to support focused concepts (selective coding) (Gilgun, 2001, p. 349-350). The codes identified in the pilot study focused coding for the current study. Coding in the current study captured deeply and more completely, HCPs' experiences with challenging situations and patients. The pilot study (Wong, 2005) was purposefully open-ended and themes such as hope and sadness emerged unprompted during interviews as respondents talked about their experiences about their work.

The pilot study transcripts of respondents (SW, C1 & C2) were re-coded to be consistent with current transcript codes. HCPs' processes and responses from both studies were compared. As interviews were conducted, this iterative comparative process gave room for emergent data that was more rich and complete. This inclusive approach contributed to a deeper understanding of HCPs' hopework. The coding guidelines offered by Charmaz (2006, p. 69) provided explicit and detailed questions needed to guide the analysis of interview transcripts. A parallel process of reviewing the literature took place while I was also engaged in interviewing, transcribing and analyzing data. The questions that arose from the data guided the direction of further investigation into the literature.

In vivo coding was used to mark examples of respondents' speech that captured their experiences or described their philosophy. For example, expressions such as 'realistic hope', or 'putting a positive spin', were commonly used by the HCPs in the study. The list of codes grew with each interview, as more concepts surfaced. I engaged in an iterative process of going back to previous transcripts to ensure that the new codes were applied and analysed in the context of the new information. This selective coding process was made less arduous by using the ATLAS ti Software. The insights gleaned from previous interviews fueled deeper insights into the experiences of HCPs, as subsequent interviews progressed. This method enabled me to identify themes, actions and processes indicating possible relationships between the categorized focused codes. An index was developed to cluster and categorize the themes and processes (see Table 5: *Index for data analysis* in Appendix G).

A central chart was created using Excel to incorporate themes and categories identified from the coded data (Ritchie & Lewis, 2003). Respondents' data (quotes, memos, notes, comments) were included, for identified themes, actions and processes in columns. The side by side comparison of respondents and data within the categories identified was facilitated by the use of this visual chart, which also enabled me to identify (literally) gaps according to the empty cells on the chart. Charting also provided a means of methodically examining and analyzing similarities, variations, patterns of association of data gathered from the respondents.

Using memo writing in data analysis

Charmaz (2006) advocated the use of memoing as a data rendering process that encouraged active engagement with the data, while still allowing "partial, preliminary and provisional" thoughts that are correctable, remain unshared and are private (Charmaz, 2006, p. 84). Memoing in my thesis journal and mind-mapping allowed me to engage in an internal dialogue about the processes I noted and observed, while still allowing me to maintain an analytical distance from the researched materials (Strauss & Corbin, 1990). Memoing provided me an opportunity to reflect on any unease that I experienced during the interview process. This technique was particularly helpful to me in delineating and recognizing inside researcher issues during the analytical process. I formalized 'inside researcher' as a memo category used to tag the transcript. (See Table 4: *Memos created from reviewing data*, in Appendix H.) Memoing also enabled me to engage in a parallel process of noting my analytical questions and thoughts *as well as* grounding myself in the reality of the participants' world.

Assessing & evaluating the research

Several means of triangulating data were employed to support the findings of the current study. In addition to the use of extant texts and data from observing HCPs' actions and processes of hope workshops, the process of member checking gave further opportunity to elicit more data and to generate deeper analysis of concepts that emerged from this study (Charmaz, 2006). Respondents were initially offered the opportunity to meet with me individually, or in a group, to discuss the research. Furthermore, an opportunity for member-checking arose as I presented my research findings at an agency wide, multi-centred videolink session for psychosocial rounds.[7] This multidisciplinary audience affirmed the experiences suggested by the findings of this study through individual post presentation feedback and emailed comments. Further plans to present my research findings at educational rounds at the cancer center, at the Canadian Association of Psychosocial Oncology (CAPO) National Conference, and at other conferences will elicit feedback, evaluative comments and discussion of concepts that will help to further substantiate and triangulate findings.

Ethical considerations in the research

Ethics approval for human participant research was obtained from the University of Victoria Human Research Ethics Board in order to ensure that this study met stringent guidelines for ethical research (Appendix I). A member of the Cancer Clinic research committee was contacted to apply for ethics approval

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[7] Powerpoint presentation entitled: Hopework: Health care providers caring for cancer patients facing end of life presented on April, 11, 2007 at the B.C. Cancer Agency.

and to introduce the proposed study to the organization. A separate ethics approval was not required from the cancer centre; the university HREB approval was deemed to be adequate for this study. The health care facility, however, requested that I keep the research committee informed of my research. I have committed to present my work at educational rounds at the Cancer Centre after completion of the study.

Preserving respondents' confidentiality is crucial in maintaining a positive working relationship and the respect of my co-workers. As an insider researcher, I was acutely aware of my ambiguous role and recognized the need to be particularly sensitive to the consequences of interviewing colleagues in their work setting. Insider researcher issues are discussed later in this chapter. I took extraordinary precautions to preserve the identity of the health care providers that I interviewed, although colleagues (including respondents) expressed their curiosity about the identities of other study participants. The final research report identified participants only according to their gender, work role and length of practice. The identity of respondents in this report was further disguised by not making gender references to HCPs' quotes. Fortunately, the relative size of the organization assures respondents a degree of anonymity about their involvement in the study. More than 20 oncologists, 30 nurses and 7 social workers/counselors (including part time and relief staff) in this cancer clinic were potential participants in this study. The identity of respondents was further veiled by numerous staff employed within the four centres of this provincial organization.

Consent

Respondents were asked to sign a consent form (APPENDIX D) that explained my research intentions and the context of the study. Respondents were provided with a supportive environment during the interview process as they discussed challenging experiences and revealed their vulnerabilities in working with palliative patients. Interviews evolved into a dialogic relationship with respondents which encouraged deeper shared experiences and fostered a more meaning-centered dialogue. I validated respondents' experiences with disclosures about my own experiences. 'Off the record' remarks made during the course of the interview was acknowledged as such. The interview process provided a powerful opportunity to instigate HCPs' self-reflection about their hopework. This act of raising HCPs' consciousness about hoping processes was ultimately one of my intentions in researching the topic of HCPs' hopes.

Participants were given the opportunity to review their transcripts after the interview. No one requested this, nor did anyone express a desire to withdraw from the study. As spelled out in the consent form, respondents benefited from: a) having an opportunity to give voice to their opinions and experiences about their work; b) being able to contribute to research that could shape professional training and help improve psychosocial oncology and palliative care practices; c) contributing to broader research possibilities [8]; d) receiving information about the topic of hope at end of life care, and e) having an opportunity to debrief and

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[8] I am involved in a CIHR-funded NET research project focusing on Barriers to Communication at End of Life (New Emerging Teams) project addressing Barriers to Communication at End of Life in palliative care.

discuss this study with other interested participants or with the researcher. This research thesis will be accessible to respondents upon its completion.

LIMITATIONS OF THE STUDY

I concurred with Gilgun (1994) that grounded theory can be "forever open-ended" (p. 118). Ideally, in grounded theory, data should be sampled until saturation is met to achieve "theoretical completeness" (Baker et al., 1992, p. 1358). However, I found that emerging data and information continued to challenge established constructs so that absolute saturation continued to be elusive and unimaginable. There were always more questions to ask to further plumb the depths of hope and the hopework of health care professionals.

Incomplete theoretical satisfaction however, was countered by evidence of the richness of the data collected and the realization that this valued information will be used in a positive way to improve HCPs' work with palliative patients. Furthermore, the nature of hopework and hoping as an evolving *process* that changes within the hoping person makes it difficult to define the process in a complete way. As a consequence, a very good 'snap shot' of this process has been captured by this study. Arguably, life's changing and fluid social processes will always offer only a partial picture of what is researched. Our knowledge is forever partial, yet our glimpses into, and analysis of processes and social situations remain valid, valuable and informative. We cannot aspire to *know* everything.

SUMMARY OF RESEARCH DESIGN

The research design for this grounded theory study relied on research approaches based on the frame and tools offered by grounded theorists Charmaz (2006) and Clarke (2005). I found grounded theory to be congruent to social work practice and an excellent fit for my researched topic: exploring the experiences of HCPs' processes of hope. The development of the grounded theory method was originally intended to explore experiences and processes (Strauss & Corbin, 1990). Charmaz' (2006) guidelines and questions for data analysis facilitated my navigation through research process with clarity and understanding. Clarke's (2005) use of analytical mapping techniques further reinforced mapping skills that I had previously used in my clinical work. Her situational analytical framework provided an opportunity to view my research efforts as a vehicle for invoking change beyond that of the micro-relation and to also potentially address systemic changes as well.

Grounded theory's generous viewpoint of including 'everything as data', and respect for the clinical experience of the researcher encouraged me to include my self-interview, representing my practice wisdom and professional experience, as part of my research. Also, it was important to include in the research design an investigation of the ramifications of doing insider research, to ensure that I understood the implications of my research from a political perspective. Finally, data management techniques such as the use of ATLAS ti Software allowed the thorough rendering of a volume of which at times seemed unmanageable. As a result, this opened up avenues of exploration that would have been limited by the conventional way of managing data. The charting method of data analysis offered by Ritchie and Lewis also provided a good framework for analysis of data. Through these tools of research design, I was able to optimally explore my research topic of HCPs' hope processes.

The next section discusses my role as an insider researcher in this study. The constructionist approach to grounded theory acknowledges that the data and the analysis of the research are derived from contributions from the mutual experiences of researcher and participant (Charmaz, 2006, p. 130). As a consequence, it is crucial that I take a reflexive stance on my inside researcher role in order to delineate how I have participated in the construction of the viewpoint from which I present this study.

RESEARCHER AS AN INSIDER

There were some indisputable advantages to my participation as an insider researcher in this study. The commonalities I shared, as a researcher and as a respondent reduced barriers in my ability to access data (Brown, 2005). I was also able to achieve an incomparably deeper understanding of the issues experienced by participants (Kanuha, 2000), not easily attainable by outside researchers. My insider knowledge gave me a particular insight and understanding of the issues that HCPs encounter in the system, as my clinical experience and well-developed knowledge of patients' needs and experiences with cancer established a common ground on which to discuss issues with participants. Consequently, I was able to ask deeply relevant questions that may not have occurred to 'outsiders'. As an insider conducting research, I believed that my familiarity with the setting and the clinical experiences of the participants enhanced my ability to make discoveries about the data. Fewer contextual questions needed to be answered allowing the interviewer to focus on HCPs' hope experiences. The socio-political nuances and complexity of practitioners' experiences working in a palliative care setting would not have been readily apparent to researchers unfamiliar with the oncology culture and palliative care.

However, educational researcher Brown (2005) regarded this close connection that exists between inside researchers and their participants as "both a strength and complexity" (p. 5). She noted the potential 'seduction' of respondents to take part in research by a trusted colleague, only to then feel betrayed by unflattering analysis at the conclusion of the research by their researcher colleague. Consequently, it was crucial for me to thoughtfully consider the dilemmas of doing insider research, to avoid being 'blind-sided' by relationship issues during the research process. It was critical for me to anticipate difficulties *prior* to contacting the organization and to establish a research relationship with potential respondents that would maintain goodwill between colleagues and myself after the study. I took a proactive stance to identify likely issues or concerns that could have emerged in the process of my research. Also, I reviewed potential solutions and safe guards to ensure that my research reflected the best practices, given the circumstances. This approach enabled me to maintain my professional credibility as a colleague and established further credibility for me as a researcher.

Many researchers explored the dilemmas of being an insider researcher (Brown, 2005; Dickson-Swift, 2006; Fraser, 1997; Kanuha, 2000; van Heugten, 2004) after experiencing personal and professional concerns *while* conducting their research. Fortunately, I benefited from these researchers' wisdom as they retrospectively shared their insights and experiences on navigating through their research with their insider status. These authors discussed the inherently emic nature of qualitative research which reflected the subjective, informed, and influential viewpoint (Kanuha, 2000) of the researcher. Qualitative research is, after all, a personal process. The blurring of boundaries between researcher and participants is an expected "hazard" of the method (Dickson-Swift, 2006).

There were concerns inherent to the researcher's relationship with participants. Researchers' personal biases could influence analysis. Data may be edited or overcorrected to compensate for the researcher's self-conscious over-involvement, by ignoring common data and spending inordinate attention on the unusual (Brown, 2005). Participants might feel pressured to participate in studies and create what the researcher wants to hear. Fraser aptly (1997) observed that data is not really anonymous when an insider researcher is appointed. This is particularly true of smaller, unique working groups where positions can easily be identified. Finally, inside researchers are prone to making assumptions based on their familiarity with participants and their environment. They may maintain the notion that they share the same language and sense of community (Kanuha, 2000) as the researched; thereby foregoing exploration of important contextual information that may explain what is meaningful for respondents. Familiarity with respondents could become counter-productive to data collection (Kirby & McKenna, 1989, p. 122). My critical stance on the research phenomena and views on data could potentially be constrained or even obscured if I retreat into my partial perspective as a health care provider in the system. These hazards of conducting insider research cannot be overlooked and merit serious thought.

Awareness and acknowledgement of the aforementioned concerns and practices constituted my foremost strategy in dealing with the multitude of disadvantages of insider status as a researcher. The experience of others (Brown, 2005; Dickson-Swift, 2006; Fraser, 1997; Kanuha, 2000; van Heugten, 2004) heightened my sensitivity to possible difficulties as a result of my health care provider role. My review of the literature on the dilemmas of conducting insider research sensitized me to the need to take a proactive stance (Meyer, 2000) and to anticipate potential complications that may arise because of my insider status. In addition to this, I re-positioned myself to regard my study from the ethical viewpoint of recognizing the 'intrinsic value' of the research that my study undertook, namely to improve HCPs' ability to work with palliative patients. By doing so, I was able to pay attention to the consequences of my insider status in light of "moral equality, moral autonomy, impartiality and reciprocity" (Fraser, 1997, p. 165) to anchor my research intentions. These principles guided me to aspire to a higher ethical standard in my research. Being mindful and aware of the relationships in the context of the research is an important aspect of insider research.

Reflectivity

The practice of self-reflection, to separate personal biases and values from the researched (Dickson-Swift, 2006; Kanuha, 2000; Fraser, 1997; van Heugten, 2004), can address issues of blurred boundaries. The familiar social work stance and practice of self-reflection was easily incorporated into my research by writing personal memos throughout the research process and by engaging in the self-interview process. This process enabled me to examine, question and deconstruct the inner and outer discourses (van Heugten, 2004) that influenced my conduct and thoughts. I sought to balance my insights and tried to avoid colluding with dominant discourses in the clinic environment. This post-structuralist stance enabled me to actively and critically process my viewpoints during the research process. The 'spaces in-between' and marginal viewpoints become apparent as I examined and questioned my motives, beliefs and values which previously had been hidden and ensconced in the familiarity of my work place and medical culture (van Heugten, 2004, p. 208). I engaged in the processes of defamiliarizing and problematizing knowledge that has been taken for granted by questioning my familiarity, comfort or unease in my relationship with respondents. The use of audiotapes enabled me as an insider researcher to disengage from the research process to take a fresh view of the data and the interviewee (White, 2001). I listened to my own intonations, remarks and familiarity with respondents and factored in how I had participated in constructing the data with my own biases and self interests.

In consideration of the 'unfamiliar', I reflected upon interviews that I had found to be difficult and challenging for me to process. I was able to reflect on this and question why this data was difficult to process. For example, I countered my temptation to debate with a HCP about their impersonal views on spirituality and I felt uncomfortable when a HCP expressed unhappiness with the political climate in the workplace. In doing so, I was able to develop insight into existing power relationships that had previously remained invisible to me.

Kanuha (2000) suggested setting aside 'natural connections' in order to focus distinctly on the researcher role. I reiterated both inwardly and outwardly my role as a researcher to create the emotional distance necessary to establish boundaries with respondents. For example, I delineated my researcher role during the interview process by marking the beginning and end of the interview with the purposeful act of referring to my interview guide and used the turning on and off of the tape recorder to officially open and close the process. I readily voiced and reiterated my researcher role during the course of the interview and specified when I was speaking 'off the record' as a friend and colleague. I initially made a conscious effort to minimize self-disclosure and the expressing of personal opinion or information, as these actions could complicate the perception of my role (van Heugten, 2004). However, I found this unrealistic and contradictory to my efforts to be genuine and sincere during the interview. I wanted to validate respondents' stories by sharing my similar experiences, to provide them with information that I knew would help in their hopework and to reciprocate this sharing of knowledge in the research relationship.

Relationships

Insider researchers' relationships within the organization and with respondents can be unequivocally fraught with complexity and tensions (Kanuha, 2000; van Heugten, 2004). However, I was able to navigate complexities because my insider knowledge enabled me to 'side-step' some of the potential issues that an outside researcher might experience. For example, I knew of a quiet interview place, when respondents would most likely be available and who to talk with to begin my research process.

van Heugten (2004) explored her subjectivity as an insider by taping her self-interviews. She adopted role reversal and Gestalt therapy 'two chair' methods (p. 207) to establish a dialogue with herself in order to explore the internal processes in her research. This inspired my own self interview better to understand how my research would impact on my colleagues, as well as to gain insight into my own experiences in maintaining hope as a clinician. My memoing, mind-mapping and journaling using 'streams of consciousness writing' (van Heugten, 2004, p. 207) enabled me to reflect on my researcher role in this project.

While I was in the clinic, I asserted my researcher status explicitly with HCPs and others in the organization. My absence from the workplace for the past year created mutual distancing between colleagues and myself. This break from work enabled me to deconstruct my familiar world and allowed me to see more clearly the biases of the health discourse and the complicity of health care providers like myself in supporting these power structures. This work hiatus enabled me to don the researcher role with more ease than if I had been still directly engaged in practice. This sense of detachment from the workplace helped me to explore the strengths and liabilities of my relationship with the HCPs and with the organization (Kanuha, 2000).

