

THE CONCEPT OF HOPE: A COMPARISON OF BONE  
MARROW TRANSPLANT NURSES AND PALLIATIVE CARE  
NURSES

by

Eliette S. M. Allec

A Thesis Submitted to  
the Faculty of Graduate Studies  
In Partial Fulfillment of the Requirements for the Degree of

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**The Concept of Hope:**  
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## Table of Contents

	<b>Page</b>
<b>Acknowledgements</b>	<b>i</b>
<b>Table of Contents</b>	<b>ii</b>
<b>List of Figures</b>	<b>iii</b>
<b>List of Tables</b>	<b>vii</b>
<b>List of Tables</b>	<b>vii</b>
<b>Abstract</b>	<b>viii</b>
<b>Chapter I</b>	
<b>Statement of the Purpose and Objectives of the Research Project</b>	
Introduction	1
Background Information	2
Significance of the Problem	4
Conceptual Framework	6
Purpose of the Study	10
Assumptions	11
Definition of Terms	12
<b>Chapter II</b>	
<b>Review of the Literature</b>	
Introduction	13
Historical Perspective	14
Models of Hope	16
Hope in Individuals with Terminal Illness or Cancer	
The Meaning of Hope	19
Strategies that Maintain Hope	23
The Benefits of Hope	26
Related Concepts	
Uncertainty, Fear and Hope	30
Religiosity and Hope	31



Realistic Hope	33
Hope and Nurses	
Influence on Hope by Health Care Professionals	34
Hope as Perceived by Nurses	35
Conclusion	41
<b>Chapter III</b>	
Introduction	42
Statement of the Problem	42
Qualitative Approach	44
Person Centered Interviewing	44
Study Setting and Sample	
Study Setting	45
Sample	46
Data Collection	48
The Interviews	48
Data Analysis	50
Ethical Considerations	52
Limitations of the Study	55
Methodological Rigor	56
Credibility	57
Transferability	58
Auditability	59
Confirmability	59
Conclusion	60
<b>Chapter IV</b>	
<b>Findings</b>	
Introduction	61
Demographic Data	62
Themes Related to the Generalized and Particularizes Spheres of Hope	66

Generalized Sphere of Hope	
Approach to Nursing Practice	66
Generally I Hope For	69
Good Health and a Long Life	69
A Life Well Lived	70
Hope is Important for the Journey	70
Particularized Sphere of Hope	
Hope for a Cure	72
Hope for a Peaceful Death	74
Summary	74
Themes Related to the Dimensions of Hope	76
Cognitive Dimension	77
Balancing Truth and Possibility	77
Switching Gears	81
Imbalance and Isolation	82
Morality Judgments	83
Summary	84
Affiliative Dimension	85
Establishing Trust And Connecting	85
Connected	88
You've Got to Laugh	89
Providing a Context	90
I Get Hope From	91
Summary	92
Behavioral Dimension	93
Fight	93
Surrender/Resignation and Acceptance	94
Affective Dimension	96
Conflicted	96
Peaceful	97
Summary	98
Contextual Dimension	98

People Come Here to be Cured	98
There was a Serious Injury/Illness in my Family	99
People Come Here to Live Until They Die	100
I Lost Someone in my Family	101
Temporal Dimension	101
Life is Day to Day	101
Living in the Present	102
Milestones	103
Summary	104
Chapter Summary	105
<b>Chapter V</b>	
<b>Discussion of the Findings</b>	
Introduction	107
Discussion of Research Question # 1:	107
How do Nurses Define and Conceptualize Hope and	
How Does Workplace Setting Influence Their Concept of Hope	
Generalized and Particularized Spheres of Hope	108
Approach to Nursing	108
I Hope for a Health and Long Life vs. I Hope for	
A Life Well Lived	109
I Hope for a Cure vs. I Hope for a Peaceful Death	109
Hope is Important for the Journey	110
Cognitive Dimension	111
Balancing Truth and Possibility	112
Switching Gears	113
Imbalance and Isolation	114
Morality of Hope	115
Affiliative Dimension	117
Connected and Sources of Hope	117
Behavioral Dimension	118
Fighting and Resigning	118

Affective Dimension	119
Conflicted vs. Peaceful	119
Contextual Dimension	121
People Come Here to be Cured/	
People Come Here to Die	121
There was a Serious Illness in my Family/	
I Lost Someone in my Family	122
Temporal Dimension	123
Life is Day to Day vs. Living in the Present	123
Milestones	124
Demographic Data	124
Discussion of Research Question #2	126
How Do Nurses Incorporate their Concept of Hope into Nursing Care and How does this Manifest itself their Practice?	
Connecting/Building Trust	126
Humor	128
Providing a Context	129
Discussion of Research Question # 3	130
How Useful is Dufault and Martocchio's Multi-Dimensional Model of Hope for the Study of Hope as It Pertains to Nurses	
Reflexivity	132
Reflection	134
Recommendations	136
Nursing Practice	136
Nursing Education	137
Nursing Administration	137
Nursing Research	138
References	139
Appendices	
Appendix A: University of Manitoba Ethics Approval	147

Appendix B: Facility Access Approval	149
Appendix C: Poster	151
Appendix D: Explanation of the Study	152
Appendix E: Research Participant Information and Consent Form	155
Appendix F: Interview Questions	161
Appendix G: Socio-demographic Questionnaire	165
Appendix H: Participant Identification Codes	167

### List of Figures

	<b>Page</b>
Figure 1. Multi-Dimensional Model of Hope	9

### List of Tables

Table 1	Years of Experience of Participants from Palliative Care Unit	58
Table 2	Years Working on Palliative Care Unit	59
Table 3	Years Working on the Bone Marrow Transplant Unit	59
Table 4	Years of Nursing Experience of Participants from Bone Marrow Transplant Unit	60
Table 5	Demographic Data Palliative Care Nurses Versus Bone Marrow Transplant Nurses	67