The liabilities in the research process that I identified were minor in nature, such as the inconvenience to HCPs' time and schedules. However, there were many beneficial aspects of conducting insider research. HCPs were all very engaged and expressed interest in the topic and the results of the study. Some looked forward to receiving some concrete strategies for doing hopework with patients. The consequences of how my research and presence impacted on my workplace and my colleagues (Fraser, 1997) in the long term will not be apparent until respondents have accessed my study. The frank, open and inviting manner in which I conducted the interviews was reciprocated by the participants, whom I believe remained thoughtful about our discussions about hope practices. I may have an opportunity to follow up in the near future to further explore whether HCPs' perceptions and practices of hopework have changed since they were interviewed.

I found it useful to access outside supervision (Fraser, 1997; Kanuha, 2000) to provide me with feedback and perspective into my role as an insider researcher. My thesis supervisor initially alerted me to the potential dilemmas of doing research in one's own workplace as an insider researcher. Although I did not encounter any dilemmas requiring debriefing and consultation, I believe that this extra effort in practicing self reflexivity on the insider issue enabled me to exercise the precaution necessary to avoid 'getting into hot water' in the work place.

Ideally, my previous relationship with colleagues should not give me any rights that would not normally also be afforded to an outside researcher (Fraser, 1997). I felt that I was able to recognize when privileged, intimate information was given to me as a social worker, friend or colleague, rather than as a researcher. During the data analysis process, I coded and memoed all the insider references in the transcripts to track the process and to ensure that I was aware of this insider researcher factor in the data. There were 22 memos written and 36 quotations by respondents acknowledging me as a clinician during the interviews. When respondents were inclined to share personal information with me as a colleague, I judiciously stopped the interview or tape recording and edited out the information which did not relate to the purpose of the interview. Respondents would not have commented on some of these intimate details if I had not been seen as a trusted colleague worthy of their confidence. The 'off the record' remark was evoked by myself only once during the course of the interviews.

Conducting interviews as an insider

I used unstructured interviews with an interview guide for reference, to elicit responses from HCPs in order to avoid imposing my biases on their views. I asked for clarification of remarks made by respondents when I already knew the answer as an insider, adopting an outsiders' curiosity about respondents' remarks, so as to avoid making assumptions that I knew about their inferences and references to situations and circumstances (Kanuha, 2000). This approach produced a 'truer' view of a respondent's experience, untainted by my own views as an insider.

Analyzing data as an insider

My awareness of the constructed nature of the research encouraged me to attempt to be as inclusive as possible in accurately representing the experiences shared by respondents. My respect for my colleagues and the work that they do guided me in acknowledging that the research undertaken was co-constructed and reflected both the respondent and the researchers' views.

Fraser (1997) suggested that the researcher had the right to edit out parts of data if there were 'significantly adverse consequences' or an ethical concern (p. 165). I offered the opportunity for respondents to review and edit their own transcripts so as to acknowledge their vulnerability in the research process. No one accepted this offer.

The solution-oriented focus of this study, aimed at exploring how health care providers maintained their hopes brought out the most helpful and positive aspects of human nature. I believe that this focus on the benefits of the study enabled me to circumvent the dilemma of data that only focuses on problems or proves to be unflattering to the respondents or the organization. A focus on the process and context of the study, rather than the content and facts (Fraser, 1997; van Heugten, 2004, p. 212) also elevates the data analysis to look at implications in the 'bigger picture' of discourses rather than focusing on the respondents' or the organizations' inadequacies. This is not to say that negative information and unspoken situations should remain hidden from view. It is to say that I intended to produce research that is useful, constructive and supportive of health care professionals. As it turned out, this study did not produce any dilemmas that were awkward or difficult to report. Frankly, this was a relief to me. I had anticipated encountering HCPs less engaged with hopework or burnt out from their work. However, this did not happen and I did not have to consider this predicament.

Triangulation

The triangulation of data in analysis also helped to neutralize my status as an inside researcher (Brown, 2005; van Heugten, 2004). This was achieved by reviewing literature supporting the value of hope experiences amongst health care providers. In addition, my direct *observations* of the respondents and others provided additional data to offset concerns of insider research biases. For example, my notes on HCPs' who attended the educational sessions on hope or patients' experiences from my past clinical work contributed to the coherence of the data. The collected data was further validated and given significance as the independent views of health providers, researchers, patients and caregivers expressed support for the theories that emerged from my analysis.

This self reflection and investigation about the ramifications of doing insider research has been invaluable. The checklist of potential problems that *could happen* enabled me to mindfully plan my research in anticipation of possible issues that may arise from my status. The strategies borne from the insider experiences of others were most helpful and will enable me to return to my workplace with an assurance that my relationships with my colleagues and my workplace are intact.

> *Hope is one of the things people never treat --- and so it has to be the same thing like disease too --- take hope away and there is no life. Not [just] in cancer patients but in any human situation --- you take hope away, and that is the end of life…it is tremendously important that…we project--- an outlook which is of hope, rather than [despair] [P1:138].*

Introduction

This chapter highlights and analyses the experiences HCPs frankly shared about their work with cancer patients facing poor prognosis. Nurses, doctors, social workers and counselors provided invaluable insight on the values and emotions that underpin and reflect the deep stories of their caring for cancer patients.[9] Respondents expressed altruistic intentions of 'making a difference' by choosing to work in oncology. The sadness and despair that permeate HCPs' work with palliative patients was offset by their deep sense of satisfaction in providing care.

HCPs were clearly engaged in internal hopework processes of reframing and envisioning their own hopes in caring for patients along their journey with their illness. Doctors assumed the difficult role of giving *the bad news* to patients as other HCPs collaborated with the doctors' pronouncement (The, 2002) by reinforcing, reiterating and reframing the 'truth' for patients.

HCPs did not articulate or define their own hopes explicitly, rather, they shared experiences that tacitly reflected their hopework. Not all HCPs were insightful about their coping and hopefulness in their work. Although HCPs appreciated how their communication skills impacted on patients, they were not aware of how their liminal hope processes could impact on patients' hopes. The

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[9] Respondents' identity code and numbered lines in their transcript follow quotations

processes of hope that underscored the behaviour of HCPs or the actions of their patients seemed largely 'invisible' to the HCPs interviewed.

An examination of transcript data revealed that all HCPs struggled with managing their hopes with their perception of reality as they faced the ambiguities and uncertainties of working in the area of end of life care. Even though HCPs found their interactions with patients extremely gratifying, their intimate relationship with patients caused them deep emotional challenges and created the most anguish (Keddy, Sims & Noerager Stern, 1996, p. 451). The hopelessness of some patients triggered HCPs to feel helpless and emotionally vulnerable. HCPs' experience of the tensions between hope and despair and reality precipitated them to define 'realistic hopes' that were congruent with their professional and personal views. The core process of balancing and shifting their hopes with reality enabled HCPs to cope in their work through engaging in problem-solving and meaning-based coping activities. These activities by HCPs were categorized into two sub-processes, a) 'tolerating the tragic' as a problem-solving process and b) 'building emotional scaffolding' process as a meaning-based coping activity. Both sub-processes are closely related to the other as psychosocial processes that involve meaning-making.

The ability of the HCP to sustain their hope realistically was impacted by personal and professional factors. Personal attributes such as optimism, imagination and 'open-heartedness' or compassion contributed towards the ability of the HCP to be hopeful. Patient-centered intentions were included within the scope of the personal, rather than professional, although the concept is idealized in the mandate of professional care for patients. Also, professional training and experience impacted on HCPs' hopework by constraining their hopes or by expanding their hopeful viewpoints.

The hopework of HCPs was supported and sustained in the context of their relationship with colleagues and patients. Social workers and counselors particularly appreciated opportunities to debrief their emotions about their work and to consult with other colleagues about aspects of patient care. Although doctors and nurses valued team and collegial support, they tended to use these opportunities for consultative purposes about patient care rather than to debrief their experiences. Positive feedback from patients engendered HCPs' hopework and strengthened HCPs' commitment to their work. Health care providers' felt rewarded by patients' expression of gratitude towards them. They felt deep satisfaction in being able to 'make a difference' in helping patients.

This chapter examines in depth, the hope processes of HCP as they care for patients experiencing the tragedy of facing end of life. The discussion is guided by the framework in Figure 2 (p. 83) which defines the core process of HCPs' hopework as shifting their hope and reality within an ambiguous emotional landscape. The ability to tolerate tragic circumstances and to build emotional scaffolding were identified as two sub-processes that enable HCPs to sustain their hope.

The core process and sub-processes of hopework take place within relational contexts and are influenced by HCPs' personal and professional resources. These relationships are illustrated by the following diagram:

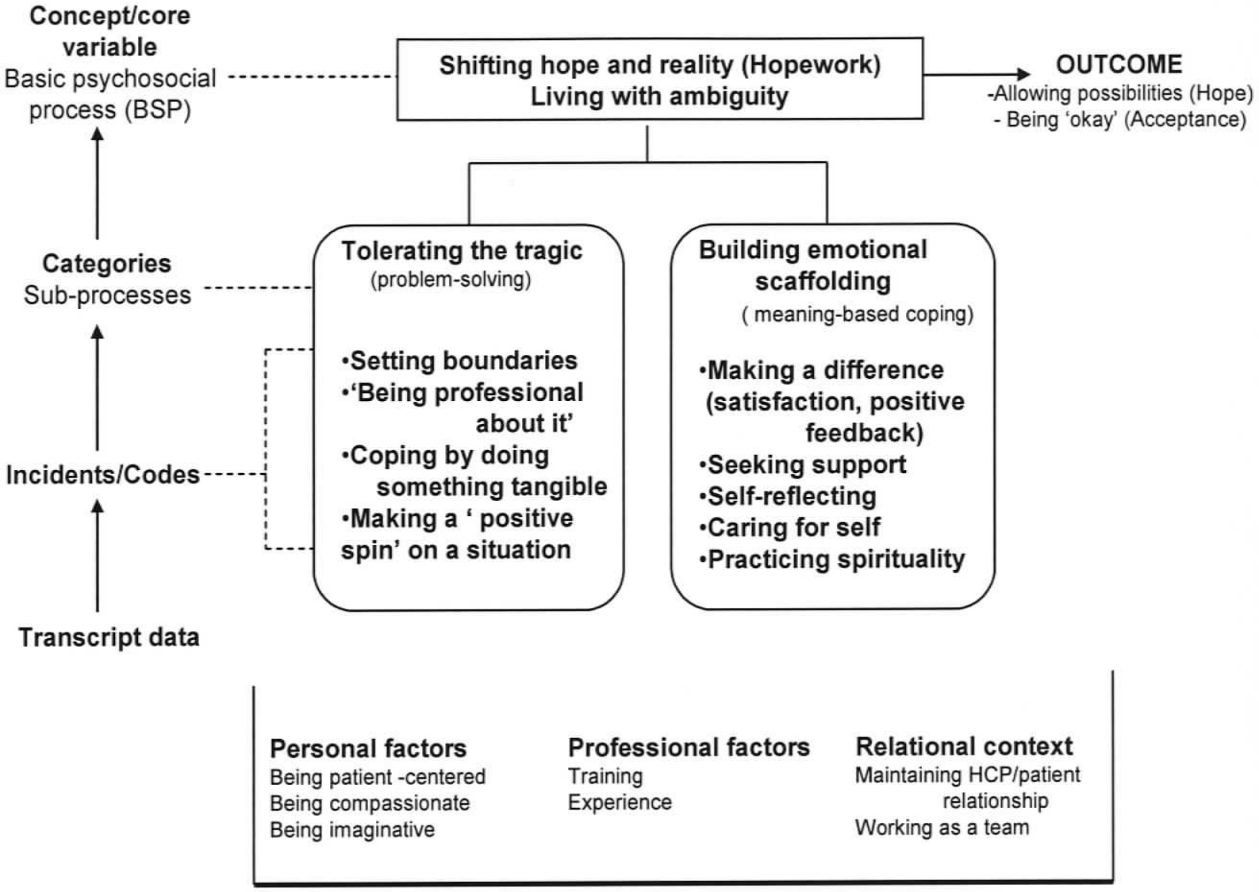

Figure 2: Factors & conditions impacting hopework

PERSONAL & PROFESSIONAL FACTORS THAT IMPACT HOPEWORK

> *Hopework –(def.) a process of constructing hope in terms of hopefulness of the situation which can be an internal process of working on one's hope, or an external process of encouraging the hope of others . Internal and external resources are used to do hopework within an interpersonal or intrapersonal context (adaptation from Simpson, 2004, p. 431).*

I. The personal relationships - Experiences from the heart of hope [10]

The interviews uniformly revealed an 'open-heartedness' or compassion amongst HCPs towards patients in their work. This emotional connection between the HCP/patient clearly impacted on how HCPs viewed their lives in the context of their patients' experiences:

> *it's easy to come to work, because no matter how crappy I feel in the morning… I know I'll feel better most likely after my first patient that I'm going to see that morning. They've probably have had a worse day already. So it makes it really easy for me to come to work. [P3:177]*

Health care professionals' hopework were inspired by patients' extraordinary resilience and strength of endurance. Their patients' regrettable circumstances highlighted the HCPs' fortunate situation and encouraged insight and personal growth. The helping relationship offered HCPs a sense of satisfaction and gratification which further enlarged the *HCPs'* personal hopes.

The HCPs' caring towards patients incorporates their patient-centered intentions and is fueled by their personal optimism and ability to evoke their imagination to hope with the patient beyond the confines of biomedical data and training.

Co-construction of hope in the relationship

The HCP/patient relationship allows the HCP and patient to shape each others' views and beliefs in what they hoped for; their pre-established hopes may or may not be altered by this interface with each other. The following excerpts

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[10] Farran et al. (1995) terminology used for the relational aspect of hope

illustrate how hope was co-constructed between a doctor and patient during telling of the 'bad news':

> *…sometimes it's harder than other times, it often depends on that dynamic that you've got going on with a patient, and even in situations where it's the worst news –and you can't really spin it--- any better than that [pauses] it comes back to what I was talking about before in terms of--- that situation bringing out the best in people. In that, it always amazes me even in those situations – they're kind of trying to ---make it easier on me! [selfconsciously laughs] and we kind of work as a team to get through this particular difficult situation that you both find yourself in. [P2:78]*

This construction of hope between the doctor and patient was a *mutually hope sustaining experience* for both parties. While giving the bad news, the doctor tried to be hopeful with the patient while the patient attempted to give hope and encourage the doctor. This example illustrates the dynamic, relational process of hopework.

II. Professional factors

Patient-centred care

All respondents articulated the importance of listening to the patient and taking the time to attend to their needs, particularly if the patient appeared to be having difficulty coping with their situation. This patient-centered stance was reflected in the stories HCPs told about their work with patients. Nurses valued their relationships with patients and their ability to provide patients with continuity of care. Predictably, counselling staff focused on the social and emotional needs of patients. Social workers and counsellors had a particularly strong belief in the capacity of patients to participating in their own psychosocial care and be able to identify interventions meaningful to their situation. Curiously, all quotes coded as 'patient-care' in the study were attributed to social workers/counselors. HCPs generally articulated and valued the ideal of the patient as central to the HCPs' formulation of their goals of care (Latimer, 1998). The HCPs' actions and behaviours would presumably and congruently reflect their patient-centred intentions.

Training & experience

Most of the respondents articulated hopes based on their disciplinary practices. I called these 'professional hopes'. Physicians largely defined hope in the context of its absence - a deficit viewpoint, whether treatment was possible or not:

> *'hopelessness' is very loaded word. I mean they're seeing realistically....certain stages of their disease you can be more hopeful -and then gets to a point... when you're standing on the edge of a cliff and there's no where to go -. It's completely unrealistic and false, and dishonest. And they know that, and you know that...[P2:176]*

Hope was firmly rooted in evidence-based practice.

> *I find it a real privilege to --- to be able to see how resilient people can be when you would think that their situation is hopeless...most people don't lose hope they always figure out something to hope for, and if I can support them to hope for--- If they can't hope to have a long life, then they can hope to have a good life, and I can help them with that, and if they are faced with a lot of debilitating symptoms, and they keep losing more and more of their independence and of what they viewed as themselves previously---Supporting them to be as independent as possible or to try and look after the most bothersome symptoms and really be on top of things like that. I think part of my job is to try to maintain hope, even when you would think that they'd give up hope, and ---roll over and die. [N3:72]*

One doctor maintained that a 'professional attitude' conveyed competency and trust in the care that is offered, thus generating hope and confidence in patients (P1). The hopes of the HCP can differ from the hopes of the patient. This *objective* medical hope of the HCP contrasted with the *subjective* vulnerable hope of the patient (Eliot & Olver, 2002). Cancer patients wanted hope from their doctors, but continued to hope whether the doctor supported their hopes or not (Eliot & Olver, 2002, p. 186).

Nurses valued their technical expertise in providing care as their means of supporting a patients' hope. Nurses defined hope specifically and tangibly, by looking at symptom management and quality of life:

> *If you talk people through things then they sometimes… seem like they can accept that: 'well, okay, maybe that is - maybe that can work' - and maybe later on down the road there could be more radiation. Which, in their minds means living longer, I think…* ***you basically gave them hope (researcher).*** *Umhm - I guess I did! You know I gave them hope… - that by taking this anti-inflammatory maybe it'll settle the inflammation down that there could be more radiation - is that false hope? I don't think it is. [N2:172-177]*

Nurses expressed uncertainties about their hopes. Concerns were expressed about whether they were 'aiding and abetting' *false hope.*

Counsellors had a meaning-centred focus in their work with patients' hopes (Parker-Oliver, 2002). Their professional hopes reflected their focus on quality of life issues by supporting the patient to live well:

> *…finding a way to negotiate dying, and dying well…* and to help patients *feel as balanced as they can, connect to their own centre…so that they can move forward with whatever… they want to do. [C:20-22]*

HCPs were invested in their patients' hope processes and were deliberate and intentional on how they revealed their own hopes to patients:

> *...it's possible you can actually keep people in hope even in a very bad situation. It depends on...your body language, your way of dealing with that situation...you can project some possibilities with any kind of situation. [P1:271-274]*
>
> *...you have to take time for them [patients who feel hopeless]... the more time you spend with the patient, the more comfortable they feel... during the time, you can actually instill some degree of...possibility and hope --- [trails off]. [P1: 290-294]*

III. Relational contexts of hopework

Hopework & the interdisciplinary team

HCPs strongly indicated their reliance on their interdisciplinary team members as a means of coping and highly valued the complementary roles of each discipline. Interdisciplinary team members emotionally 'buffered' the work for some HCPs:

> *...nurses and counsellors, people ... get very close to patients. Physicians, in fact, are not that involved most of the time with patients... they find out more about the emotional aspects of patients... from the colleagues rather than directly from the patient. [P1:76]*

The doctors acknowledged that their limited interaction with patients distanced them from patients' psychosocial issues, and readily conceded that HCPs on the care team complemented their work and provided them with valued collegial support and information.