## Abstract

An exploratory and comparative study of the concept of hope, as described by nurses working on a Bone Marrow Transplant (BMT) unit and a Palliative Care unit. Semi-structured interviews were conducted with 6 nurses from each unit using Martocchio and Dufault's Multidimensional Model of Hope as a conceptual framework. Several questions regarding the concept hope as it relates to nursing practise were posed: 1) How do nurses conceptualize and define hope, and does workplace setting influence their concept of hope? 2) How do nurses incorporate their concept of hope into nursing care and how does this manifest itself in their practice? 3) How useful is Dufault and Martocchio's Multidimensional Model of Hope for the study of hope as it pertains to nurses? Data were analyzed using thematic content analysis. Findings reveal both similarities and differences between the two groups in the manner in which hope was conceptualized. Both groups of nurses used similar statements when describing cognitive and affiliative aspects of hope. Cognitively hope was described as the process of balancing truth with possibility. Decisions related to inspiring hope were filtered through a process of moral decision-making. Hope was incorporated into nursing practice through interactions where nurses connected with patients in a meaningful and sincere manner. These resulted in affirmation of personhood for patients and engendered trust between nurses and their patients. Nurses from each unit differed in their statements about behavioral and affective aspects of hope. The BMT nurses tended to adopt a fighting stance and reported feelings that were conflicted, such as both joy and pain, related to hoping. Conversely Palliative Care nurses reported behaviors that included resigning the fight and surrender. Further these nurses associated feelings of peacefulness and calm most closely to hopefulness. Patient care assignments need to reflect nursing time spent supporting the hope needs of patients. Further adequate administrative measures that support nurses in moral decision making should be implemented.

## Chapter I

### Statement of the Purpose and Objectives of the Research Project

#### Introduction

This study is an exploration of the phenomenon of hope as perceived by registered nurses working on a Palliative Care Unit and a Bone Marrow Transplant Unit at two different tertiary care hospitals in Winnipeg. The research project sought to describe how nurses conceptualize the phenomenon of hope and determine if and how workplace setting influences the manner in which nurses define hope. Furthermore, the study examines how hope is incorporated into nursing practice. Dufault and Martocchio's "Multidimensional Model of Hope" (1985) provided a framework for the study and its findings. The Multidimensional Model of Hope (MMH) was developed utilizing data gathered from chronically ill individuals and has never been used to examine how hope is conceptualized by individuals free of illness. It is the assertion of the researcher that the dimensions described in the model are broad and describe interactive behaviours that may be manifested by both nurses and patients during the hoping process.

Chapter one includes a description of the background of this research area. The significance of nurses' conceptualization of hope as a research topic is discussed and an explanation of the conceptual framework is provided. The problem statement and research questions are delineated. Definitions significant to this research are also provided.

### **Background Information:**

Research related to the phenomenon of hope has a rich, albeit short, history particularly among theologians and philosophers. As early as 1959 Ernst Bloch a German born Jewish atheist Marxist authored a book entitled "The Hope Principle" (1959). Bloch viewed the world metaphorically as on a journey proceeding on a mission from the unfinished past toward a future which is not yet determined. He viewed individuals as living and acting on the 'front' of time and hope as being part of that frontier of existence (Schilling, 1967). Although he was greatly criticized by fellow Marxists for the esoteric and frivolous nature of his work, he has generally been credited with stimulating discourse (Schilling) on the nature of hope, not only among theologians and philosophers but eventually among psychologists and nurses.

Leviton (1971), a rehabilitation psychologist examined the different perspectives of professional health care providers and their patients about rehabilitation issues that gave rise to tension in their relationships. She reported that one of the most of the contentious areas cited by both patients and professionals was that of hope contrasted with reality. Most patients in her study reported a preference for a hopeful approach to therapy whereas health care professionals underscored the importance of realistic goals. Patients generally preferred a hopeful approach because "hope is comforting; reality is painful; loss of hope can lead to serious emotional consequences; and expert knowledge is imperfect" (p. 237). Health care professionals



avored a realistic approach because of the positive value attributed to knowledge or 'truth' by professionals and they also reported that it protected their professional integrity. Furthermore health care professionals stated that the hopeful approach impeded the rehabilitation process and eventually lead to depression because of 'false hope'. The study points out that hopes and hoping can be a major source of tension between patients and their health care providers.

Hope has also been the focus of psychological research. Ezra Stotland (1969) was one of the earliest researchers who contributed to the conceptualization of hope. He was a social psychologist who developed and authored "The Theory of Hope" as a result of his work with individuals suffering from mental illness. Stotland conceptualized hope in terms of probability and significance of goal attainment, and linked these concepts to the motivation to act. Hope, as defined by Stotland, is the greater than zero expectation that a goal will be achieved. Stotland's theory is significant because it has provided a framework for other researchers such as Raleigh and Boehm (1994), and Stoner and Keamfer (1985) who examined the concept of hope among chronically ill individuals and people diagnosed with cancer. Nurse researchers have generally concluded, however, that Stotland's model of hope does not sufficiently address the 'multidimensionality of hope. The model emphasizes the cognitive aspects of hope and therefore the social or affiliative and affective components of hope are not addressed sufficiently.

The significance of hope as an effective coping strategy was described by Greene, O'Mahoney and Rungasamay (1982). They studied sixty chronically ill individuals, acutely ill and hospitalized with deteriorating conditions, who reported hope as a coping strategy which they utilized when confronted with difficult aspects of acute and chronic illness. This was reported once again by Hirth and Stewart (1994) among individuals awaiting heart transplantation.

Raleigh (1992) studied 90 patients with chronic illness and cancer and reported that patients listed family and health care providers as the most common sources of hope. This was achieved when patients perceived that there was active listening or affirmation during their interactions with health care providers. Participants in the study reported that "sustained and meaningful" (p.447) relationships with health care providers contributed to hopefulness.

### **Significance of the Problem**

Hope takes on a special significance in health care settings. Illness is typically associated with pain, uncertainty and vulnerability. Health Care providers are sought out by patients in the hope that cures, treatments and comfort can be provided. There is reason to believe that hope enhances an individuals' ability to cope with chronic and terminal illness (Dufault & Martocchio, 1985; Green, O'Mahoney, Rungasamy, 1982; Hall, 1989; Herth, 1990). While many would suggest that hope is one of the core values of health care culture (Wildes, 1999), most 'hope' researchers would agree that

the phenomenon of hope is under-researched and under utilized as a therapeutic intervention (Bruera & Nekolaichuk, 1998).

Researchers such as Hall (1989), Perakyla (1991) and Simpson (2002) maintain that patients in acute care settings are often dependant upon health care providers to support their need for hope. They suggest that the nature of that relationship is one of inequity in power with the patient having less power, less information and less control. Illness can often erode an individual's independence, and undermine his/her autonomy. The illness experience can create a situation whereby people are dependent upon and vulnerable to what health care providers say and do in terms of what can be hoped for. Simpson (2002) states "since health-care providers have, on balance, more power than patients, we need to ensure that we do not increase the power imbalance by taking something away from patients ..." that will undermine patients' ability to cope with the consequences of illness.