Other members of the interdisciplinary team had less satisfying recollections of their team experience. The nurses expressed a desire for a voice and partnership in teamwork, as they were often left to deal with patients' worries and concerns after the patients see the doctor. These HCPs also felt constrained from giving their professional opinion to patients and families who desired to talk further about their situation.

The nurses in the study provided psychosocial support to patients after bad news was given but deferred to the expertise of the counselling staff when counsellors were available. The nurses articulated strongly their desire to acquire more skills in dealing with the psychosocial issues they faced with patients. One social worker astutely observed that HCPs would be able to share the burden and stress of caring for patients if HCPs better understood the roles of team members (SW3). Social workers were particularly vocal about the difficulties that arose from the hierarchal nature of health care teams:

> *I think there does have to be an understanding about what we do… I don't think a lot of doctors really understand what we do. So they… want to get rid of the situation because they don't know how to deal with it… most of them have probably never seen the counselor and have gone through their own experience of it. So they probably don't really know--- what we do. So I think that's important… respect and being recognized and that we're equal team players… there's such a hierarchy. [SW3:528-533]*

Mismatched hopes

Health care providers' stress was at times attributed to the subtle tensions between the interdisciplinary team, rather than resulting from direct patient care. The following excerpt illuminates how a HCP's balancing of hope and reality is further complicated by other HCPs actions or non-actions:

> *I thought he was probably actively dying, his level of consciousness was going down. And yet, I didn't feel I was allowed to say that, to the family. I didn't feel that they wanted me to tell them that. So--- it's hard to know*

> *what to say in situations like that when they're asking something but they don't want to hear....[trails off]...I think that would be the appropriate... thing would be the doctor to give them very straight forward information. It's always difficult as a nurse when the patients ask for information about [clears throat] their condition and that sort of thing, because ---it's limited what nurses should be telling patients. Their information should be from the physician. [N3:83-87]*

Nurse N3's exposure to the patient and family's fluctuating hopes positions this HCP to address the immediacy of their concerns. Yet the complexities of the medical hierarchy, the interface of interdisciplinary roles and the labyrinth of emotions constrain this HCP from being able to address the patient and family's concerns. Multiple layers of hopework underlie the everyday experiences of palliative care, where the hopes of patients, families and HCPs remain unspoken, unidentified and unacknowledged. HCPs often experience the exquisite tension at the pinnacle of this delicate balance of hope and despair with the patient and family at this juncture of their journey. The hopework of HCPs is influential and of critical importance, yet nurses, doctors and social workers/counselors rarely talk to each about their hopes for their patients.

The next incident illustrates how the limited hopework of HCPs can acutely impact on patients' hopes. A counsellor gave an account of trying to ameliorate a patient's devastated hopes after the patient had a truth-telling session with his doctor:

> *this physician was saying " I will give this to you [referring to further treatment], but it is the VERY last thing, and we told you from the beginning that you're going to die of this disease, and you haven't accepted it". And I think this is a very harsh way, I think to deal with somebody....[C:61-6]*

These scenarios illustrate communication dilemmas that can emerged *between* HCPs as well as between HCPs and their patients and family members. Significantly, these incidences illustrate how poor communication and understanding of hope processes can result in the HCPs' failure to understand how *individuals' hopes* underpin the behaviour of the actors involved. Was the doctor who continued to treat the dying patient acquiescing to the family's need for hope? What was the patient hoping for when he requested more treatment? When hope is overlooked and 'invisible' at end of life, misunderstandings can arise in the relationships of vulnerable patients and HCPs alike. Clarity about the HCPs' and the patients' hopework is crucial for patients facing critical psychological and physical transitions in their palliative situations.

HOPEWORK – SHIFTING HOPE WITH REALITY

The emergence of hope & despair

> *So I'm not saying that I'm necessarily always do the right thing in terms of what patients want - and also I do find it a struggle sometimes to kind of strike the right balance between - trying to be hopeful, [pauses] but also trying be realistic.*
> *... I don't kind of want them to miss the opportunity... if they want to --- if they've got things to do, I don't want them to miss the opportunity because... they've got this...dream that things are going to be completely different from what they ---most likely are going to be like --- and they actually have to be able to deal with that.*
> *... I want to give them some skills and knowledge to be able to deal with that --- while retaining the hope that... it may make it better than that... you have to maintain some--- balance between that. And that can sometimes be difficult. You don't want to dash their hopes. [P2:152-4]*

The journey into hopelessness and despair emerges when a patient recognizes that they may die from their diagnosis of cancer. Doctors on the health care team assume the role of the 'truth teller' and are thus challenged to address patients' medical concerns as well as attend to their complex emotions. None of the doctors felt that their medical training prepared them for this latter role. Physicians needed time to develop the 'art' of truth-telling. They adhered to a stringent professional ethic that necessitated being 'honest' in the delivery of the prognosis. One oncologist emphatically stated, "it's wrong when you know someone's completely terminal to give them unrealistic hope of survival".

Doctors felt challenged in their attempts to balance the bad news and at the same time help patients maintain a sense of hope. Their medical training inadequately prepared them to engage in the dilemma of balancing their hopes with the 'reality' the percieve:

> *'tell the truth…be honest, but don't take away the hope'… I didn't know what that meant! [emphatically] It takes a while to figure out… refocus it towards something that's more realistic and… it became that way. But at the same time… you have be honest about the survival and prognosis…. [P3:85]*

The doctors felt that they were able to help patients maintain their hope in this truth-telling process but only after years of honing their communication skills (Fallowfield & Jenkins, 2004). All admitted lacking skill in this area at the onset of their medical practice. Nurses and social workers played a key role in providing medical and social perspective to the patient in the aftermath of truth-telling.

HCPs' support for patients' hopes usually reflected their particular disciplinary practices. For some HCPs, being hopeful took the form of information-giving and 'enlarging possibilities' (Simpson, 2004) for the patient.

Doctor P2 talked about a patient who was devastated by bad news received from two previous doctors:

> *...at the end... I didn't say that [it was all 'doom and gloom']... at the end...he was very grateful and seemed much... better--- felt better about himself in that situation - because somebody had been hopeful with him, rather than just giving him bad news. [P2:139]*

The doctor alleviated the patient's worries and despair by elaborating on possibilities for the patient. HCPs emphasized the importance of providing palliative patients with information about what to expect in the future as a means of helping patients to envision future possibilities and engendering hope (P3;N2).

Living with ambiguity

The pervasive tension between hope and hopelessness throughout the end of life care experience for the patient and health care professional causes both parties to confront *living with ambiguity*. It is an ongoing struggle for HCPs to balance hope with reality amidst uncertainties that surface from the tenuous nature of patients' health. This search for 'realistic hope' and the adjustment and shifting of professional and personal hopes gave respondents their greatest angst and thus became the overarching concept or variable in HCPs' hopework.

The predictability of science and medicine was of comfort to HCPs who appreciated the evidence-based nature of their work. Confidence in professionalism was used by one HCP as a means to instill hope in patients:

> *It's important... to depict the feeling ...that you care about the patients' situation. And... to project your professionalness[HLW1]...so many patients have trust in you[HLW2]. Because...if you don't project... competency, then, that could put off the patient, completely. It is important that you give competence, which leads to trust[HLW3]. [P1:166]*

However, uncertainty and the unknown eventually overshadowed any conclusiveness that medicine offered patients during end of life care.

The hopes of HCPs shifted as they became exposed to and experienced other perceptions of reality. HCPs were able to suggest other hopes for patients to address quality of life issues when they realized that their medical or professional hopes were no longer potent. Rigid viewpoints of what can be medically hopeful softened as life taught HCPs about inexplicable recoveries and statistical anomalies.

The actions of HCPs in the study were coded and categorized into two coping processes that were identified to encompass their experiences in mediating their experiences of hope and reality. The processes of 'tolerating the tragic' and 'building emotional scaffolding' enabled HCPs to be more hopeful in their work despite the challenges of working within the context of uncertain and ambiguous outcomes. The following discussion elaborates on the emergence of these two processes that capture the actions of HCPs in the data.

I. Tolerating the tragic

Social worker Shechter (1999) used the term 'tolerance for the tragic' in reference to her exploration of the psychodynamics of clinicians' hopes in dealing with tragedies. She viewed hope as a character trait or attitude that can be nurtured in the clinician as well as in clients, rather than viewing it as a process (Shechter, 1999, p. 372). However, her thoughts about building an emotional tolerance towards tragic situations are relevant to this study of clinicians' hopework with patients facing end of life. Hopework incorporates the sub-process of *tolerating the tragic* by engaging in activities such as: setting boundaries, being professional, coping by doing and making a positive spin. These activities emerged from the findings as ways and means in which HCPs defended themselves and built practical, tangible tolerance towards dealing with their heartrending work (see Table: 6 in Appendix J for a list of challenging situations experienced by HCPs).

Experiences of 'the tragic'

Health care providers felt unsettled being exposed to patients' vulnerable emotions despite recognizing that they were not responsible for causing patients' fears, anxiety, anger and despair. Health care providers were personally impacted by patients' negative reactions towards them regardless of how many years they've been in practice (P1). In spite of their considerable training and experience in dealing with patients' emotional pain, social workers and counselors were not inured to patients' despair and anguish over lost hopes. Health care providers experienced their greatest challenge anticipating the loss of patients with whom they have developed a relationship over time. Patients who experience emotional difficulties adjusting to their prognoses also created challenges for HCPs.

Sadness of work

All respondents alluded to the inherent sadness of their work as they described their experiences as *disheartening, depressing,* [emotionally] *dragged down*, *heavy, overpowering,* and filled with grief and tears. Guilt and helplessness about their inability to change the outcome for their patients also surfaced for some HCPs:

> *I'm sure I've failed in many occasions, where ah, I've not dealt with it, you know, in the proper way [P1:34]…. Many times, I wished that I could have done more--- <u>but, that's okay</u>. [P1:117]*

However, upon reflecting on the sadness, a social worker was able to comment on 'okayness':

> *A place of <u>'okayness' is interesting</u>… because it's sort of like…<u>sometimes it really doesn't feel okay</u>? But, I'm talking about the net result is… I feel 'okay'--- I have to accept this. And for me, it comes from a sort of a spiritual belief …it gives me a sense of inner peace and harmony about having to say goodbye. [SW2:40.*

Although feelings of helplessness and sadness were painful, HCP coped by delineating their involvement with patients:

> *not that I…don't stop for a moment to take a little pause when you know somebody that I have developed a relationship with, passes away [trails off]---but I don't, <u>I don't stay there, I can't stay there</u>. [N1:54]*
>
> *I sometimes wonder if my views are a bit abnormal to the norm because I do feel so at ease with the life-death. <u>Not that it's not hard. It's painful</u>. [SW3:87]*

Grief work

Although all respondents were cognizant of the grief that patients experienced in facing their palliative diagnoses, only the social workers and counsellors spoke overtly about their own grief process and what they did to address their personal experiences of grief:

> *…we don't know when we are gonna die…, so this is your time so, it's about staying connected to their process and acknowledging my own grief, my own sadness about the losses in their life and the losses for their families… so I can be there and in a compassionate way and centred way… and so that way, I can really use my colleagues at work (smiles) to debrief and just to talk through the---how it is impacting….[C1:18]*

Others expressed a sense of helplessness when confronted by patients' grief:

> *"it's the end" is what she said - and [I] just said to her, I don't think it is--- the end - because I don't think it is - but what should I have said? [N2:156]*

Anger

HCPs sometimes bore the brunt of patients' anger and frustration after they had received news of their diagnoses. Distressed patients may express their fears through their anger and frustration as they struggle with their overwhelming illness. HCPs were able to de-personalize patients' anger and expressed understanding and insight about the reason for patients' anger. The experience of being the recipients of patients' anger was nevertheless distressing and difficult for HCPs.

Patients' hopelessness

HCPs found it difficult to cope with patients' reactions of hopelessness and sadness in medically 'hopeless' situations:

> *…when I was doing… [ward work], I did find that [being exposed to dying patients] difficult to get away from], I would worry about my patients when I went home, and I would find it more emotionally draining because I had more contact with them. [P2:52]*

Another HCP talked frankly about their own feelings of helplessness when patients expressed their hopelessness:

> *[sigh] When a patient is hopeless…well for sure I send them to a patient family counselor ...often times I wish I had a background in patient and family counseling to know what to say to some of these people when they're so hopeless…*
> *… hopelessness is sometimes a word I don't know if I have in my vocabulary - I think there's always something that can be… ways and means that can find some kind of answers…. Obviously I've met people that are that way - maybe I don't want to spend as much time with them as someone who is hopeful - because - I don't know what to say--- a lot of the times. [N2:147-149]*

HCPs recognized their own vulnerabilities to patients' hopelessness and acknowledged the value of maintaining a distance from emotionally draining situations:

> *They're (medical oncologists) the ones who are admitting [patients] to the hospital when they are near the end… and we actually don't, so we get it right to that point---then we kind of stop. Maybe that's good as well for us, makes it easier. [P3:166]*

Study findings revealed that health care providers varied in their comfort level in dealing with emotionally-charged situations. Social workers and counselors stepped into the breach to 'hold the space' for patients who expressed their hopelessness:

> *to just, hold that space with them and to allow them to grieve, and allow them have their anger about it , their sadness, what ever level of feelings that that have about it… that's a really special thing. [C1:69]*

Counselors talked about the importance of doing their own 'inner' work so as to be able to address patients' hopelessness.

The findings revealed differing disciplinary practices in dealing with patients' hopelessness. Physicians and nurses were able to acknowledge and work with patients' hopes to some extent, but were not prepared or comfortable in dealing with patients who expressed their hopelessness. Several respondents expressed relief that they were able to refer emotionally volatile patients to counselling professionals.

The paradox of hope and hopelessness

Hope cannot exist without hopelessness. Parse (1999) described this as the 'hope-no-hope paradox'. Health care providers in the study acknowledged the importance of respecting patients' hopelessness:

> *They're appropriately feeling hopeless - and you don't want to take that away from them - because that's something that they have to go through. [P1:181]*
>
> *I hope I don't… negate their feelings – I want to try and understand where they're coming from… Then <u>you can try and spin it and make them go away feeling a little bit better about it</u>. But then there are other situations where it's not so much hope – <u>they're feeling hopeless because it is hopeless. It's realistic hopelessness.</u> [P2:171]*
>
> *Just being with them, accompanying them, wherever they are. So if they're in despair, or sad, to know that that's okay… to be there. And if they are determined (emphasis). I think that's really important to expect them to feel comfortable with me, wherever they are. [SW:26]*

Acknowledging and respecting a patient's expression of despair was defined as a core part of the intervention by social workers and counselors. The focus of hope literature on fixing hopelessness and restoring hope countered the viewpoint held by counselling HCPs, who appreciated patients' expressions of hopelessness and hopefulness. A less accepting view of hopelessness was generally reflected in the literature. One reviewed article by palliative care physicians maintained that "a hopeless person is someone who has lost all purpose… [and] losing purpose is a pathological state" requiring intervention and treatment (Brooksbank & Cassell 2005, p. 236). Respondents in the current study generally expressed acceptance of hopelessness. Hopework entails living with the ambiguity of possibilities that may or may not benefit the patients' situation.

Ways & means of tolerating the tragic

HCPs' experiences reflected tangible ways in which HCPs balanced hope and reality. These behaviours and actions were categorized into the following incidents (or codes): setting boundaries, being professional, coping by doing and making a positive spin.

Setting boundaries

Study findings suggest that HCPs relied heavily on maintaining their boundaries from the patients' experience so as to enable them to effectively attend to the patients' care. Creating a therapeutic distance was an important means of developing a buffer from becoming too attached to patients. This was particularly evident amongst the doctors and some nurses and, to a lesser extent, the social workers and counselors. The latter group was more at ease and prepared to engage with patients' emotions because of their familiarity in working with patients' emotions.

Patients' hopelessness triggered helplessness amongst all of the HCPs. Although patients' hopelessness was acknowledged to be normal, nurses and doctors admitted to lacking the skill to address these emotions and preferred to refer distressed patients to social workers and counsellors. This eagerness of HCPs to refer such challenging patients to counselling colleagues can undermine the patients' primary relationships with their doctors and nurses, relationships patients consider essential for their hopes (Koopmeiner, 1997).