Hope is enacted through interactions such as conversations between health care providers and their patients (Perakyla, 1991). Nurses in acute care settings are responsible for the day-to-day care of patients and interact with patients/families more than any other health care professional. Nurses therefore are afforded opportunities to impact patients' and their families' need for hope. It is important to understand how nurses conceptualize hope because this will in part affect how capable or willing they are to engage in interactions with patients that validate and support patients' need to hope (Hall, 1989; Simpson, 2002).

Research related to how hope is conceptualized by health care professionals, and its effect on their practice is limited. Yet if, as the research suggests, health care professionals are key to inspiring and promoting hope for those in their care, we need to gain a better understanding of what hope means to them and what significance it has in their practice. Furthermore, we should attempt to understand how nurses' workplace settings affect their views of hope.

### **Conceptual Framework**

Dufault and Martocchio's 'Multidimensional Model of Hope' provides a framework to study hope and how it pertains to nurses and their practice. This model incorporates two spheres of hope, particularized hope and generalized hope, as well as six dimensions involved in the process of hoping which include: the affective, cognitive, affiliative, behavioural, contextual, and temporal dimensions. Dufault and Martocchio's model is a useful framework because it explains hope as multifaceted and process oriented. It is not limited by concepts that are linear and trait oriented. The two spheres and the six shared dimensions influence each other and affect how the hoping process manifests itself.

Dufault and Martocchio (1985) developed the "Multidimensional Model of Hope" (MMH) as a result of studies conducted with 35 elderly cancer patients (65 years and older) and with 47 terminally ill persons (14 years and older). Data were collected over a two year period through participant observation, in multiple settings including homes and hospitals. The propositions and

assumptions are supported by data from their research and stated as exemplars. The MMH does not expand on any given theory of behavior nor does it seek to explain and predict behavior. Rather, the investigators sought to articulate a model that identifies and describes behaviors related to hope.

The two spheres of hope 'generalized' hope and 'particularized' hope influence each other but remain distinct. Generalized hope refers to an overall sense of optimism that each individual possesses in accomplishing life's daily tasks. It is the belief that life holds some "future beneficial but indeterminate developments" (p.380). Generalized hope is broad in scope and is not linked to a particular object of hope. Dufault and Marocchio describe generalized hope as an "intangible umbrella" which protects the hopeful individual like a shield and allows an optimistic view of life. Particularized hope is concerned with specifically desired outcomes, which may include an object or even a state of being. Particularized hope demands an investment in and a commitment to something specific, toward which the hoping person can focus energy. In this study particularized hope is related to nursing practice.

Under some circumstances the manifestations of the generalized sphere of hope become more apparent. These would include occurrences when particularized hope is threatened or abandoned or when particular hope is less consequential given a high degree of uncertainty and rapidly changing conditions such as one may find in critical care situations. Manifestations of generalized hope are also more evident when individuals have identified

particular hope and adopt a generally hopeful outlook. The two concepts of generalized and particularized hope as defined by Dufault and Martocchio are analytically distinct but also contain overlapping dimensions. The combined dimensions form the 'gestalt' of hope.

The dimensions of hope are each defined by a set of components that structure the experience of hope. The changing emphasis within and among the dimensions and their components characterize the process of hoping. Multiple processes of hope related to different objects and events may be active within the same person at the same time. The dimensions of hope and their components are summarized in Figure 1.

Dufault and Martocchio's model includes five fundamental assumptions, which are stated implicitly and explicitly.

- The first assumption is that hope is not only multidimensional but it is also dynamic. This is explicitly stated within the model. The word hope can be a noun as it relates to a desired goal but it is also a verb as it relates to a process. It is not limited to a single act and may change in response to changing circumstances.

The second assumption, which is identified in the model, is that hope is related to realistic possibility. Each individual must determine which goals are realistic and which are not based upon their own cognitive processes and experiences. There are issues surrounding the aspect of reality is referred to in the model. Dufault and Martocchio are careful to recognize that reality is defined according each individual's perception but disagreement among

researchers persists as to whether or not this is a significant factor related to the process of hope.