All respondents clearly expressed the need to learn to detach from their work in some manner. Setting boundaries was helpful for HCPs to maintain a balance in their work. This was achieved by HCPs acknowledgement of the limits of their professional role, the limitations of their disciplinary role within the team and knowing when to 'take a break':

> *keep a balance. Some people can be really detached….But then, most patients can probably detect that …and that's not good…you have to involve yourself to the extent that you think is healthy for you. [P1:69]*

> *----'professional distance' sounds kind of formal, but there has to be… otherwise… you'd be just <u>mush</u>, you wouldn't be able to do anything effectively for anybody. [N1:59]*

> *being 'strong' also means knowing ourselves and our limitations….in our work, we need to know when we've reached our threshold of being saturated by the pain and sadness of our work. When to take a break! [SW1:39]*

Setting emotional boundaries was important:

> *it's the old empathy versus sympathy thing. And that was the way I was trained, and ---because the explanation was, that you can't be very effective for people if you… become "too involved", which is true… [N1:55]*
>
> *I have some sort of-buffer? (laughs) I try and connect but it's not going to go to my heart… [SW:45]*

Understanding one's professional limits was also important:

> *staying in between --- should be the aim of the person in this work. No one particular person can be there all the time. [P1:72]*
>
> *I don't think it's my job to keep people alive necessarily. [SW3:83]*

Respondents had strategies that enabled them to maintain an emotional detachment from their patients. Some boundaries were provided by their work environment, such as scheduling that limited their time with patients:

> *I may opt to maintain a distance from that… I can go out and think about something [else]… move on to the next bit…that allows you to maintain some distance… to cope with things that otherwise might be overwhelming … - by the nature of the work that I do… you can choose to get involved or not… on the whole… you don't get… involved if it's going to impact on… your ability to do your work. [P2:14]*

Some HCPs, especially doctors and social workers, had flexibility in trading the cases that may not be the best 'fit' for the HCP, to alleviate 'death saturation'. Also, being involved in a variety of roles in the workplace, such as doing research, teaching and serving on committees helped to offset focusing overly on stressful patient care issues (P3).

Health care providers used ‘professionalism’ to define and limit their involvement with patients facing end of life and shield themselves from ‘death saturation’ (P1:117). Multidisciplinary roles were compartmentalized to address the complex needs of patients by providing a logical and expeditious way of meeting patients’ needs. Unfortunately, disciplinary specialties also have the disadvantage of fragmenting patient care.

Social workers and counsellors used a self- reflexive process to delineate the counsellors’ personal processes as being separate from the patients’ processes:

> *I really think that the most crucial element for us as counselors is to be in touch with ourself. And to have done our own work around our experiences with death and dying and to be comfortable….We have to have got to a place within ourselves that it’s okay…. there has to be some personal growth for the counselor. [SW3:176]*
>
> *I have quite a significant space between compassion I would feel for the family, and the compassion that I feel for the patient. Usually there is a space there, and I think that’s what lets me keep on doing it? My heart couldn’t break each time, like it would break if it was someone close to me. [SW:27]*

Health care providers also coped by differentiating patients’ experiences from their own experience. The following affirmations helped HCPs to maintain their personal identities:

> *…the patient is the one with the disease, and I can go home and you know, do whatever I want …it’s difficult sometimes - but it’s not me. [P2:85]*
>
> *I always sort of figured that I was just a part of that whole journey for patients so I do whatever I can do to help them through that journey, and I’m not the whole journey. [N1:54]*

> *I do have that, that philosophy about people's right to, to choose and be on their own path and respect their individual, their individual place in their life. [SW3:87]*

'Being professional about it'

HCPs' coping reflected their disciplinary practices and training. Doctors, and nurses to some extent, differentiated their roles from patients to maintain their emotional boundaries. This was described by a HCP as being 'professional about it' [P1]. Social workers and counselors, on the other hand, maintained their professional/patient boundaries through psychodynamic processes that enabled them to separate their personhood from that of the client. They tended to view the patients' experience as separate from their own internal processes, enabling them to maintain a therapeutic distance in their work.

Emotional tolerance was further enhanced by the use of the professional identity to delineate responsibilities involving the patient. A counsellor's affirmation of their role helped them to create an emotional space from the patient:

> *I get back into my beliefs of people have exactly what they need and have, and have all the support they need and that really they're okay.*
> *My goal here is support, witness, information, accompaniment, facilitation, but recognizing the autonomy of the client, their strength, integrity---. But when I am feeling really stressed out, or I'm really busy, and going fast, what I tend to do, is I get into that DOING mode. And then I tend---I think that it's MY responsibility based on doing something, versus their work, but that's not what's it about at all. [C2:35-36]*

HCPs relied on support from their professional colleagues in their work. Common understandings and shared experiences of patients' stories also created a sense of solidarity that made personal support from co-workers distinct from support received from outsiders. This camaraderie amongst HCPs also had the potential to reinforce medicalised views of hope.

Professional identity provided health care providers with a frame of reference in which to anchor their work. Professionalism helped HCPs, particularly the doctors and nurses, in maintaining a professional distance from the patient. Doctors expressed a strong professional ethic obliging them to take responsibility to confront cancer patients with their palliative prognosis. Although they bore the burden of truth-telling and giving the bad news, they expected the health care team be available to support their assessments, interventions and decisions in providing care to the patient.

Nurses uniformly valued and identified with the relational aspects of their work and, like the social workers, perceived themselves as members of an ancillary team effort. The nurses and social workers/counselors were assigned specific practical tasks and responsibilities in their work with patients. Although the social workers and counsellors also considered the patients' biomedical situation, they adopted a holistic view of patients and approached patient needs from a meaning-centred viewpoint.

Coping by doing

HCPs managed to cope in their work through problem-solving or 'doing for' the patient. Although there were feelings of satisfaction when patients' symptoms and pain and psychosocial dilemmas were addressed successfully, there were also limitations as to how much could be physically done for patients.

Even then, some of the goals of treating patients were tangibly rewarding and satisfying. Success and satisfaction reflected disciplinary differences in the goals set and achieved. For example, the diverse viewpoints of successful interventions described by HCPs in the study included: enabling a patient to walk after they received radiation treatment, the satisfaction of seeing a patient's pain controlled or fixing a patient's strained relationship with family members. It appears that HCPs are ultimately challenged to shift their hopes to address possibilities beyond the biomedical frame of reference and beyond their professional hopes, when illness precludes conventional, tangible interventions.

HCPs' structured 'doing' work often protected them from becoming over involved with patients. As HCPs are occupied with 'doing for' other patients and adhering to the pace of scheduled appointments, they can emotionally shift away from difficult situations:

> *It is disheartening, and of course, the reaction doesn't last for too long, because you know, you go on your way and get involved in something else straight away.... that is actually what saves the situation for the physician, because he needs to [be involved] in other things, and therefore not sit around and brood over what exactly happened, and that's what I would do because I'm not going to sit and go over the same thing... brood over it myself. That is not going to help. So, the sooner you get involved in something that keeps you occupied---. [P1:114]*

The focus on 'do-able' tasks helps some HCPs in coping with the work:

> *...you can deal with the practical end of things, that doesn't seem to be as a big an issue for the patient. I shouldn't say that ...so matter of factly, but ...it's easier to talk about logistics and practical things than it is to get into the emotional side of things. [N1:4]*

This *doing for* patients also distracted some HCPs from coping with the patient's issues about dying. Although keeping busy through distraction and avoidance enabled some HCPs to cope better, the counselling staff found busyness and 'doing' unhelpful:

> *…if I'm so busy that I am getting distracted from the process, I would not be comfortable, that I would rather take a bit of time to actually think about what's going on, to even talk with the person…so for me, it would be--- not good to be so busy---in fact, the times that I've felt badly are when I've been so busy that I haven't had that chance to connect with somebody that I've known well….distraction doesn't work for me, therapeutically….being mindful…even if I've got three minutes with her, I can … clear my own mental clatter, so that I'm fully present with them…[SW2:31]*

Another counselor reflected that *their* 'doing' mode was often born out of trying to impose their hopes on a patient:

> *Sometimes I can shift into focus on doing rather than being--- accompanying and witnessing. So that's where I get tripped up. I think that is where my own hope comes…at times, it can be very difficult to watch someone who is feeling hopeless. I think for me, that is the most physical impact. That's hard… [C2:22]*

For social workers and counselors, the focus on 'doing' signified lost opportunity to delve into patients' emotional concerns.

The 'positive spin' of hopework

Heath care providers' efforts to making a 'positive spin' for patients reflect their personal processes attaining realistic hopes. This process of adjusting hopes and viewpoints are means by which HCPs can cope and live with the ambiguities of the work they do. The positive spin tends to 'soften' the news for patients, preserve their hopes and reflects the HCPs' sensitivity to patients' vulnerabilities. In order to 'spin' hope, the HCP is challenged to imagine new and different possibilities and "enlarge on the possibilities of the situation" (Simpson, 2004, p. 436). The 'art' of the positive spin is wisdom distilled from the HCPs' hopework in stretching and balancing their beliefs of healing possibilities.

HCPs need to believe their 'spin' in order to feel congruent about using it. Positive spins are reigned in within the realm of realistic hopes, as powerful medical discourses disallow 'false hopes'. HCP providers who were less attached to the physical care of patients, such as social workers and counselors, found identifying and reframing hopes to be more inherent in their practice. These HCPs viewed life from a broader perspective and were able to view hope more expansively with their patients and thus expanded their hopes with less effort. The act of putting a positive spin on situations helped HCPs find an acceptable balance between the 'glass half full' and 'the glass half empty' and addressed the tension between balancing hope with reality and hope with hopelessness. The following methods of 'spinning' hope were articulated by respondents:

View cancer as a chronic illness

If cancer is viewed as a 'chronic' illness, one can learn to 'live' with the disease as patients with other chronic illnesses such as diabetes, COPD and heart disease have learned to do. Evidence of increased cancer survival rates in the general population supports this claim.

Focus on the positive and 'what can be done'

HCPs can develop a positive attitude in viewing situations from a 'glass half full' perspective, enabling them to focus on what can be done:

> *You are doing things and you know that you are helping people, so if you ...put the health and achievement on one side, as against the failures, usually the achievement wins. I mean, achievement doesn't mean cure. It means help. So if you have helped the person... to a certain extent…you…still manage to do that much for her/him…to look at the half full and half empty glass. That is the way to do it, but not everyone is able to succeed in that. [P1:117]*

The HCPs' partial perspective of their individual contributions to the patients' total cancer journey also enabled them to believe and rely on the "ripple effect" of their actions (Shechter, 1999).

View success incrementally & often

Purposeful feedback about incremental successes in their treatment, is regularly given to patients to encourage them in their hope to survive. Another doctor felt that it was extremely important to draw a patient's attention to the smallest positive changes in their condition to give encouragement and reinforce their hope, even though the overall picture is not optimistic (P3).

Do not explain success elaborately

One doctor found it helpful to curtail their vision of success: "*you do have success, so long as you don't explain success--- too elaborately*" [P1:127].

This strategy of not elaborating on successes in treatment may not alter the end result of this progressive disease, but it does enable the HCP to help the patient appreciate that, at the moment, the situation is going well. Treatment was contextualized by providing an incremental view of success.

Use reframing

Holocaust survivor and psychiatrist Viktor Frankl stated, "w*hen we are no longer able to change a situation…we are challenged to change ourselves (quoted by Callan, 1989, p. 34).* An integral part of the hoping process is to be able to change one's perception of the situation. One of the social workers describes 'reframing' as an intervention:

> *… We know that if we rearrange our thinking, sometimes our perceptions change too. So there's a natural inclination for me [as a social worker] to want to… 'intervene' . [SW2]*

This social worker further elaborates on the notion of reframing the patients' situation by saying:

> *I will tend to put a positive spin on some of these situations. So I think it is absolutely essential, [being hopeful]. There's no question this person 'x' is going to die, between now and that moment…the person is terminally alive. [SW2:41]*

Distinguishing possibilities from probabilities – the power of statistics

One doctor found it helpful to tell patients the *truth* in a selective manner that allowed the patient to be more hopeful:

> *…you really don't have to tell them that the chance of survival [is]… less than 15% or 10%. You don't have to tell them that. You can tell them that ---'the disease has come back but we have ways and means of dealing*

> *with it, and people's …response [to] this sort of treatment differ, so we [can]… see how you respond to it'… if the disease continues to grow despite treatment…. you have to tell them bluntly that… it didn't work, and then try to help them to deal with that…hopeless situation. [P1:105]*

This practitioner's wisdom is supported by a recent study (Thorne et al., 2006) that determined that "*numerical information was powerfully associated in the patient's accounts with the desire to be hopeful*" (p.327) and that it was important that patients' hopes be supported with 'reality-based' possibilities. The authors suggested that HCPs with the least adequate communication skills tended to rely on giving statistics to patients in order to avoid patients' emotional response to their discussion about their prognosis.

II. Building emotional scaffolding

Zilberfein & Hurwitz (2003) suggested that social workers use 'emotional scaffolding' in their work with palliative patients (p. 315). This term refers to the process of 'holding the space' for individuals to give them an opportunity to emotionally tolerate and cope with their poor prognoses. In the context of this study, I identified 'building emotional scaffolding' as a sub-process used by HCPs to maintain their own hopework. HCPs in this study strengthened themselves emotionally by focusing on the satisfaction of 'making a difference' for patients, seeking support, engaging in self-reflection and being active in self-care and spiritual practices.

Itzhaky & Lipschitz-Elhawi (2004) directed hope interventions at practitioners, as they surmised that "the way therapists react to the helplessness experienced by their clients has a significant effect on the client's ability to overcome feelings of hopelessness" (p. 46). This viewpoint was further echoed by Simpson (2004, p. 429). To maintain their own hopes, social workers were encouraged by Itzhaky et al. to practice self reflection, seek supervision, find support in the community, use self-therapeutic techniques (such as relaxation or reflection), set realistic goals, use reframing, find meaning (especially meaning in dying) and spirituality and use cognitive techniques to reject negative thinking (Itzhaky & Lipschitz-Elhawi ,2004 ,p.49-51).

Many of these identified hoping and coping behaviours were used by the social workers and counsellors in the study and less so, by the nurses and doctors. Social workers and counsellors were significantly more involved in self-care activities and spiritual interests because of their disciplinary training which focuses on the psychological, social and emotional well-being of their patients. HCPs in this study appeared to be more purposeful in the practice of self care the longer they have been practicing their profession.

'Making a difference'

HCPs expressed an extraordinary degree of satisfaction in working with cancer patients despite the exposure to a patient population that has high mortality, anxiety and depression rates (Breitbart & Heller, 2003). Sources of HCPs' satisfaction included a) direct positive feedback from patients; b) inspiration from patients' experience; c) gratifying interventions; d) being able to challenge the 'odds'; and e) having a positive work environment.

All the health care providers strongly acknowledged how patients inspired their work and deeply impacted their own appreciation of life. The HCPs' relationship with patients was described as 'a gift', 'a privilege', and 'an honour' by several respondents. One doctor talked about being exposed to the 'best qualities in people' in their work, where the patients' resilience was 'inspiring, rewarding and humbling' (P2). N2 echoes this sentiment by adding:

> *there probably isn't a day goes by where we don't get somebody saying 'thank you for that' or 'thank you for doing that' - or 'Man, you made a difference when you just said this' or 'You told me that I could take this medication - and... that made a big difference' - and so for me to be able to have people appreciate what you do - makes - makes my life...[N2:82]*

Some health care providers felt deeply inspired by their patients:

> *I see the colours in the leaves, and I walk along and I have one in my pocket! (she goes to her coat pocket and pulls out a brilliant red leaf) I have to pick up these things because they're so gorgeous! I'm so much more aware--- of what the gifts are, out there. [SW:48]*
>
> *I sort of think of it as a very personal journey so... I feel very honoured to be part of somebody's journey.... it's amazing work to me, like it's a very spiritual kind of work, which is really important to me so I do feel very honoured by it. And that gives me a lot of value. [SW3:33]*

The intimate, relational aspect of HCPs' work was singled out as a source of satisfaction for some:

> *...working with patients who are dying and their families...a pretty relational area of nursing it's <u>not focused on things to do, but how you are.</u> [N3:11]*
>
> *...we are talking about things that are to me, so important. Relationship issues that come up, helping them to change that communication, so that BEFORE they die, they are repairing...and that just feels so neat, so positive. [C2:16]*

Counselling staff found it meaningful and satisfying to be able to help patients gain perspective on their illness, to facilitate the resolution of unfinished business and to facilitate grieving:

> *I am very heartful about it, but it's, the spiritual rewards are so amazing to me that I just hold it in a lot of esteem. [SW3:33]*

The doctors expressed great satisfaction in 'challenging the odds' by successfully resolving medical issues. They were inspired by the faintest glimmers of hope and success in their work. Challenges energized them to persevere and to be tenacious in their efforts to 'make a difference'. This produced a euphoric energy that outweighed the sadness of the work and compensated for past losses:

> *…you have a person…unable to lift their legs up at all. You know overall the patient's prognosis is quite bad…you give him some treatment…he gets up and walks…goes home to enjoy [more time]…that is a big achievement…you don't explain success too elaborately. Within limits, you have success…even if you have failed …9 patients, [and] the 10th patient walks, that is a huge satisfaction…the success rate is low…it ['s] very rewarding. [P1:355-374]*

One doctor talked about their hope for the patient and the doctors' gratification at seeing tangible results:

> *if I didn't think that I had the chance to help somebody, or there's hope for help for somebody longer term, or hope to take away somebody's pain, I would find it hard to come to work in the morning. [P3:153]*

Whereas boundary-setting and leaning on one's professionalism were defensive means of coping and maintaining hope for HCPs, positive feedback from patients directly engendered HCPs' hopefulness. One doctor remarked with some humility, that oncology patients tended to express extraordinary gratitude to them even when little could be done to alter the course of the person's disease. The satisfaction of successful intervention provided tangible rewards for HCPs. The small successes were valued and deeply appreciated because they were infrequent and difficult to achieve. These glimmers of success were relished greatly and provided sustenance for HCPs until other hopes came to fruition. Positive feedback from patients further acknowledged possibilities and encouraged hopework in the HCPs.

Seeking support

The social workers and counselors in particular, appreciated receiving emotional support and the opportunity to debrief difficult cases with their departmental colleagues:

> *Having the support of team is big. And we do have the support. There's a, <u>there's a… safe space in here</u>. (gesturing to offices around) In this space, this physical space, and the ability of team to shared their struggles. "I don't know what to do with this person, I don't know how to help them, or I don't know what the resources are, or it just hurts so much right now, I've talked to this person, it's triggered this happening for me", so I feel that this is a space where I can do that. And <u>we can cry, and that's okay… we can share our sadness, or our weakness, or our poor skill, or sense of poor skill</u>, that doesn't lead to difficulties interpersonal with the team after. That's why I think we can be pretty honest about what is going on… I can't imagine doing this work without the kind of support that we have. So I think that's really important. [SW:49-50]*

These HCPs acknowledged the parameters of their ability to help patients and were willing to refer their patients to other counselors within their workplace or counselors in the community. This sentiment was also clearly articulated by nurse N1 who saw their role as participating in a part of a patient's life by stating, "I'm not the whole journey".

Colleagues were valued for their consultation and practice wisdom. The degree of support sought by nurses and doctors from their colleagues was expressed in a more constrained and less emotive way:

> *Well not that there aren't some days where …you maybe feel that way, but… Maybe talk to somebody about it --- 'What would you have done?' -. That's one - [sigh]… one area where you know nurses and probably, the doctors do the same thing - 'What would you do?' - or 'How would you handle this?' - we rely a lot on that. [N2:74]*

> *things that are useful to me are - colleagues, having the support… of my colleagues and having a group of people who I get on with, who I can talk to…on an everyday level…over a patient that you've seen, and kind of debrief each other on a kind of informal basis… I'm fortunate working here that I've got friends that I can do that with - and colleagues also, and that there is that kind of informal support network. [P2:17]*

Self-reflection

The social work literature identified self-reflective training as critical in the preparation of professionals working with individuals facing end of life (Itzhaky & Lipschitz-Elhawi Shechter, 1999; Zilberfein & Hurwitz, 2003). The process of self-reflection enables practitioners to gain insight into personal processes such as transference and resistance and insight into issues with death and dying that may impact upon their work with vulnerable populations. Respondents showed that their exposure to the deep suffering of patients caused them to appreciate their own well-being and strengthened their emotional resolve to 'make a difference' in their work.

This encouragement to practice self reflection was further supported by the literature pertaining to physician well-being (Shanafelt, Adjei & Meyskens, 2003; Weiner, Swain & Wolf, 2001). Shanafelt et al. (2003) stressed the importance of addressing oncologists' grief and dealing with their well-being when they have become disheartened by the relapse of "favoured" patients. The 'well-being' practices outlined by physician writers (Shanafelt, Adjei & Meyskens, 2003; Weiner, Swain & Wolf, 2001) paralleled the hope maintenance practices advocated by social work authors (Beder, 2000; Itzhaky & Lipschitz- Elhawi, 2004; Ruvelson, 1990).

A self-reflective practice was portrayed by respondent social workers and counselors as an intimate, fundamental part of their counselling work with patients. Working with patients facing end of life triggers the process of self-reflection amongst HCPs. Self reflection helped HCPs to develop insight and awareness of how their own hope narratives may differ from their patients' hope narratives. This general awareness and sensitivity to *difference* enables HCPs to be more generous in their views of patients' hopes by allowing them to imagine other possibilities outside of the medicalised view of hope (Simpson, 2004, p. 439).

Shanafelt, Adjei & Meyskens (2003) noted that doctors tended to shelve their unresolved emotions and spend little time in processing the sorrows or suffering that they experienced in working with cancer patients (p. 2617). The authors estimated that 25-50% of oncologists were vulnerable to burnout, thereby affecting the care that they provided to their patients. Shanafelt et al. (2003) also emphasized the importance of renewing spiritual practices, seeking support and grieving losses. Likewise, Weiner, Swain & Wolf (2001) concluded that doctors' participation in well-being activities enable them to optimize patient care. Their list of strategies included balancing work, adopting a philosophically balanced view of life, engaging in self-care, spiritual practices and valuing supportive relationships.

Study findings indicated that patients' experiences in facing end of life greatly impact on HCPs' hopework and encouraged HCPs' self-reflection about their priorities in life. One physician candidly remarked:

> *in this kind of field you do watch a lot of people--- see a lot of people either in the process of dying or after they've died… you'd … be an idiot I think to watch that and not learn something from it… [P3:47]*

The immediacy of working with dying patients compelled HCPs to engage in self-reflection, which increased their awareness and sensitivity to the needs of others. This 'death exposure' also encouraged HCPs to process their personal thoughts about life as well as death and contributed to their personal growth. The health care providers engaged in a coping process that enabled them to be 'emotionally positively rewarded' in their work (Folkman & Greer, 2000).

Personal experiences of loss enabled HCPs to gain insight into their own views on hope and hopelessness. Their practice viewpoints were impacted by their self-reflection about personal encounters with illnesses or losses in their own lives. Health care providers saw their own vulnerabilities mirrored in their patients:

> *if it were my aunt, or something like that, or somebody that I know really well. I would be much more emotional and volatile and experiencing my own grief. [SW2:12]*
>
> *my question was, can I do this work? I didn't know if I could or not---because of the intensity. And I was able to do it ... I didn't (long pause) have an emotional lack of energy. So-- (long pause) Yeah, that would have been my question---can I do this emotionally? And yes, I can! [SW:46]*
> *if I had a situation very close to me where somebody in my family was diagnosed... I sometimes wonder if I'd ever be able to work in oncology if I had an experience like that very close to me, if I wouldn't maybe want to make change---at that point. I don't know. Thankfully I haven't had to look at that. [N3:99]*

The majority of respondents considered themselves to have an optimistic outlook. Health care providers generally admitted to subscribing to the *half full* rather than the *half empty glass* viewpoint, an expression and belief that surfaced often during the course of the interviews. Respondents reported that they intentionally focused on the more hopeful and positive aspects of patients' situations when they knew that the patients' outlook was poor. These possible 'hopeful' aspects of the situation had to be congruent with their perceived reality; they had to be 'realistic hopes'.

Self-care

There was a general recognition of the need for self care amongst the health care professionals participating in the study. Practitioners with less experience seemed less purposeful in their pursuit of taking care of themselves. One more recently trained HCP was aware of the value of self-care, but found the work exciting, engrossing and energizing and thus did not feel the need to attend to self-care at present (see Table: 7 in Appendix K for HCP's self care practices).

In this study, social workers and counselors in particular, balanced their personal and work lives by engaging in peer support and practicing self-care as a means of building their emotional scaffolding. The pilot study (Wong, 2005) showed that social workers and counsellors counterbalanced their disclosure of their work with distressed patients by volunteering information during their interviews about their self-care behaviours. The self-care activities enabled counselors to modulate their emotions and feelings to maintain a balanced perspective in their lives (Wong, 2005, p. 13). Other HCPs took a less proactive stance towards self-care by protecting their vulnerabilities by limiting their emotional connections with patients. My insider knowledge provided me with information that members of the counselling team also limit their exposure to patients' tragedies by working part-time to maintain balance in their lives.

HCPs' used their prerogative to limit their involvement with patients whom they found overwhelming. This study revealed that doctors and nurses maintained their emotional equilibrium by limiting their exposure to challenging patients and by referring such patients to other disciplines. HCPs' ability to sustain themselves emotionally, psychologically and physically is a critical contribution to their emotional scaffolding and enables them to tolerate the work they do to maintain a hopeful balance in their work.

Some respondents felt that talking to colleagues helped them to debrief and process their experiences. One respondent thought that formalized supports were awkward and preferred the informal support of colleagues. Contrary to this opinion, another respondent mentioned the usefulness of organized group support sessions. A clinic support group was formed in the past year for cancer clinic staff who wanted an in-house venue to debrief their experiences in working with cancer patients.

These observations of the different ways in which HCPs coped and tolerated the stress of their work indicate the multiple layers of hopework. Some HCPs coped and sustained their threadbare hopes by minimizing their involvement with suffering patients in order to fortify their existing hopes. HCP's who are more experienced in *tolerating the tragic* and in *building emotional scaffolding* seemed more able to conduct hopework with more confidence and perhaps be more positive in their relationship with patients.

Spirituality

Respondents made reference to the importance of being 'grounded', 'mindful' or 'in the moment'. Spirituality was identified as an important aspect of their self care routine particularly amongst counselling staff. Some health care providers, including some of the nurses and most of the social workers and counselors, tapped into their spiritual resources for their work with patients facing end of life. Spiritual beliefs and practices enabled some HCPs to 'let go' of dying patients to the care of others and framed 'dying as a sacred experience' that aided in the transition between life and death. Patients' experiences and search for meaning triggered HCPs to explore their own sense of meaning and spirituality:

> *It causes me to look at how I 'm living---and try to ask some important questions about that--- sometimes they teach me SO MUCH! I'm just in AWE of how they manage (sounding incredulous), and inspired by--- THEIR searching for meaning, it then enables me, or ---facilitates my wanting to look at my spiritual life. [SW:45]*

The social workers were unequivocal about the importance of spirituality as a resource to help them to cope with the work that they do:

> *...it's a spiritual practice for me ... to have that kind of way of looking at the universe and life ---sustains me, it makes me feel ---when suffering exists, we grow in thoughts in our own cognition, we [face] the course of human suffering just by the way we work --- by the way we respond rather than react to it---. [SW2:24]*

Nurses were less explicit about their thoughts pertaining to spiritual beliefs, although one nurse alluded to spirituality as a resource that enabled them to respond 'in the moment' with patients (N3). Another nurse felt they benefited from support within their church community. One physician acknowledged religion as a resource for others but did not actively participate in spiritual practices themselves. Respondents with spiritual resources commented that their spiritual beliefs contributed to their personal growth and helped them to cope in life and in their work.

Outcomes of hopework

Health care providers' hopework focuses on possibilities based on the hopefulness of the situation. Perakyla (1991) viewed hopework in its entirety by recognizing that the process can assert or dismantle hope (p. 409). The ultimate outcome of HCPs' hopework is to find that balance between hope and reality, evidenced in their openess to possibilities and in their acceptance of the situation.

Allowing possibilities

HCPs were able to envision possibilities for patients in their hopework within themselves as part of their psychodynamic processes. They were able to employ various methods to encourage patients' hopes by cultivating their own hopes. Information was provided to patients to help them navigate the future, views of the prognosis were softened to give patients a more hopeful perspective and possibilities were enlarged upon:

> *…even if you don't believe in it [the possibility of a patient doing well], it's better to --- to not outright lie, but soften …whatever you're telling the person…[trails off]…. if you take hope away, then, that will be the end of it [patients' hope]. [P1:94]*

As they gained experience and practice wisdom, HCPs were able to witness and relate 'true' stories of exceptional patients who survived despite of statistical probabilities. They were able to provide 'possibilities' (hope):

> *…now that I've been around for a while – is that I do have patients that have defied expectations – and there's more of them now than there used to be – I can be honest with patients, and say, 'this is what usually happens, but you know, I've got patients who are alive several years after I've told them this sort of information … you give them that information but you say 'but there's always people who do better than expected and they have had amazing results with this'… So in situations where… it doesn't look good… I'm more frequently saying to patients – but, there's all these patients, and then I've got examples of those patients that do better than you'd think. [P2:194-198]*

HCPs who have been able to 'stretch' their viewpoints with the new knowledge of 'exceptional possibilities' can help enhance patients' hopes. Unfortunately, patients' hopes are still vulnerable to the more rigid views of those HCPs who have not evolved to this knowledge, or who *choose* to adhere to viewpoints strictly pertaining to a biomedical perspective. Respondent P3 shared how they learned to be 'realistically hopeful' through their gradual exposure to scenarios that expanded their hopes:

> *…it took me a few years to… figure out how to go about it. I realize now that that it's a matter of… redefining what to hope for---for the patient… you can… move that hope to something else. Like hope that you can be pain free for the next couple of weeks, hope that you'd be able to spend Christmas with your family, hope that you'll be able to make that vacation that you wanted to do …refocus the hope to something that is more realistic… That's something I learned over the years. [P3:82]*

This HCP learned that hopes for patients were not solely associated with treatment and cure but could also encompass quality of life issues--- a more holistic view of the patient.

Nurses and counselling staff, in particular were left to address patients' emotions after the relaying of the bad news. Oftentimes, patients were not fully aware of the implications of what they had been told by their doctors putting HCPs in an awkward situation:

> *there 's a way that you're holding that information, you're holding that knowing that, this is not going to turn out well… it is an important thing to be really conscious of… people are so sensitive to picking up those non-verbal messages from health care staff. So it is really important that you help them take in the information, absorb the information, and then, find their way to be with it so they are okay. [C1:78]*

HCPs other than doctors, had limited power and responsibilities in giving the bad news but experienced the burden of dealing with patients' emotional suffering in the aftermath of being told about their prognoses.

Acceptance – Being 'okay'

The sadness of the situation 'just is' (P3:72). Acceptance was a philosophical stance assumed by several HCPs who reflected on the normalcy of the dying process and the temporal nature of life. These views were reflected by all disciplines although more explicitly by the social workers and counselors. HCPs accepted and worked within the parameters of limited goals for treatment:

> *I think most physicians have this ---sense of achievement that they are able to do something, not necessarily cure a patient….You feel that you've contributed something… <u>there is a sense of acceptance too…. if you have done enough for them</u>, so there is nothing you can do, in terms of the disease itself. <u>Then you have to accept that goal.</u> [P1:9]*

> *Sometimes there's absolutely nothing you can do about it. And I think to realize the difference between the two is…important … realizing that…this person's hopeless for a lot of really good reasons. I'd feel hopeless if I were in this situation too [P3:177].*

SUMMARY OF FINDINGS

A meaningful picture of the hopework of health care professionals emerged from this study. Although their hoping processes underpinned their daily professional practice and impacted their relationships with patients, HCPs were not overtly aware that they were engaged in their own hopework throughout their interactions with patients. Even before seeing patients, HCPs conceptualized a framework of hope in order to guide their conversations and behaviours with patients facing life-threatening diagnoses. They negotiated and mutually constructed visions of the future within their relationship with patients while they were engaged in providing interventions to patients. These HCPs shifted their hopes and continued to work on their 'positive spin' as they journeyed with patients and their illness. Although the HCPs and patients may hope for different things, both were engaged in the hoping process (Eliot & Olver, 2002).

Learning to live with the ambiguities of realistic hope was the overarching core process in the HCPs' hopework. Health professionals were challenged to find ways of seeing the 'glass half full' from the 'glass half empty' and to be able to develop a 'positive spin' for patients. This process required the HCPs to be able to acknowledge possible scenarios and multiple realities beyond the confines of the biomedical viewpoint. Time and experience honed this process of hopework.

The processes of hope for HCPs are multi-faceted and complex. Hope processes of HCPs were affected by three factors/conditions according to the findings of this study. The health care providers' *personal hopes* were impacted by individual qualities such as open-heartedness, optimism, imagination and intentions to be patient-centered. Secondly, *professional hopes* were defined and determined by their training and experience, which accounted for disciplinary differences of respondents' hopework. Finally, HCPs' hopes were defined within the HCPs' relationship with patients and their colleagues.

HCPs felt that they attended to patients' concerns but they did not easily recognize or consider patients' hope narratives. Hope was not perceived as an entity for discussion but assumptions seemed to be made that everyone shared the same hopes. Most HCPs were not aware of their own hope processes and how this impacted on their work and affected their relationship with patients. This lack of awareness of the hope processes by HCPs leads me to surmise that HCPs were not aware of the part they played in shaping the hopes of patients with their hope narratives.

Despite some disciplinary differences in their hopework, some core values emerged consistently across disciplines. Respondents desired to 'make a difference', adopted a patient-centred approach and demonstrated an open-heartedness and compassion in their work. They struggled to identify 'realistic hopes' congruent to their professional and personal values. These hopes were manifested in the 'positive spin' or hope narratives that HCPs used to do their hopework.

Health care providers engaged in several processes in their hopework to enable them to cope with their work. They delineated personal and professional boundaries in their work to defend themselves from 'death saturation'. They learned vicariously through patients' experiences and viewed their lives in context of their patients' experiences. The practice of self-reflection coupled with an optimistic desire to 'make a difference' motivated HCPs in their work. Personal and professional satisfaction and meaningful relationships with patients and co-workers encouraged HCPs in the face of 'hopeless' situations.

'Coping by doing' for patients provided a limited means of sustaining the hope of HCPs and patients. Tangible goals of hope provided HCPs and patients a way of assuaging feelings of helplessness and allowed individuals to avoid melancholy emotions. For those HCPs who addressed patients' emotional pain and suffering, self-care and the focus on spirituality was a prominent aspect of their hopework. Generally, HCPs experienced helplessness when they were not able to intervene in patients' suffering and despair in a tangible way. Some HCPs, particularly the social workers and counsellors relied on their spiritual and philosophical beliefs to process their thoughts regarding these situations.

The mutual construction of hope between the HCP and patient (Larsen et al., 2005; Simpson, 2004) was identified as another process within HCPs' hopework. The findings suggested that the HCP/patient relationships illuminated HCPs' understanding of their own hopework. Patients' stories impacted on HCPs' concepts of hope and increased their awareness of patients' needs and gave them an impetus to hope to improve patients' quality of life.

Findings and existing literature

The findings of hope processes amongst respondent HCPs were congruent to the conclusion that hope is multi- faceted with experiential, spiritual, rational and relational qualities (Dufault & Martocchio, 1989; Farran et al., 1995). The co-constructed nature of hope between the HCP and patient was further supported by the data in this study (Clayton et al., 2005; Elliot & Olver, 2002; Parker-Oliver, 2002; Snyder et al., 2005). Self-reflective practices amongst respondents also reinforced the literature primarily written by social workers who stressed the important role that reflexivity plays in working with palliative patients (Ridgway, 2004; Zilberfein & Hurtwitz, 2003). Respondents engaged in active problem-solving processes in their hopework, and the actions of 'hope-doing' towards helping patients balance their hopes was evident and supports findings in current literature. However, the emergence of the meaning-centered, internal hopework of HCPs and how they cope with their caring for patients is a finding not reflected in the literature reviewed.