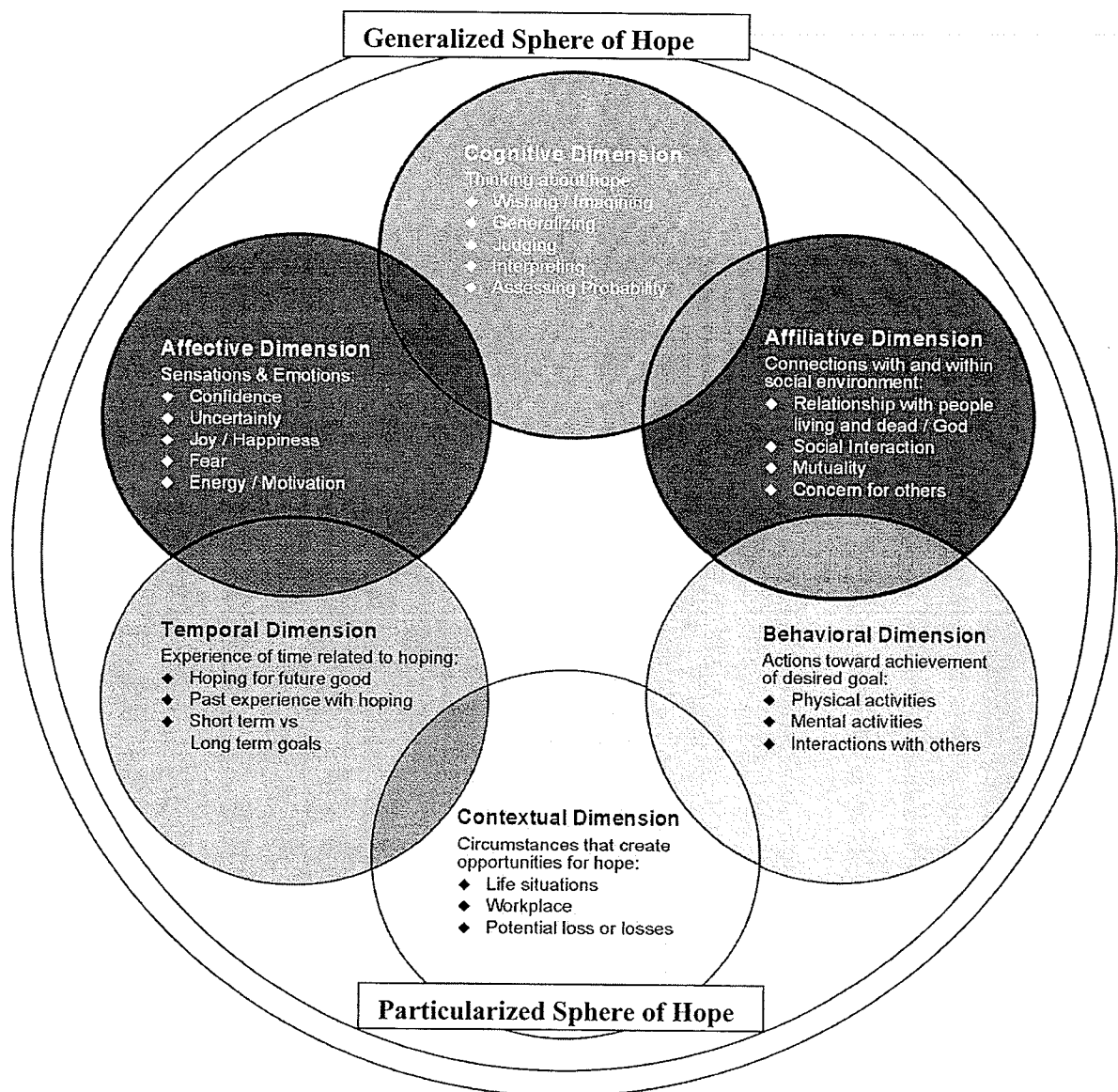


Figure 1

- The third assumption explicitly stated is that uncertainty is always the precursor to hope. Without uncertainty there is no reason to hope. Hope is linked only to those events that create instability for the individual even

when those events are of a positive nature. There is no reason to hope when an outcome is assured.

- The fourth assumption, not explicitly stated in the model, is that hope serves as a prerequisite for action. Hope for a future good must be present for an individual to take actions toward achieving it.
- Finally Dufault and Martocchio state that hopefulness and hopelessness are not linear opposites at each end of a continuum. Rather, their conceptualization suggests that there is always some dimension or sphere of hope, present in any individual. Hope is assumed to be multidimensional and process oriented rather than linearly unidimensional and trait related.

### **Purpose of the Study**

The purpose of this research was to explore the phenomenon of hope as perceived and defined by registered nurses working with Palliative Care and Bone Marrow Transplant patients. The study also sought to describe how nurses incorporate their concept of hope into their practice and whether this was affected by their workplace setting. The specific research questions were:

1. How do nurses conceptualize and define hope, and does workplace setting influence their concept of hope?
2. How do nurses incorporate their concept of hope into nursing care and how does this manifest itself in their practice?



3. How useful is Dufault and Martocchio's Multidimensional Model of Hope for the study of hope as it pertains to nurses?

### **Assumptions**

The following assumptions were made related to this research project:

1. Uncertainty is always the precursor to hope. Without uncertainty there is no reason to hope. Illness creates uncertainty for patients and for those who are involved in their care (Bruera & Nekolaichuk, 1998; Dufault & Martocchio, 1985; Hall, 1989).
2. Hope is an important aspect of coping with serious chronic and terminal illness (Dufault & Martocchio, 1985; Hirth & Stewart, 1994; Raleigh, 1992).
3. Hope is related to possibility, which is determined and perceived by each individual and based upon individual cognitive processes and experiences (Dufault & Martocchio; Hall, 1989, Penson, 2000).
4. Nurses can influence/ affect hopefulness among the patients they interact with (Herth, 1995; Koopminers et al., 1997; Miller, 1989).
5. Nurses experience hope for patients in their care which guides nursing interventions and the goals for outcomes of care (Perakyla, 1991).
6. Nurses are able to reflect upon and articulate their experiences related to the concept of hope as it pertains to their practice.

The list of assumptions arises from Dufault and Martocchio's 'Multidimensional Model of Hope', a review of the literature surrounding the phenomenon of hope and the researcher's own personal observations within her own practice as a nurse.

### **Definition of Terms**

For the purposes of this study the definition of hope is derived from the MMH. Hope is a multidimensional life force characterized by a confident yet uncertain expectation of achieving a future good which to the hoping person is possible and personally significant. Further, hope work is defined as recurrent interactional patterns of behavior among caregivers, patients and family members that either enhance or diminish hope in the clinical setting.

## Chapter II

### Review of the Literature

#### Introduction

A review of the literature begins with an overview of the concept of hope from a historical perspective. Most of the research surrounding the concept of hope reflects the experience of individuals who are ill, therefore research related to hope as experienced by individuals diagnosed with illness is presented. The benefits, related to hope and individuals with illness as described in the literature, are discussed. Concepts related to hope including uncertainty, religiosity and realistic hope are examined. Current research related to hope as it is perceived by nurses and how it relates to nursing practice is reviewed. The literature review is confined to the field of nursing, although psychological and theological and philosophical literature is incorporated into the discussion of the history and conceptual models of hope.

#### Historical Perspective

The Miriam Webster Dictionary (1976) provides two definitions for the term 'hope' as it is both a noun and a verb. Hope as the noun is characterized as a "desire accompanied by expectation or belief in fulfillment" and "as someone or something on which hopes are centered" (p.551). Hope as the verb is defined as "to cherish a desire with expectation of fulfillment" (p.551).

Hope is personified in Greek mythology by the pitiful creature remaining in Pandora's Box (Snyder et al., 1991). Pandora was overwhelmed by curiosity and she opened a box given to her by Zeus. She unwittingly released all manner of ailments into the world but hope was also placed in the box to provide solace to 'mortals' and assuage Zeus' conscience.

Throughout history the concept of hope has evolved to become broadly ingrained into western culture. The advent of Judaic and Christian religions gave rise to the notion that one could hope for a better life, if not in this world, then perhaps in the one after death (Dallmayer, 1989). Judaic and Christian traditions have viewed hope as a "goad to action" (Wildes, 1999). Throughout all of their trials of wandering, God was ever before the Hebrew people and continued to 'lure' them out of their complacency and comfort toward the 'land of milk and honey'. Christians believe that hope is embodied in the event of Jesus' birth, death and resurrection. Indeed in recent times the Christmas Season is often commercially characterized as the 'season of hope'.

Nineteenth century poets such as Shelley and Tennyson portrayed hope as both a blessing and curse. Odes were composed in which hope was romanticized as a source of strength, which allowed people to persevere when that which was most cherished was threatened in some manner. Conversely hope was also portrayed as a burden because at its core hope includes an element of uncertainty as well as possibility.

...between desire and fear thou wert poor heart, a wretched thing...Then Hope approached, she who can borrow for poor to-day from rich tomorrow, And Fear withdrew..." (Shelley, 1904, p.275)

The rocks have bruised thee sore, but angels' wings, Grow best from bruises, hope from anguish springs." (Tennyson, 1864, p.72)

Ships were used as a symbol, by artists such as William Blake (1757-1827) and Max Beckman (1884-1950), to visually represent the concept of hope. Blake created the symbol of the moon boat or ark as an image of hope (Warner, 1980). As an object of light, the moon symbolizes the promise of the return of the sun. The moon, which goes through its cycle with reassuring regularity, has been linked with women's reproductive cycles thus signifying the promise of birth and the renewal of life. The moon ark was used by Blake to depict hope in terms of "sanctuary as well as of rebirth and immortality" (Warner, 1980, p.46). Similarly Beckman used two ships at sea to represent hope in his painting 'Viareggio'. The ships as well as the sea are used to depict the "unreachable promise of still justified hope" (Shulz-Hoffman, C.; Weiss, C., 1984, p.32).

In more recent times the phenomenon of hope has become an important aspect of health care culture. The medical model founded on the teachings of Hippocrates, implores the physician to maintain hope even in the face of death (Warr, 1999). Health Care Institutions, such as the Winnipeg Health Sciences Centre (HSC) and the Health Sciences Centre Research Foundation, have acknowledged the significance of hope with such

logos as “May hope flourish in this place” and “Hope and Excellence in Research” which, appear on fund raising literature and annual reports.

### **Models of Hope**

McGee (1984) utilized propositions gleaned from the literature to extend a model of hope. The purpose for this model was to gain knowledge about the concept of hope so that “health care providers can become a more powerful force against unrealistic hopefulness and unjustified hopelessness among patients...” (p.34). McGee proposes that hope and hopelessness are polar opposites on a continuum but that despair and hope are overlapping concepts. Hope is conceptualized as having both a state and trait component. As a trait, hope is an individual’s predisposition toward a hopeful or a hopeless view of life. The state component of hope refers to perceptions of probability of goal attainment and perceptions of external and internal resources required to achieve desired goals. Individuals’ responses to illness are grouped into one of six categories which include: unjustifiably hopeful, realistic copers, fragile copers, chronically fearful, and unrealistic hopelessness. The role of health care professionals is to support patients toward the level of ‘realistic copers’. This model is narrow and linear in its approach to the concept of hope because of the emphasis it places on realistic hope. Realistic hope is not well defined by the model nor is it supported by research.

As mentioned earlier Ezra Stotland, a social psychologist developed a 'Theory of Hope' based upon his work as a social psychologist. Snyder et al (1991) further elaborated on this model and offered a new model of hope. They propose that hope is a "stable cognitive set" (p.571) which is derived from goal directed determination and plans or 'pathways' to achieve desired goals. Hope is viewed as a consistent personality trait which has two components, agency or 'the will' and pathways 'the way'. They suggest that emotions are not irrelevant to the phenomenon of hope, but that they are "simply the sequelae of cognitive appraisals of goal related activities" (p.573). Hope can be nurtured in the low hoping individual by the establishment of cognitive sets focused on agency or on pathways. This model is strongly focused toward the quantification of hope and disregards the profoundly personal experience of hope.

Nekolaichuk, Jevne, and Maguire (1999) attempted to capture the personal meaning of hope within the context of health and illness. In order to develop a model of hope, they created a research tool using a 'semantic differential technique' or pairs of adjectives. Questionnaires were developed based on Dufault and Martocchio's model of hope and contained six concepts related to hope. Five hundred and fifty participants were asked to share their personal views about hope by rating each hope related concept with 50 pairs of adjectives. The non-probability sample equally represented both healthy adults and those with chronic or terminal illness. A model of hope emerged from the data which suggested that individuals

experience hope in three interconnected realms. The experience of hope was described as an inner experience which was labelled the realm of personal spirit. Hope is influenced by the predictability of situations and was labelled as the realm of risk. The realm of authentic caring reflects the experience of hope within relationships. Hope is influenced by the comfort and caring provided by relationships, but also by the credibility of those relationships. The researchers did not report what or if differences existed between the group of healthy adults and those with chronic or terminal illness. The model lacks the breadth of Dufault and Martocchio's model and therefore does not reflect the complexity of hope.

Certain critical attributes of hope are shared by each of the models. The first is a focus on time, specifically the future. A second attribute of hope is that of energized action or behaviours focused toward goal attainment. Finally, actions are directed toward achievement of a goal that is considered to be 'good' or desirable by the hoping individual. The complex nature of hope is not well reflected by any of the models. Within their definitions of hope, all of the models qualify that hope must be realistic, but they fail to consider how reality should be determined and by whom.



## Hope in Individuals with Terminal Illness or Cancer

### The Meaning of Hope

Kaye Herth (1990) interviewed 30 terminally ill individuals to explore the meaning of hope during terminal illness and to identify strategies that terminally ill individuals use to maintain and foster hope. The sample included individuals diagnosed with cancer, AIDS and ALS. Herth used a convenience sample of terminally ill adults from three hospice programs. A semi-structured interview format was used and participants were also asked to complete the Herth Hope Index scale. The interview guide was provided to participants at initial contact to allow them time to reflect upon their responses one week prior to being interviewed. The descriptions that resulted were comprehensive and in-depth. Interviews were conducted on three separate occasions with each participant. The findings revealed that these terminally ill individuals viewed hope as dynamic and complex involving thoughts, feelings and actions. Hope allowed the participants to develop a new awareness of the 'possible' which led them to live their lives in a manner that they had never tried before. Hope was also defined as an inner power that "facilitates transcendence of the present situation and movement toward new awareness and enrichment of being" (p.1256). Hope-fostering strategies that were identified by the participants included interpersonal connectedness, attainable aims, uplifting memories and affirmation of worth. Hope-hindering factors included abandonment and isolation, uncontrollable pain and discomfort, and devaluation of

personhood. Interestingly levels of hope as measured by the Herth Hope Index were consistently higher at the third interview than at the first interview. This could be related to various factors including familiarity with the scale and a desire to please the interviewer who by the third interview would have become better known to the participant. Further, the participant may have had more opportunity for self-reflection, which may have contributed to higher levels of hope.