Introduction:

Findings from this grounded theory study emphasized the critical importance of hopework in the HCP/patient relationship and addressed how HCPs sustained their hopes in their work with palliative patients. Analysis of findings crystallized the experiences of HCPs' hopework to 'fit' within the empirical world and provided a framework for acknowledging that hope processes have 'relevance' in HCPs' interactions with patients facing end of life (Charmaz, 2006, p. 54). Furthermore, HCPs who were presented with the findings of this study confirmed that the processes identified resonated with their own experiences, thereby providing the relevance needed in developing an emergent theory (Hutchinson, 1993).[11]

The focus on the clinicians' hopes in this study refined, extended, challenged and superseded mainstream extant concepts (Charmaz, 2006, p. 168). This study challenged the assumption in mainstream hope literature that HCPs 'know' about hope and are able to help patients sustain hope without thought given to the HCPs' need to attend to their own hope processes. The findings supported the notion that hope is nurtured within the HCP/patient relationship. It is in this context that HCPs and patients' intimate hope narratives influence each other and hope is co-constructed. This mutual process of hopework between the HCP and patient was not clearly acknowledged in existing literature.

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[11] This study and findings were presented to HCPs at a multi-site psychosocial rounds at a Cancer center on April 11, 2007.

The study demonstrated rigor by closely aligning with the grounded theory methodology used to explore how HCPs constructed their experiences of hope (Strauss & Corbin, 1990; Charmaz, 2006). The exploration of HCPs' experiences caring for palliative patients offered rich and in-depth data that contributed to the formulation of a framework for understanding the hopework of HCPs. The time constraints of this study limited efforts to explore variations in behaviours and interactions that may challenge the emergent theory (Hutchinson,1993, p. 207). Hence, the emergent theory of the hopework of HCPs caring for oncology patients facing end of life is not yet generalizable. However, the findings show remarkable consistency and congruency defined by the study's triangulating sources such as: the reviewed literature, extant texts, findings from the pilot study, my personal experience as a patient, my professional experience as a clinical social worker, and finally, feedback from HCPs' member-checking.

Further findings in the literature

The findings that emerged from this grounded theory analysis precipitated further theoretical sampling of literature that specifically focused on hope processes and coping in oncology. The core literature on hope initially reviewed in Chapter Two, established the importance of HCPs' hopes in their relationship with patients and how HCPs' attitudes can threaten patients' hopes (Benzein & Saveman, 1998; Holtslander, 2004; Jevne & Nekolaichuk, 2003; Miller, 1989; Penson, 2000). The core literature reviewed vaguely addressed HCPs' processes of hope. The literature authored by social workers, although directed at social workers, was found to provide the most insight about the psychosocial aspects of hope and working in end of life care (Beder, 2000; Itzhaky & Lipschitz-Elhawi, 2004; Ruvelson, 1990). This insight was absent from the mainstream hope literature. A number of disciplinary practices outside of the predominant nursing contributions also wrote about the hopework of health care providers. Bioethicist Simpson (2004) explored the role of hope in healthcare by focusing on how HCPs' can 'morally' attend to the vulnerable hopes of patients in end of life situations (p. 443). She noted that:

> *…due to specialized knowledge that health care providers have and the ability to control access to treatments and other forms of assistance, many patients will rely on health care providers to support their hope. Hopes cannot…be sustained by the patient alone…(Simpson, 2004, p. 445)*

Health care providers have a responsibility to recognize and understand how their own hope processes impact on their patients' hopework. This study raises the profile of hopework to significantly contribute to filling gaps in the current literature on hope in health care. The hegemonic medical viewpoint of hope is challenged by a) exploring HCPs' complicity in patients' hopework, b) questioning assumptions that HCPs can 'know' patients' hopes without exploring their own hoping processes and by c) revealing the specifics of how hopework is mutually constructed in the relationship between HCPs and patients.

DISCUSSION:

> *...when professionals evaluate their own level of hope, they are evaluating their ability to be effective helpers. Professionals must find a way of sustaining a hopeful orientation in the presence of those who don't comply with treatment, don't get well, won't take advice, and don't convey a sense of appreciation (Jevne & Nekolaichuk, 2003, p.197).*

Processes of hopework

Patients' hopework was amply addressed in the literature (Eliott, 2005; Farran et al., 1995) but HCPs' hope processes remained largely invisible and unexamined. The overarching question guiding this examination of HCPs' experiences: "How do health care providers sustain their own hopes while caring for cancer patients facing end of life?" was addressed by a unique examination of HCPs' psychosocial processes. The relational context of hopework was one of three critical factors and conditions identifying this hope process. Personal and professional factors also impacted on the HCPs' hopework. Although there is a tendency to view the hoping process from a positive, hopeful perspective, hopework also encompasses the process of dismantling hopes (Perakyla, 1991) in search of 'realistic' hope.

Hoping as a coping process

Hoping has been identified as a primary form of the coping process (Toktali (1987) cited by Itzhaky et al., 2004, p. 47). Although it is not within the scope of this study to explore in-depth the intertwining relationship between the two processes of hoping and coping, hopework enables coping. This coping process was well-illustrated by Folkmans' (2000) theoretical model of the coping process developed to explain how individuals cope with stress and attain psychological well-being during serious illness (Folkman & Greer,2000, p. 12).

According to Folkmans' (2000) model, the harmful, threatening or challenging nature of stressful situations causes individuals to appraise their options for coping. Personal beliefs, values and commitments influence how threats are appraised (Folkman & Greer, 2000, p. 12). Coping strategies entailed problem-focused coping or emotional coping. Successful coping resulted in a favourable resolution of the stressful event. However, if a resolution was not possible, Folkman identified meaning-based coping as a means by which individuals can 'relinquish untenable goals and formulate new ones, make sense of what is happening, and appraise benefit where possible' (Folkman & Greer, 2000, p. 13). The successful resolution of the problem sustains the coping process by the achievement of positive emotions.

I adapted the framework of the Folkman (2000) appraisal and coping model to the hoping and coping processes experienced by HCPs in this study. Similarities were noted between the coping processes used by patients facing serious illness and HCPs facing the challenges of caring for palliative patients. This adaptation of Folkmans' model provides a coherent structure in which to frame the processes of hopework:

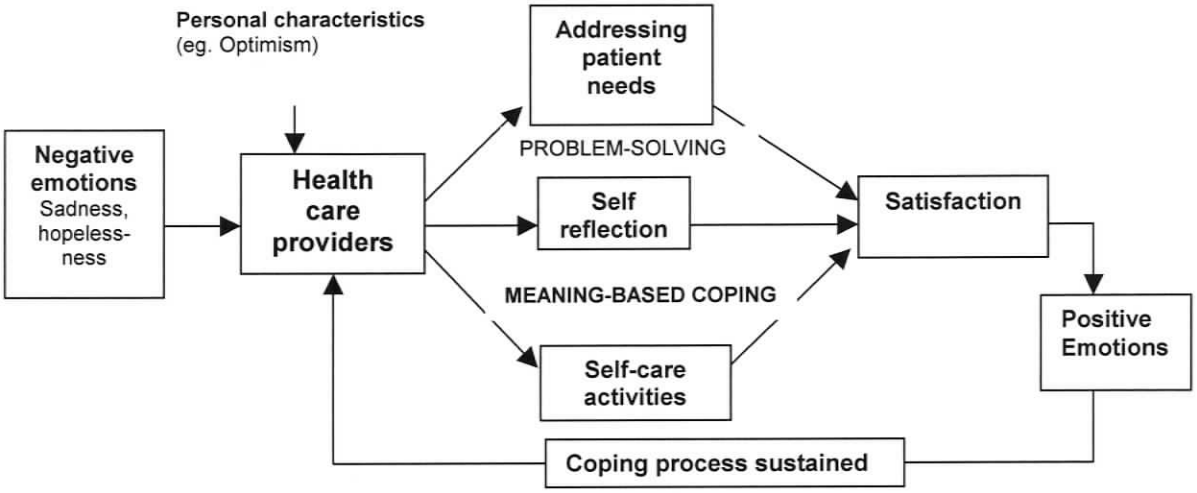


Figure 3: Coping processes of HCP in response to negative emotions.
Adapted from Folkman & Greer (2000) Theoretical model of appraisal & coping processes

Hope co-constructed and sustained within relationship

The findings in this study showed that both HCPs and patients' hopes are mutually cultivated and nurtured in the HCP/patient relationship. Interactions with patients caused HCPs to adjust their own professional and personal hopes as they accompanied patients on their journey with illness. Respondents talked about being inspired by patients' resilience and gratified by patients' positive feedback. They felt supported by patients when they had difficult news to deliver and were 'heartened' by the hard-earned successes in their work with patients. Although the literature supported claims that patients' hopes are nurtured by their relationships with HCPs (Groopman, 2004; Larsen, Edey & Lemay, 2005; Ridgway, 2004), writings have been less explicit about how HCPs' hopes have been nurtured. The following diagram illustrates how patients' emotions and experiences permeate HCPs work in their relationship:

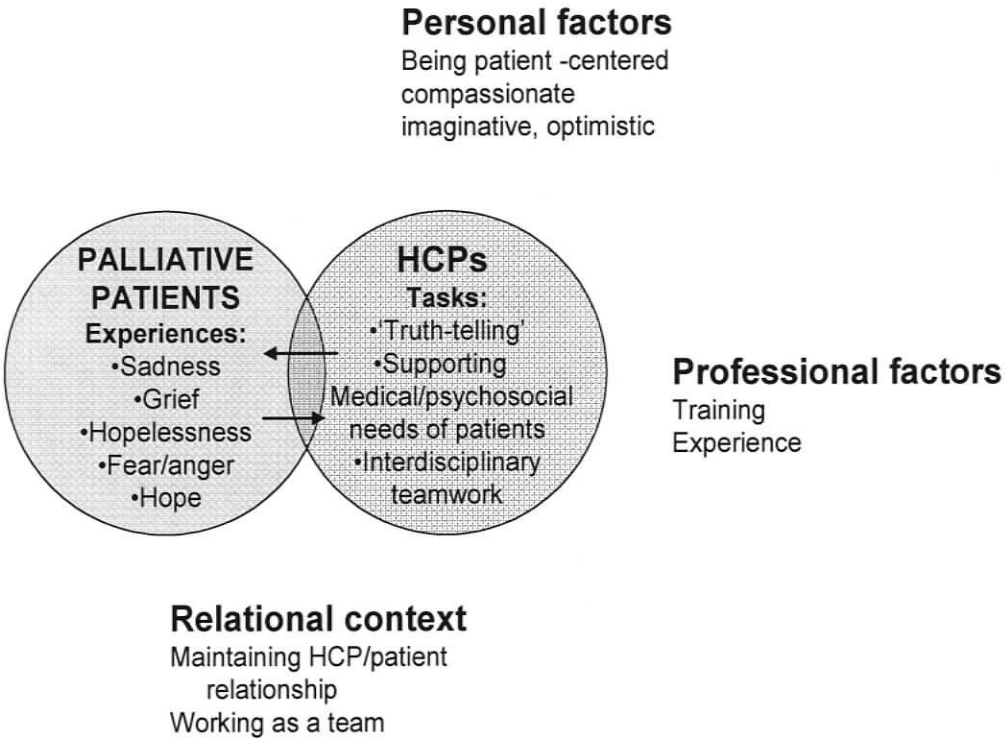


Figure 4: Factors & conditions impacting hopework between HCP & patient

Personal and professional factors influence how HCPs respond to the patients' experience of illness and their needs. HCPs' training, experience and personal qualities impacted how and what 'truths' were given to patients. These factors also influenced how HCPs addressed the medical and psychosocial needs of patients, and how HCPs functioned as individual team members to support patients. At this juncture, 'truth-telling' is formulated whereby HCPs' pessimistic professional and personal hopes for the patient can potentially damage patients' vulnerable hopes.

Inherent in this process of construction of hope between HCP and patient is the assumption that the HCP has compassion towards the patient. If HCPs lacked interest in being patient-centered and disregarded patients' needs and concerns, hopework may take a detrimental direction. 'Open-heartedness' was notably present in the hopework in the HCPs interviewed in this study. Although the HCPs did not seem to share the same hopes as their patients, their compassion and sense of caring impacted on their mutual hopework. HCPs' narratives reflected their caring by the use of phrases such as: "my heart doesn't break", "open-heartedness", "it's not going to my heart" to describe interactions with patients. This quality of being 'open-hearted' substantiates describing the relational aspect of hope as the 'heart of hope' (Farran et al., 1995).

Shifting hope with reality through meaning-based coping

Health care providers engaged in processes of adjusting and shifting their hopes as they journeyed with patients' tragic experiences through emotionally ambiguous terrain. This core psychosocial process was identified as a consistent variable amongst actions and experiences that HCPs shared in the study. Study findings suggested that the search for realistic professional and personally congruent hopes gave HCPs their greatest angst. This process of shifting and modulating hopes was ultimately identified to represent the overarching concept in their hopework.

Two sub-processes defined HCPs' actions in their hopework, a) tolerating the tragic and b) building emotional scaffolding. Although both categories of actions were meaning-based coping processes, *tolerating the tragic* has a greater problem-solving orientation as illustrated by HCPs' actions of setting boundaries, 'being professional' , coping by doing, and spinning hope. On the other hand, psychodynamic activities to achieve meaning in work by 'making a difference', seeking interpersonal support, using self-reflection and self-care and practicing spirituality reflected more meaning-based coping in the sub-process of *building emotional scaffolding*. Although HCPs experienced satisfaction by supporting patients through practical means, ultimately, their hopework relied on meaning-based coping activities with the goal of finding a 'realistic hope' that they found to be palatable as health care practitioners. Parker-Oliver (2002) observed that "the key to hope lies in the meaning, not in life events" (p. 16), which supports the view that HCPs' hopes are encouraged by the meaning they attach to their work and not by the achievement per se.

Findings further suggest that HCPs' participation in these processes impact on their beliefs and values and have potential to shift their hopes. The softening and expansion of the HCPs' hopes can change the way in which the HCP communicate and address patients' needs. The satisfaction of hopework is realized when HCPs a) felt that they 'made a difference' in patients' lives, b) perceived 'realistic hopes' that satisfied their inner struggles with balancing hope and realism and c) were able to find acceptance of the multiple realities of hopefulness and hopelessness, by 'being okay' with the outcome.

The following diagram illustrates the dynamic processes of hopework:

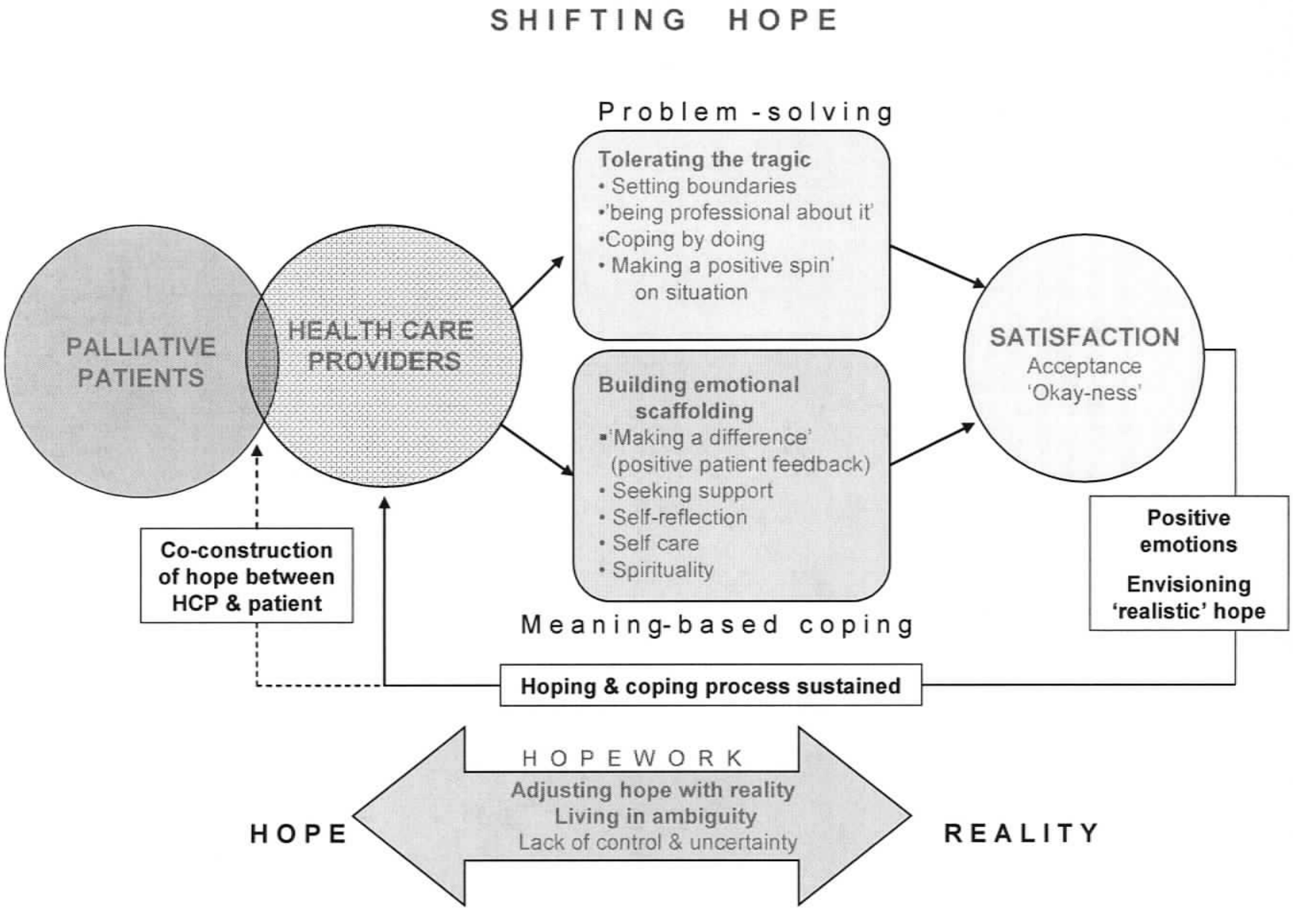


Figure 5: HCPs' hope processes

The satisfaction achieved from HCPs' hopework sustain the HCPs' ability to remain hopeful and committed to their challenging work. This dynamic process of the HCPs' shifting hopes takes place in an emotional, social and psychological landscape that changes with each new patient and medical challenge. HCPs engage in a continuous process of modulating and shifting their hopes in their hopework. This hope process has the potential to broaden their understanding of their own hopes as well as to enhance their appreciation of patients' hopes. The HCPs' hopework seems to be an instinctive process to seek realistic hopes. I posit that this inclination to adjusting one's hope can be enhanced by educating HCPs' about the importance of hope and the processes of hope at end of life care.