Hall (1994) utilized interpretive interactionism to explore the experiences of 10 individuals in the advanced stages of HIV disease in order to delineate a definition of hope and the manner in which hope was maintained. Each individual was interviewed on 3 separate occasions and each interview lasted from 45 minutes to 2 hours. The interviews focused on experiences related to their illness that had created epiphanies for the participants. These were moments that had marked on their lives in a powerful way. Major epiphanies included statements about moments that had been life shattering and forever changed the life of the individual. Minor epiphanies were those that that revealed tensions and provided continual turning points. Cumulative epiphanies were major turning points in the individual's life that resulted from an accumulation of experiences. The definition of hope inducted from the findings was contrary to previous definitions found in the literature.

Specifically Hall's findings did not support the assertion by some researchers that hope is a function of how realistic it is related to the

person's diagnosis. The meaning of hope for this sample reflected an optimistic view of the future that involved having a future in spite of the diagnosis, as well as a renewed 'zest' for life. Furthermore, hope for these individuals meant finding a reason for living that had not been evident prior to their diagnosis. The data revealed that the individuals maintained hope in four major ways which included involvement in work or vocation and establishing supportive social networks. Most significantly the findings revealed that 'miracles' were an important factor in the maintenance of hope. While some of these miracles had a religious flavour, many participants described the miracle of life change. These resulted in part from lifestyle changes brought about by their diagnosis. The participants felt that they were a "living miracle" (p.291). These miracles, according to Hall, were not according to Hall forms of denial, nor did they prevent participation in activities that were health enhancing. Hall states that this was a coping strategy used by participants when they were too overwhelmed by their illness and dying.

Morse and Doberneck (1995) used a slightly different approach in delineating the meaning of hope as it pertains to individuals with illness. They utilized interview data from four patient groups including heart transplant patients, patients with spinal cord injuries, breast cancer patients and breastfeeding mothers. Using a made for television film, "Snowbound: The Jim and Jenny Stolpa Story" as an exemplar, the researchers used content analysis to develop seven "abstract and universal

components” (p. 278) of hope. These were: a realistic assessment of the predicament or threat; the envisioning of alternatives and establishing goals; bracing for negative outcomes; a realistic assessment of personal resources and of external conditions and resources; the solicitation of mutually supportive relationships; the continuous evaluation for signs that reinforce the selected goals; and a determination to endure. These conceptual components were then verified by a review of the interview data obtained from the four distinct groups. Morse and Doberneck maintain that the seven components of hope derived from the content analysis of the movie were clearly reflected in the interview data. Further they noted different patterns for the manner in which hope was manifested by each group.

Heart transplant patients were described as focusing hope toward the chance of obtaining an organ. These participants had no alternative but to wait for an organ and persist in maintaining a positive outlook. This type of hope was labelled as ‘hoping for a chance for a chance’. Hoping in the spinal cord injured group was manifested as working toward small incremental gains and thus was labelled as ‘incremental hope’. Breast cancer patients continuously dealt with the threat of devastating treatments or that of recurrence of cancer. These women fought to keep negative thoughts at bay. Hope manifested itself as getting past different barriers and therefore was labelled as ‘hoping against hope’. Breastfeeding mothers developed hopes around ‘what ifs’. They were preoccupied with

the development of alternative plans in case competing demands prevented them from breastfeeding. Hope in this group manifested itself in the resolution of potential problems and was therefore named as 'provisional hope'. Morse and Doberneck suggest that the intensity of hope was not influenced as much by the likelihood of goal attainment as it was by the number of alternatives available to achieve that goal. The fewer the number of alternatives available to the individual the greater the intensity of hope.

The research literature reflects the highly complex nature of hope. The meaning of hope is individual and it is influenced by the context, which creates the opportunity for hoping. Hope is linked to possibility and uncertainty more significantly than it is associated to reality. Hope allows individuals to cope with or manage the uncertainty associated with illness more effectively. Finally hope can be fostered or hindered through relationships with others. Hope results from a connectedness with others and allows transcendence toward an awareness that enriches life experiences.

### **Strategies that Maintain Hope**

Miller (1989) found that hope inspiring strategies were utilized by the 60 participants in her study who had survived a critical illness. The strategies included thought processes whereby individuals consciously chose to assess unfavourable perceptions about events as less threatening. Individuals remained hopeful by maintaining a determined mental attitude

that a positive outcome was possible. Relationships with family and significant others allowed the participants to feel that they mattered and that there were others with whom they could share their difficulties. Participants also reported that relationships with health care professionals that were encouraging, warm and sincere contributed positively to hopefulness. Spiritual strategies included those that enabled a transcendence of suffering based on a relationship with God. Finally goal attainment was also used to maintain hope. These goals were usually short term and valued by the participant.

Ersek (1992) used a grounded theory approach to delineate processes of maintaining hope for individuals undergoing bone marrow transplant. She interviewed 10 men and 10 women who were undergoing bone marrow transplantation. Three interviews were conducted with each participant during each phase of the bone marrow transplant process. The findings revealed that there were two main components to the process of hoping which were labelled as 'dealing with it' and 'keeping it in its place'. 'Dealing with it' involved behaviours and thoughts involved in confronting the negative possibilities associated with the illness experience. These included appraisal of the illness experience as a threat, allowing emotional responses including fear and sadness, and finally 'working through' it and 'moving on' where participants sought to limit the impact of the threat and achieved temporary closure. 'Keeping it in its place' was defined as the process of managing the impact of illness and its treatment. Strategies

within this component included managing cognitions, emotional responses to illness, maintaining a sense of control, maintaining a fighting stance, minimizing uncertainty, and focusing on the future day to day.

Saleh and Brockopp (2001) conducted interviews with nine bone marrow transplant recipients to gain a better understanding of concept of hope. More specifically the researchers sought to identify strategies that participants used to sustain hope. Using a semi structured interview guide each participant was interviewed during their hospitalization for bone marrow transplantation. The analysis revealed six major themes that functioned as strategies to foster hope. These are similar to those reported earlier by Herth (1992; 1993). Participants reported that establishing affirming relationships with family, friends and health care providers assisted them in remaining hopeful. Anticipating survival, living in the present, and fostering ongoing accomplishment were also important aspects of maintaining hope. Finally, staying positive and feeling connected with God were also used extensively by participants as strategies to remain hopeful.

Research with individuals who are ill demonstrates commonalities in the strategies used to maintain hope. A positive or determined mental attitude toward desired goals enhanced hopefulness. Meaningful and sincere relationships with others that were supportive and nurturing also fostered hope in individuals who were ill. These relationships included family, friends and health care professionals as well as a relationship with

God. Gaining an understanding of illness within the context of their lives and establishing attainable goals were also identified, by individuals with illness, as strategies that were used to maintain hope.

### The Benefits of Hope

It is generally acknowledged in the literature that illness taxes an individual's coping resources (Lazarus and Folkman, 1984). Hope enhances a person's ability to cope with illness by mediating the consequences of stressful situations and by facilitating the appraisal of events as manageable (Folkman et al, 1991).

Rideout and Montemuro (1986) examined the relationship between hope and adaptation to illness. The study involved a convenience sample of 23 individuals with chronic congestive heart failure who attended a heart failure clinic in a tertiary care hospital. A 'descriptive analytic' survey was utilized to collect data. The data were collected at one point in time. The participant's physical status was assessed by the clinical nurse specialist at the clinic and quantified using Lee's 13 point scale<sup>1</sup>. Participants were asked to complete the McMaster Health<sup>2</sup> Index to determine levels of physical and social function. Finally the Beck Hopelessness scale<sup>3</sup> was used

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<sup>1</sup> A 13 point scale that assigns numerical value for the presence and extent of each of the signs and symptoms associated with heart failure including: dyspnea, crackles, abnormal heart rate, right heart failure and chest film abnormality.

<sup>2</sup> A scale which uses yes/no responses to questions regarding a range of physical and social functions including: mobility, self-care, housework, sensory communication, social participation, leisure time, hobbies, family, and feelings about friendships.

<sup>3</sup> A 20-item true/false scale consisting of statements such as the likelihood of attaining desirable goals or improvement in living conditions. The lower the scale the less hopeless the individual is.



to assess levels of hopelessness. The researchers were not able to establish a correlation between levels of hope and physical function, but there was a moderate to good relationship ( $p = -0.501$ ) between levels of hopelessness and social function. Participants who scored lower in terms of hopelessness had a higher score in social functioning. The research suggests that hopeful individuals are more likely to remain engaged in life's activities than those who are not hopeful, regardless of physical function.

Kaye Herth (1989) conducted research with 120 individuals, who were receiving chemotherapy, to determine the relationship between hope and coping response. The Herth Hope Index<sup>4</sup> was used to measure levels of hopefulness while the Jalowiec Coping Scale<sup>5</sup> assessed coping response. The participants suffered from varying types of malignant tumours and were receiving chemotherapy in either, an inpatient, an outpatient or a home setting. A purposive sample was utilized to ensure even distribution among all three settings. Herth reported a significant relationship ( $p = 0.001$ ) between the level of hope and the level of coping response. Further she reported that levels of hope and coping were adversely affected by the amount of interference with family and social functions related to the chemotherapy.

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<sup>4</sup> A scale, which includes 32 items to which participants respond 'applies to me' or 'does not apply to me'. The scale includes statements about positive expectancies, personal competency, and future orientation. The higher the score achieved the greater the level of hope. Cronbach alpha of 0.84 and 0.89 were determined in pre-testing and during the present study.

<sup>5</sup> The JCS is a 40 item, 5 point Likert scale, which asks participants how often coping strategies are used. Coping strategies are grouped into eight coping styles: confronting, evasive, optimistic, fatalistic, emotive, palliative, supportive, and self-reliant

Hirth and Stewart (1994) reported similar findings in their study involving 31 patients awaiting cardiac transplantation in four different centres across Canada. The study sought to examine the relationships between hope, coping and social support. Participants were asked to complete the Miller Hope scale<sup>6</sup> and the Jalowiec Coping scale in order to assess hope and coping levels. The Norbeck Social Support<sup>7</sup> questionnaire was used to determine levels of social support. Using Pearson Product Moment Correlation to examine relationships among variables, Hirth and Stewart found that hope was the only significant predictor of coping effectiveness. Interestingly, participants in this study reported a higher level of hope than was obtained by Miller and Powers (1988) utilizing the same scale among 522 healthy individuals.

Post-White, Ceronsky, Kreitzer, Nickelson, Drew, Watrud-Mackey, Koopmeiners, and Gutknecht (1996) explored the relationships between hope, sense of coherence and quality of life among 64 individuals who were diagnosed with cancer. A semi-structured interview tool was modeled on Hinds (1984) grounded theory approach to determine how participants defined and maintained hope. The Herth Hope Index was used to assess levels of hope while a 13 item subset of Antonovsky's Sense of Coherence

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<sup>6</sup> The Miller Hope scale is a 40-item scale using a 6-point Likert format ranging from very strongly disagree (1) to very strongly agree (6). It measures satisfaction with self, others, and life, as well as avoidance of hope threats and anticipation of a future. Cronbach's alpha for internal consistency was .93 as determined by Miller and Powers (1988).

<sup>7</sup> This scale was developed to measure social support. It includes 3 functional aspects of social support including affect, affirmation, and aid as well as 5 structural aspect which include, network size, source of support, duration of relationships frequency of contact and network loss. Inter-correlations between all functional items is reported to be 0.72-0.92 and for structural items 0.88-0.96.

Scale<sup>8</sup> determined participant's perception of the manageability of life. Quality of life was measured by the Dartmouth Quality of Life Tool<sup>9</sup>. The researchers demonstrated that individuals with a strong sense of coherence were more likely to appraise stressors in a more positive manner and assess difficult events as manageable. These individuals were also more likely to report higher levels of hope and a better quality of life. Interestingly, the relationship between severity of illness and levels of hope was not significant.

Fowler (1997) studied 42 individuals with Parkinson's disease to determine the relationship between hope and health promoting behaviours. The study demonstrated a positive relationship between hope and health promoting behaviours. Fowler noted, however, that participants in her study reported higher levels of hope than was reported by Herth (1992) with individuals who were essentially healthy. She suggests that illness perhaps provides an impetus for, or motivation to hope.

While these studies demonstrate co-relational and not causal relationships, there is reason to believe that hope enhances an individual's ability to cope with illness. Hope has been linked to a better sense of coherence which allows individuals to assess difficult events as manageable and in turn enables better coping. Furthermore hopeful individuals are

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<sup>8</sup> Antonovsky's Sense of Coherence Scale assesses the degree to which individuals perceive life as comprehensible, the manageability of life situations and the importance or meaningfulness of each life situation.