Disciplinary differences in hopework

Respondents in this study were motivated by the satisfaction of meaningful work, which was of particular significance to them as individuals. HCPs' hopework and how they supported patients' hopes reflected their disciplinary viewpoints. For instance, anthropologists Delvecchio Good, Good, Schaffer & Lind (1990) found that the oncologists' hopes were generated by being challenged by the 'biological frontiers' in their work (p. 73):

> *Although the biological world is perceived as dominant and resistant in the long run to the influence of the will, providing hope is seen as a clinical imperative. It is the specialist's personal sense of 'hope' in being able to 'make a difference' that frames commitment to clinical practice as well as research in oncology. (Delvecchio et al., 1990, p. 72)*

Doctors in this study were 'heartened' and hopefully responsive to the slightest improvements in a patient's condition. Their ability to view biomedical successes incrementally, partially and patiently engendered their hopes for successfully with treating their patients, thus sustaining their hopes.

Nurse respondents in the study seemed to exist within the fused reality of the biomedical and psychosocial realm in their hopework. Although nurses clearly gained satisfaction in their work by addressing the physical care needs of patients, there was generally, a keen interest in the relational, psychosocial aspects of care. However, there was some dissatisfaction expressed by nurses, who admitted that they lack expertise and experience in addressing the psychosocial concerns of palliative patients. Unlike the doctors, who seem content to leave the psychosocial care of patients to social workers and counselors, there was a curiosity and willingness by the nurses to address hope issues and an eagerness to learn how.

The transitions that nurses were experiencing at the time of their interviews in this study impacted the extent in which they engaged in discussing this topic of hopework. This was evidenced in their interviews; some nurses expressed concerns about changes and limited supports in their work environment that impacted their work, and likely, their hopework. I wondered whether the unsettled experience of the nurses in this study was indicative of broader issues of the nursing professions' evolving identity within the medical discourse (Clarke, 2005).

The social workers and counsellors' patient-focused, meaning-centered philosophy of care enabled them to attend to hopework at a deeper level. The counselling professionals attended to patients' narratives and seemed more invested in address patients' quality of life issues rather than on tangible biomedical goals.

Interdisciplinary contributions to hopework

Health care providers in the study used specific hopework strategies to support their patients' hopes as they engaged in the actions of *coping by doing* and *making a positive spin*. These strategies aimed to achieve 'realistic hope' - to preserve patients' hopes, yet allow them to experience the reality of their illness. In order to participate in these strategies, HCPs needed to be able to envision possibilities to activate their internal hopework. The imaginative strategies of spinning hope were identified as: *viewing cancer as a chronic illness, focusing on what can be done, viewing 'success' incrementally and often, not explaining 'success' elaborately, reframing, enlarging the view,* and *narrowing the view of the situation*. HCPs who likely suffered the angst of learning through trial and error the various ways of supporting patients' hopework can impart their collective wisdom to benefit more new practitioners. Although these strategies may need to be evaluated on their own merit, they may have some value in practice by softening the experience for palliative patients who encounter inexperienced practitioners.

The interdisciplinary perspectives undertaken in this study illuminated the disciplinary differences in how HCPs address patients' needs. There is potential for multi-disciplines to share expertise with each other that can enhance patient care. In addition, the study also identified the strengths that each discipline contributes to the health care team. Several respondents observed that the system's hierarchal values prevented them from optimally using their abilities and to share equitably in the work. These hierarchal standards need to be challenged in order for the health care team to truly benefit from the strengths and unique skills of its interdisciplinary team members.

This study illuminated the considerable expertise and knowledge that the social work discipline can contribute towards addressing challenging issues such as patients' hopelessness and HCP coping practices in palliative care. Social workers' tendency to focus on patient care obscures the strengths that their own disciplinary practice can lend to hopework in the context of the interdisciplinary team (Parker-Oliver, Bronstein & Kurzejeski, 2005). Despite social work's long-standing history of collaborative practice within interdisciplinary teams in health care settings, their subtle participation in providing support and facilitating processes within teams is often overlooked and unacknowledged.

Social workers' understanding of patients in their psychosocial, spiritual, economic and political worlds provides them with a deeper view of patients' experiences within the medical world. Social workers can expand the health care teams' vision of hope for patients in the context of the lifeworld rather than beyond the narrow confines of the medical realm. The profession has a unique perspective to offer in the area of hopework for HCPs as evidenced by the enlightening articles written by social workers about their clinical practice (Beder, 2000;Callan, 1989;Itzhaky & Lipschitz-Elhawi, 2004; Parker-Oliver, 2002; Ridgeway, 2004;Ruvelson, 1990; Schechter, 1999; Zilberfein & Hurwitz, 2003).

Although the social work contributions to the literature seem scarce, the limited writings by social workers about the hopework of social workers can potentially stimulate discussion and investigation about the hope processes of other disciplines in health care. The professions' exploration of social workers' hopework uniquely contributes to collective interdisciplinary knowledge about meaning-centered approaches to patient care, which knowledge is so crucial in working with dying patients.

This study's multidisciplinary perspective on the hopework offers a rare view of the potential for hopework as a patient-centred, meaning-focused interdisciplinary practice. Hopework transcends disciplinary differences.
The information gleaned from this micro-level study of hopework practices of HCPs can influence health care professionals' education and training at the meso-level. The situational analysis of hopework maps how individual hope experiences of HCPs is relevant to the broader medical discourse (Clarke, 2005). (Refer to Chapter Three: Figure 1, p. 46)

Mismatched hopes & communication

As evidenced by scenarios described by HCPs' in the study, mismatched hopes can cause critical communication issues between patients and HCPs and similarly, between HCPs. Unfortunately, such miscommunications are commonplace when differences arise regarding the interpretation of patients or HCPs' hopes. The emotional casualties caused by HCPs who view a patients' future as bleak and despairing, often find their way to counselling offices. Patients express their feelings of despair about their diagnoses, prognoses and their loss of hope in response to receiving the 'truth' about their illness. This everyday experience of damage to patients' hopes can be prevented through the HCPs' development of awareness and sensitivity to support patients' hopework.

IMPLICATIONS FOR PRACTICE

Hope is vital for patients' psychosocial, emotional and likely, physical survival:

> *Without hope, nothing could begin; hope offered a real chance to reach a better end. Hope helps us overcome hurdles that we otherwise could not scale, and it moves us forward to a place where healing can occur. (p. 177) I would posit that the words spoken and the gestures made by physicians and surgeons, and nurses and social workers and psychologists and psychiatrists, and family and friends, influence the synaptic connections. No one should underestimate the complexity of factors that coalesce in this biological process. But I interpret it to mean that no one is beyond the capacity to hope. (Groopman, 2004, p. 190)*

The importance of self-reflective practice in hopework

Simpson (2004) cautioned HCPs against making assumptions about patients' hopes and drew HCPs' attention to patients' vulnerability to the ministrations of health care professionals. She emphasized the need for HCPs to undertake the practice of self-reflection to acknowledge their complicit role in threatening patients' hopes. The insightful narratives of HCPs in this study showed how HCPs' self-reflective practices were inherently triggered by the nature of their work providing palliative care. There is a need for intentional rather than reactive self-reflection amongst HCPs about their hope processes. HCPs can learn to be more self-reflective about hopework through training and education. The literature shows remarkable consensus supporting the practice of self-reflection for HCPs working in palliative care, and suggests various means in which HCPs can cultivate their self-reflective practices (Beder, 2000; Itzhaky & Lipschitz-Elhawi, 2004; Ruvelson, 1990; Shanafelt et al., 2003; Weiner et. al., 2001; Zilberfein & Hurwitz, 2003). These practices include examining emotional tolerance, finding meaning in living and dying, grieving losses, engaging in peer support and seeking a balanced life.

Supporting health care providers' hopework

Although health care providers did engage in processes of hope within themselves and in relation to their patients, it was not overtly identified as 'hopework'. Their work was guided by their sense of realistic future possibilities for patients (Jevne, personal communication, 1999). Health care providers' discomfort in addressing patients' hopelessness needs to be addressed through education and training. Inability to understand the significance of hope processes and the failure to appreciate how hopework impacts caring for patients during end of life can result in patients' suffering and compromise their quality of life. This was evidenced in the emotional pain and suffering patients face following bleak discussions of their poor prognosis that I often encounter in my practice.

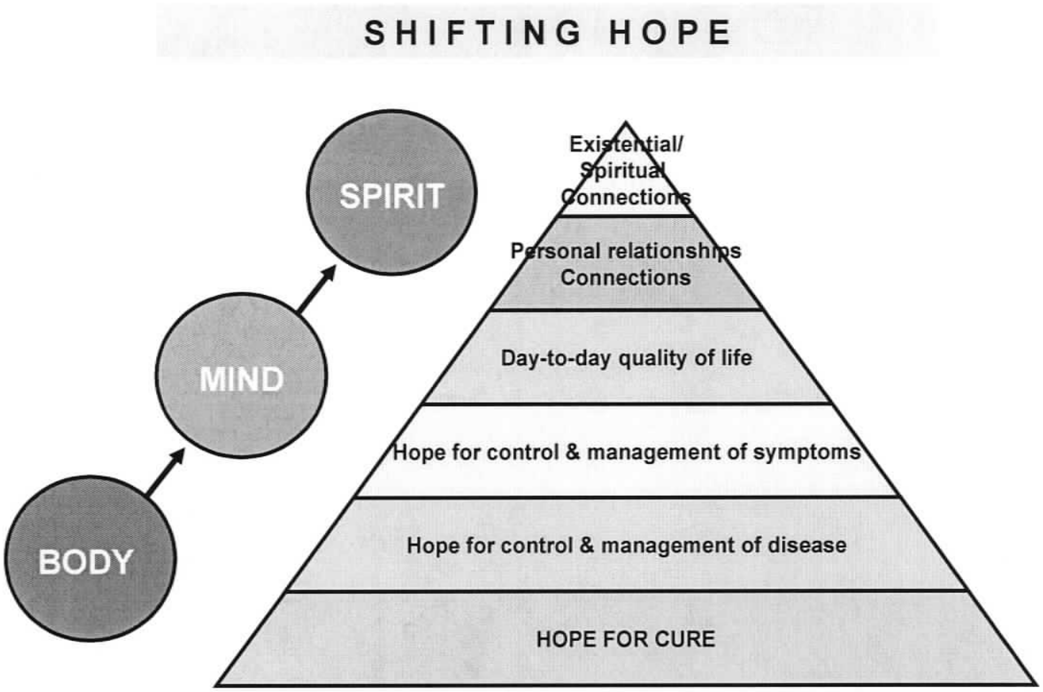
Learning hopework - Spinning hope

This grounded theory study of HCPs' hope processes indicated that HCPs' varied in their abilities and willingness to address patients' hopes. Although the social work and counselling professionals showed an inclination and ability to navigate the hopework terrain with greater ease, hopework needs to be acknowledged and learned by all HCPs. This study further substantiated the relational nature of hopework and reinforced the knowledge that all HCPs who are in contact with patients at end of life participate in patients' hopework, whether or not they are consciously aware of this process. Health care providers can respect, learn about and respond to patients' hopes without having to agree with them (Back & Arnold, 2003, p. 441). The 'collateral damage' to patients' hopes can be ameliorated by HCPs' understanding how their own hopes and hoping processes are intertwined with patients' hopework.

Health care providers need to be conscious of how hope processes underlie the behaviours of patients as well as their own conduct. HCPs' understanding of the co-constructed nature of hopework provides them with a reason to acknowledge and to explore their own hope processes. Training and educating HCPs about hope concepts would enhance their abilities to address the issues of truth-telling and finding realistic hope for themselves as well as for patients, without putting the vulnerable hopes of palliative patients at risk. Understanding the hopework processes enables HCPs to be more sensitive to the nuances of their communication with patients and causes them to listen to patients' hopes behind the words spoken. Hopework can be taught to HCPs using the same hope interventions directed to instill, encourage, nurture, foster hope in patients.

Making hopework visible

A conceptual model of hope can help health care providers visualize the multifaceted views of the experience of hope. The following hope model was developed as a visual model of hope based on what I have learned about patients' hoping processes in my years in practice:



The Hope for Cure often remains as a pervasive hope in a persons' desire throughout their illness, however, as their illness progresses, their hopes can shift. This model acknowledges the patient in context of body, mind and spirit. Although hope is not a linear process, this framework implies that hope is psychodynamic. Hopework focuses and shifts towards 'realistic' hopes when it seems that hopes based on curing the body and managing symptoms and disease are no longer viable. Mindful activities of hopework include cognitive means of coping through viewing life more incrementally and focusing on relationships rather than tangible hope objects. Enjoyment of day-to-day, moment-by-moment activities has potential to shift towards existential resources and spiritual connections as the body's abilities diminish with progressive disease. Hopework and hope interventions often occur in the transitions 'in-between the lines', as a patient' needs change with progressive disease (Wong, 2003).

Figure 6: Shifting hope model

This hope model has been used as a teaching tool for HCPs as well as an intervention tool for patients and families, although it was initially developed as a teaching tool for HCPs. Some of my colleagues have adopted this framework in their practice and have found it useful because it reminds them to envision patients' hopes beyond the biomedical frame of reference. The levels of hopework provide a template for them to explore different concepts of hope with patients who progressively become debilitated by their disease. This hope model also provides HCPs a template for monitoring their own hopes and the hope of others and patients' hopes.

A visible image of the hope process provides a nexus for HCPs, to compare and discuss their hopes with each other and with patients in a tangible way. This shifting hope model reinforces the meaning-focused intention of working with hope processes by mapping the patients' journey. Although a visual hope model does not reflect the complexity of the hopework revealed in this study, it provides a point of discussion and a place for HCPs to anchor their thoughts in terms of the processes of hope in their practice.

IMPLICATIONS FOR FUTURE RESEARCH

This grounded theory exploration about the psychosocial experiences of the hopework of HCPs caring for cancer patients facing of life provides a snapshot of their struggles to adjust their hopes to their perception of reality. The results 'open the space' for further investigation about other ways in which HCPs conduct their hopework with palliative patients. For example, what are other factors that impact on HCPs' hope processes? In this study, nurses were less forthcoming about their experiences with hope. Perhaps their focus on coping with current changes in their work environment distracted them from engaging with hopework concepts. How do cultural variations impact on the processes of hopework and the sub-processes? How do differing disciplinary practices of hopework impact on the interdisciplinary team?

Although this study inspires many questions about hopework it also provides insights about the value of sharing interdisciplinary knowledge. This study exemplifies how practice wisdom gained from years of practice can be translated into research possibilities that have the potential to change interdisciplinary practices. A centralized hope research data base of varied disciplinary interests has been established by psychologist Dr. Ronne Jevne of the Hope Foundation of Alberta, giving promise to furthering the interdisciplinary sharing of new knowledge about the practices of hopework. Patients are the ultimate benefactors of successful and willing collaboration of the disciplinary wisdoms regarding hopework.

CONCLUSION

This investigation into the psychosocial processes of hopework was inspired by the many hope narratives of cancer patients whom I was privileged to attend to in my years of psychosocial oncology work. Hopework is identified as a critical process that mutually exists within the HCP/patient relationship in a palliative care context. Furthermore, HCPs engage in personal and professional hoping processes impacted by their relationship with their patients. This study's examination of hopework based on the experiences of HCPs indicates the complexities of this multi-dimensional process.

My questions about hopework: How do HCPs sustain their hope caring for cancer patients facing end of life? Where do their hopes come from? What do they hope for? and How do embedded medical structures affect their hopework? was addressed by examining the actions and processes that HCPs shared about their experiences caring for palliative patients. Hopework in the context of HCPs working with palliative patients tapped into the internal processes of hope. HCPs engaged in the processes shifting their hope as they worked with palliative patients facing ambiguous circumstances that challenged HCPs to search for the meaning in their work. HCPs tapped into psychodynamic processes of tolerating the tragic and building emotional scaffolding. Although all the HCPs interviewed engaged in hopework, they did so at different levels of complexity.

All HCPs engaged in hopework in reaction to patients' tragic circumstances and tended to respond by 'coping by doing.' Some HCPs, such as social workers and counselors with training in exploring their own psychodynamic processes, were more able to engage in hoping processes and seemed better equipped to imagine possibilities beyond the medical realm. Although medically-trained HCPs begin with a medical view of hope as cure and treatment, this hope perspective changed as they gained experience and became aware of other possibilities which became part of their hope narrative. In this way, HCPs' hopes were nurtured within their relationship with patients. This enabled them to sustain themselves in their challenging work in caring for patients facing end of life.

The current hope literature strongly emphasizes patients' reliance on HCPs to support their hopes (Farran et al., 1995; Groopman, 2004). In order to do this, HCPs need to understand their own hopes and the hopework that they do. The intentional cultivation and use of hopework by HCPs strengthens their ability to optimize their caring work towards patients facing end of life, as their hopework is done in tandem with the patient's hoping process.

The hopework of HCPs is deeply influenced by the wider medical discourse. Within the medical culture, the construct and qualities of hope remain "elusive, mysterious, and 'soft'" (Farran et al., 1995, p. 5) as they juxtapose the definable, measurable qualities of 'hard' science and medical discourse. This grounded theory exploration further explains how hope works in HCP/patient relationships and provides a tangible framework to acknowledge hopework as an inherently valuable process in caring for patients at end of life, as well as in respecting and acknowledging ourselves as social and emotional beings.

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APPENDIX A

In my own voice: Death and despair

I came into the hospital with the words "malignant spinal tumour" on the admissions paper I held in my hand. The look in people's eyes told me how grim the situation appeared. The medical team sent me for bone scans, ultrasounds, blood work, and finally, a biopsy. Although the biopsy came back negative for malignancy, they were not satisfied and still wanted to know what kind of malignancy I had.

I knew what a spinal tumour meant: after all, I had worked as a social worker in the Cancer Centre for the past 10 years. I knew the symptoms of the cord compression and the likelihood that a spinal tumour meant metastatic disease, rather than a primary cancer.

The news was very bad. My colleagues were stunned with the news. My family was not fully cognizant of the implications of the diagnosis. I had to share the possibilities with my husband and , eventually, with my 9 year old daughter and 12 year old son.

I found myself strangely calm going through the numerous tests. I had a 40% cord compression. My legs were weak and unsteady. All those years of being supportive to patients in their emotional turmoil had taught me the value of living moment by moment and to appreciate what I had. I had hope.

I felt in my heart that everything was all right. Was this hope? My mind questioned why I felt so calm, unafraid, and peaceful. My mind methodically turned over possibilities. I decided that I would not return to work if I had metastatic malignancy. I envisioned renovating our home to accommodate a wheelchair if I were not able to walk again. I considered chemotherapy and radiation and how difficult it would be for me to come into the clinic where I work to be treated by colleagues.

I intuitively felt that this tumour had been in me for a long time. It was nothing new. I could live with it. Being a realist, I entertained the possibility that I might have a much shorter life because of it. I wept and grieved over all the unfinished business I had with my children.

The doctors focused on the bad news. Their task was to keep me in their reality. As my family doctor put it, "Helen, you know too much. We can't hide anything from you." Was it so bad that they would hide information from me to protect me?

I focused on being thankful for what I had. I felt strong mentally, physically, spiritually. I gathered all the "hopelets" that came to me ---the negative test results that found no malignancies; the opportunity to be mindful, to meditate, to pray: the loving caring thoughts from my family, friends, and colleagues. I was glad to be alive. I felt fortunate. I was in excellent hands and confident in the abilities of my care team, even though they despaired of my diagnosis. I did not let their despair affect my energy or touch my and hope and inner peacefulness.

The tumour wrapped around my spine was removed along with pieces of my vertebrae. Two 6-inch titanium rods were screwed into place to support my spine. The pathology report was negative for malignant cells. My surgeon had been doubtful that the tumour was benign until the pathology report came back after surgery. Even then, my internist cautioned me that the tumour samples were undergoing further pathology review. I was warned that I was not "in the clear" yet and malignancy might still be evident. I was not allowed to be hopeful.

I had good reason to be overwhelmed with despair and to fell hopeless. Most the professionals around me were extremely negative and offered me no hope. Fortunately, my family doctor and one oncologist colleague were able to allow that I might *not* have cancer, as test results came back negative, one by one. I was eventually diagnosed with hemangioma, a benign tumour around my spine.

I had always encouraged patients to break their experiences down into small, manageable pieces. I would ask them to look not at the "big hope" (ie. of being cured of disease) but instead to look at all the little "hopelets," at what exists and what one has. Now, I believe in this more than ever.

To flower, we need hope. Despair can wither our spirits and take up precious energy and time. Hope can generate energy. It pulls us forward even when we are not always sure where we are going. It allows us to harvest the love and hope of others around us. It makes healing possible in the best sense --- in our spirits, in our minds and, perhaps, in our bodies.

We must allow individuals in overwhelming circumstances to gather up their "hopelets," allowing each drop to collect into a pool of inner strength and peacefulness. Ronne Jevne says, "Hope is about possibility, not probability." In the realm of our spirituality and mindfulness, each step of the way hope leads us, leads us through the path of finding ourselves.

Helen Wong, BSW is a patient and family counselor with the BC Cancer Agency, Vancouver Island Centre

Excerpt from: Wong, H. L. (2003). In my own voice: Death and despair. *Transitions in dying and bereavement: A psychosocial guide for hospice and palliative care* (pp. 57-59). Baltimore: Health Professions Press.

APPENDIX B

The table below shows the authorship of the hope articles reviewed, along with the disciplinary interests that emerged from this overview of the literature:

	Nursing	Psychology	Social Work	Philosophy	Medicine	Psychiatry
Theoretical concepts of hope	7	2	2	1	-	-
Value/importance of hope	2	2	-	-	-	-
Clinicians' hope	2	-	4	-	1	-
Biology of hope	-	-	-	-	-	1
Hope Interventions	4	4	2	-		-
Communication of Bad News	1	1	-	-	1	1
TOTAL	16	9	8	1	2	2

Table 1 – Disciplinary interests on hope

APPENDIX C

	Eliott et al.(2002) psych	Peter son et al.(2004) psych	Jevne (2003) psych	Benzein (1998) RN	Miller (1989) RN	Penson (2000) RN	Callan (1989) SW	Clayton (2005) psych	Ridgway (2005) SW	Links (1994) psychiatrist	Hagerty (2005) psych	Thorne et al. (2006) RN	Brooks bank (2005) physician	
Encourage active hoping	x													1
Cognitive interventions		x			x				x					3
Attend to relational aspects			x		x				x		x	x		5
Professionals to sustain own hope			x	x					x	x	x		x	6
Hope normalized					x									1
Determinism						x								1
Philosophical Spiritual views						x				x				2
Sense of control						x	x	x						3
Goal accomplishment						x		x	x					3
Cultural considerations						x			x					2
Meaning focus							x						x	1
Reality based							x	x		x		x		4
Acknowledge individual unique hope							x		x		x		x	4
Developmental process							x							1
Name hope							x		x				x	3
Help live with ambiguity							x							1
Identify strongest hope source							x		x					2
Borrow energy							x							1
Attend to day to day								x						1
Re-anchor hope									x					1

Literature review - Hope Intervention analysis table

APPENDIX D

The Psychosocial Experience of Health Care Professionals Working with Palliative Patients in Oncology

You are being invited to participate in a study entitled: **The Psychosocial Experience of Health Care Professionals Working with Palliative Patients in Oncology** being conducted by clinical social worker, and graduate student, Helen Wong. The study will involve an interview which will be tape-recorded and transcribed with your permission and approval.

As a graduate student, I am required to do research as part of the requirements for a Masters Degree in Social Work. My research is being conducted under the supervision of Dr. Susan Strega, Ph.D., Professor in the School of Social Work at the University of Victoria.

Purpose of Study

This research project explores the psychosocial impact of working in end-of-life cancer care for health professionals, which will include doctors, nurses, social workers and counselors who work with patients with life-threatening diagnoses and poor prognosis in an oncology setting.

Findings from this study could help improve patient care by identifying ways to support health care professionals working with difficult end-of-life issues. This would enable such professionals to offer optimal care for their clients.

You are being asked to participate in this study because you have been identified as a health care provider involved in the direct care of palliative patients. A cross section of participants with varying experiences and length of practice are sought for the study. Your participation will consist of being interviewed either at your workplace, or alternate location to accommodate your schedule.

Risks

Participation in this study may cause some inconvenience to you due to your time constraints. You may find it emotionally challenging to talk about the stressful nature of your work with terminally ill patients. As a clinical social worker, I will ensure a supportive and a safe environment committed to confidentiality if you feel distressed during the course of the interview. However, if you would feel best supported by family, other colleagues, or through your Employee Assistance Program, I will help you access these resources.

Benefits

The potential benefits of your participation in this research include:

1. An opportunity to talk about your views about working with palliative patients and the challenges you experience.
2. Knowledge that your participation will contribute to ongoing research to improve psychosocial practice in oncology and palliative care through shaping in-service training in working with palliative patients.
3. Knowledge that this study becomes an exploration of the use of hope by health care professionals working with end of life issues in oncology which 'nests' within research conducted by CIHR funded NET (New Emerging Team) Research groups focus on Barriers to Communication at End of Life care.
4. An opportunity to receive current information about the experience of cancer patients' use of hope.

5. An opportunity for interested participants to debrief and discuss this study individually with the researcher, or with other interested participants.

Confidentiality & Anonymity

Only your professional role, gender and length of time working in a palliative care setting, will be referenced in the study. The research will refer to the setting as 'a cancer clinic'. The content of your interview will not be discussed with your work colleagues. However, due to the limited number of participants in this study and small professional community, it is possible that your colleagues may be able to identify your responses in the written study.

All tapes and transcripts from the interviews will be stored in a secured location with a lock. Electronic documents will be password protected. Transcripts or tapes will not contain respondents' identifying information. All documents associated with your interview and observations will be identified only by code number or pseudonym.

You will never be identified by name in any reports derived from the completed study. Only pseudonyms or a code will be used in the report. All tapes will be demagnetized and transcripts shredded within 10 years of the interview. This time frame reflects the potential data analysis for subsequent publishing of research outcomes.

Your rights

Your participation in this study is entirely voluntary and you are free to refuse to answer any question or end the interview at any time. If you have any questions or concerns about the study, please contact my thesis supervisor, Susan Strega at (250)721-8333 or email her at sstrega@uvic.ca. You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria (250)472-4545 or ovprhe@uvic.ca.

I welcome you to contact me if you would like more information or have further questions by calling me at (250)382-7799 or emailing: hwong@uvic.ca. As a colleague, I appreciate your consideration to participate in this study. However, I would like to reiterate that **your participation is completely optional, and you should not feel obliged to participate in any way, or feel that you need to offer an explanation if you choose not to participate.**

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered.

Consent

My participation in this study is entirely voluntary and I know that I may refuse to participate or withdraw from the study at any time without concern for repercussions in any form. If I choose to withdraw from the study after being interviewed, all information collected in the interview will be destroyed. My signature below indicates that I consent to participate in this study and that I will receive a copy of this consent form for my own records.

I do____/do not____agree to my interview being tape recorded.

Signature: ______________________________ Researcher: ________________________
Printed name: ___________________________ Helen Wong

Date:__________2006 **Thank you for responding to this invitation**

APPENDIX E

Consent for Secondary Analysis of data

Thank you for participating in the study entitled: ***Psychosocial impact on cancer clinic social workers/counselors working with palliative patients***, conducted in the Fall of 2005. As you may recall, this research was conducted by Helen Wong, BSW, RSW, MSW candidate, as a requirement for her Qualitative Research Methodologies course (Sociology 515 - Qualitative Research) under the direction of Professor André Smith.

This unpublished research paper and supporting data collected from the interviews with you will provide invaluable information for the current study of which you are likewise invited to participate, entitled:
The Psychosocial Experience of Health Care Professionals Working with Palliative Patients in Oncology

Your permission is sought for the release of data and information (including audiotapes and original transcripts) collected from this preliminary study from the auspices of Dr. Andre Smith, professor, Department of Sociology, University of Victoria, to the undertaking of researcher, Helen Wong, who will provide security and confidential regard for the materials as its contents are further analysed for the current study. Dr. Susan Strega, professor, School of Social Work will be providing supervision for the use of this research material.

Consent
I give permission for the release of data and information pertaining to the interviews conducted by Helen Wong, MSW candidate for her study entitled: ***Psychosocial impact on cancer clinic social workers/counselors working with palliative patients*** submitted December 2005 to Dr. Andre Smith, UVic professor of Sociology; to Helen Wong for the secondary analysis of data for her current research, **The Psychosocial Experience of Health Care Professionals Working with Palliative Patients in Oncology.** I understand that she will keep the data within the strictest confidence as outlined by the consent form for the current study. The data will be destroyed after 10 years.
My signature below indicates that I consent to this secondary analysis of data pertaining to my interviews in the Fall of 2005, and that I will receive a copy of this consent form for my own records.

I do____/do not ____ agree to my interview data and information to be released to Helen Wong.

Signature: ______________________________

Printed name: ___________________________

Researcher's Name: ______________________ Date: _________
Helen Wong

APPENDIX F

Interview guide

Background:

1. Tell me about your work. How long have you been working with cancer patients?
2. What kind of training, or background do you have for the work?
3. How often do you see patients near the end of their life, or given a very poor prognosis?

Practice:

1. What is it like for you to work with patients with a poor prognosis?
    a. What do you find challenging? Enjoy?
    b. How do you cope with your constant exposure to palliative patients?
    c. How do you cope with the challenges? What do you find helpful?
2. What would you consider to be important in working with someone facing a poor prognosis?
    a. Attributes?
    b. Aspects?
3. How do you sustain yourself in working with patients who feel hopeless?
    a. How does this affect you?
4. Are there further thoughts you would like to share about this topic, or a related topic? (Open discussion.)

APPENDIX G

1	**Personal Data**	1.1 Gender, age 1.2 Education 1.3 Professional experience (time worked) 1.4 Caseload 1.5 Context of work (area of responsibility)
2	**Professional role**	2.1 Work/Tasks &Interventions 2.2 Challenges – structural/time constraints 2.3 Training & preparation 2.4 Communication skills 2.5 Beliefs & Values (Epistemology & Ethics)
3	**Caring at end of life**	3.1 Caring for palliative patients 3.2 Truth-telling 3.3 Death exposure 3.4 Difficult cases 3.5 Sadness of work 3.6 Hope(lessness) of patients 3.7 Anger
4	**HCP Coping**	4.1 Emotional work 4.2 Setting boundaries/professionalism 4.3 Detachment 4.4 Self care 4.5 Supportive relationships (team)
5	**HCP as a person**	5.1 Beliefs, Values & Philosophy (Ontology) 5.2 Inner resources/resiliency 5.3 Self reflection 5.4 Satisfaction
6	**Hopework**	6.1 Realism & Hope 6.2 HCP/Patient relationship 6.3 Caring environment 6.4 Hope doing/Hope being

Table 5: Index for data analysis of HCPs' hopework

APPENDIX H

MEMOS (35)	# of references in data
Acceptance	19
Allowing possibilities	15
Assumptions re: profession	3
Balance in life	14
Being present	11
Communication issues	6
Coping by doing	15
Coping by reframing	7
Coping	9
Dealing with the unpredictable	2
Detachment	3
Distinguish personal from professional	6
Ethics	4
Evidence based	9
Grief	3
Holistic view of patient	10
Hope defined	11
Hopework	55
Inner reflection	18
Insider reference	35
Limits acknowledged	12
Meaning & spirituality	11
Medical hierarchy	1
Mindfulness	6
Open-heartedness	12
Patient centred	5
Patients'anger	4
Personal satisfaction	4
Professional assessment	5
Relationship:HCP & Patient	13
Surprises me	6
Team roles	9
Training	11
Transitions in palliative care	1
Truth-telling	13

Table 4: Memos created from reviewing data[1]

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[1] HU: Hopework of HCP 6Feb2007
File: [C:\Documents and Settings\Helen\My Documents\THESIS - DATA ANALY...\Hopework of HCP 6Feb2007.hpr5]
Edited by: Super
Date/Time: 25/02/07 11:48:26 AM

Human Research Ethics Board
Office of Research Services
University of Victoria
Technology Enterprise Facility, Room 218
Tel (250) 472-4545 Fax (250) 721-7836
Email ethics@uvic.ca Web www.research.uvic.ca

University
of Victoria

APPENDIX I

Human Research Ethics Board
Certificate of Approval

Principal Investigator	Department/School	Supervisor
Helen Wong **Master's Student**	**SOCW**	**Susan Strega**
Co-Investigator(s):		

Project Title: **Practice Views of Health Care Providers for Patients Facing End of Life**

Protocol No.	Approval Date	Start Date	End Date
06-05-292b	**08-Dec-06**	**27-Oct-05**	**26-Oct-08**

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

Dr. Richard Keeler
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions or minor amendments may be granted upon receipt of a "Research Status" form.

06-05-292b Wong, Helen

APPENDIX J

# of quotes attributed to situation	Physician	Nurse	Social Worker/ Counselor	TOTAL
Patient's anger	2	1	2	5
Young children involved	1	-	-	1
Talking with people with out previously established relationship about their poor prognosis	1	-	1	2
Multiple deaths (running a support group)	-	-	1	1
Patient refusing curative treatment	1	-	-	1
Hopeless & depressed patients	1	1	5	7
Someone who you feel connected with is dying	5	2	3	10
Breaking the news of transition to palliative care	1	2	-	3
When patients are asking for more treatment, but you know it won't help	-	1	-	1
Younger patients	2	-	1	3
Patients unable to comprehend situation	1	-	1	2
When the treatment isn't working	1	-	2	3
Severe emotional pain/reaction to prognosis	3	-	4	7
Offering help, but patient not responsive	-	2	1	3
Patients without spiritual beliefs	-	-	1	1
Addressing needs of family & patient together	-	1	-	1
Patients with cancer types likely to die	1	-	1	2
Disagreeing with other HCP's viewpoint	-	1	1	2
TOTAL	20	11	24	55

Table 6: Challenging situations experienced by HCPs

APPENDIX K

SELF-CARE *	Physician	Nurse	Social worker/ counsellor	TOTAL
Talking to colleagues	P2	-	SW, SW1, SW2, SW3,C	6
Balanced work setting (doing other work of interest)	P1,P2	N3	-	3
Maintaining outside relationships	P3	N3	-	2
Outside interests	P3	N1	-	2
Spiritual/mindfulness/grounding	-	N1, N3	SW,SW1, SW2,SW3, C,CM	8
Fitness/health (massage, gym, resting, good food	-	N2, N3	SW ,SW3, C	5
Time off	-	N2,N3	SW1	3
Work part time	-	-	6	6

Table 7: HCPs' self-care practices

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* The spaces do not indicate the absence of these activities, the information merely did not surface during the interview