<sup>9</sup> This tool was developed by the Department of Community and Family Medicine at Dartmouth Medical Center. It is a 9 item tool using 5 point Likert scales to indicate agreement or disagreement with statements about physical fitness, feelings, daily and social activities, pain, change in health, social support and perceived quality of life.

more likely to report a higher quality of life regardless of the severity of disease.

### **Related Concepts**

#### **Uncertainty, Fear and Hope**

Morse and Penrod (1999) re-analyzed data from three previous studies to gain an understanding of the relationship between the concepts of hope and uncertainty. They suggest that the goal of individuals confronted with illness is to somehow change their present situation. Most individuals seek to minimize or alleviate the effects of disease. Several pathways to attain this goal may present themselves but the person does not know which offers the best outcome. The goal is clear but the means to achieve is not and this creates a state of uncertainty for the individual. Hope was found to be immobilized during this state of uncertainty. Despite the presence of a goal the lack of a means to achieve it did not allow the person to perceive a future.

Wonghongkul, Moore, Musil, Schneider and Deimling (2000) examined the relationship between uncertainty, hope and appraisal of harm. They surveyed 71 women with breast cancer and found that high levels of hope corresponded with lower levels of uncertainty. This resulted in a decrease in the level of harm and threat appraisal.

Cohen and Dawson (2000) explored the experience of autologous bone marrow transplantation among 20 adults who had undergone the treatment. Open ended interview questions were used to ensure that the content

discussed was determined by the participant not the interviewer. Content analysis of verbatim transcripts revealed the prevailing theme of fear that was balanced with hope for survival. Fear was related to the unknown, loss of control, and death. Participants revealed that the most effective coping strategy used to minimize the effects of their fears was a focus on hope for survival. In fact, hope for survival was consistently reported as the primary reason for engaging in this difficult therapy.

### **Religiosity and Hope**

As mentioned earlier, terminally ill individuals who participated in Hall's study (1994) reported religious miracles as a way that hope was maintained. Hall stated that these were extraordinary ways in which individuals were sensitized to and asserted control over their problems, emotions and bodies. The participants reported that miracles in combination with religion promoted a belief that God still cared enough to watch over them or care for them when they could not care for themselves. Hall observed that "Church or religious belief served as a vehicle to understand death or the keep a positive attitude in difficult situations" (p. 288).

Mickley and Soeken (1993) reported a positive relationship between hope and intrinsic religiosity among Anglo-American women with breast cancer, but this was not reflected in a group of Hispanic-American women with breast cancer. They suggest that religiosity may be more ingrained

into the culture of Hispanic Americans and therefore experienced differently by the women in the study.

Fehring, Miller and Shaw studied 100 elderly individuals to determine the relationships among religiosity, spiritual well being, hope and depression. They administered Gorsuch and McPherson's Intrinsic and Extrinsic Religiosity Index<sup>10</sup> along with Paloutzian and Ellison's Spiritual Well Being Scale<sup>11</sup> and the Miller Hope Scale to participants. Each scale had a reliability of 0.83 or greater. The researchers concluded that intrinsic religiosity and spiritual well-being were positively correlated with higher levels of hope. These also corresponded with positive mood states.

Benzein, Norberg and Inger Saveman (1998) examined the concept of hope as defined by a group of healthy Pentecostals in Sweden. They interviewed 16 men and women regarding their experience of hope. Hope was defined by these participants as a heavenly and earthly phenomenon which they related to the resurrection of Jesus Christ. They considered the Bible as the ultimate truth which also functioned as a frame of reference for any life situation. Hope was experienced as a future imagined reality and focused on eternity and life after death. Prayer was the primary activity which the participants engaged in to maintain hopefulness. If prayers were answered hope was enhanced.

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<sup>10</sup> The Intrinsic/Extrinsic Religiosity Scale is 14-item scale with a 5 point Likert response format that asks participants to indicate agreement or disagreement with statements about intrinsic religiousness (i.e. My whole approach to life is based on my religion) and extrinsic religiousness (i.e. I go to church to spend time with my friends).

<sup>11</sup> The Spiritual Well-Being Scale uses two subscales to measure religious well-being and existential well-being. Participants use a 6 point Likert scale to indicate agree or disagree with statements.

### Realistic Hope

Salander, Bergenheim and Henriksson (1996) used a grounded theory approach to study individuals who had been diagnosed with malignant brain tumours. Their findings suggest that patients acted cognitively to protect and create hope surrounding the diagnosis and treatment of malignant brain tumours. The finding that patients maintained hope, even when faced with the certainty of a poor prognosis, was attributed by the researchers to "cognitive construction of illusions" (p. 988). The individuals in this study, however, reported that they felt well and remained functionally the same individuals that they had been prior to their diagnosis. It appears that the participants' personal experiences and realities related to illness, were relegated by the researchers to that of illusion and denial.

Realistic hope is mentioned in several models and studies related to hope. There is a definite implication within the literature that if an individual, diagnosed with a serious or terminal illness, professes a strong will to live or demonstrates high levels of hope then that person is somehow not accepting of reality (Dufault & Martocchio, 1985; Elliott, Herrick & Witty, 1991; Hinds, 1988; McGee 1984; Stoner & Keampfer, 1985). The assumption which underlies this assertion is that health care professionals are in the best position to distinguish between realistic and unrealistic hope within the context of illness (Bruera & Nekolaichuk, 1998). Realistic hope has not emerged as a significant concept related to hope. Researchers have not reported realistic hope as a prevailing theme when exploring the

concept of hope with individuals diagnosed with chronic and terminal illness (Hall, 1989; Herth, 1990; 1993; Nekolaichuk, Jevne, & Maguire, 1999).

The emphasis placed on realistic hope, by nurse researchers, is perhaps related to the dilemma described by Leviton (1971). Health care professionals favoured a realistic approach, rather than the hopeful approach preferred by patients, to rehabilitative care because of the value that they assigned to knowledge. Knowledge was equated to the truth and consequently the more knowledge that one possessed the better they were positioned to assess the realities of a given situation. Unfortunately we cannot know all that we do not know and therefore attempts to qualify hopes as realistic or unrealistic seem futile and unhelpful.

## **Hope and Nurses**

### **Influence on Hope by Health Care Professionals**

Koopmeiners, Post-White, Gutknecht, Ceronsky, Nikelson, Drew, Watrud-Mackay, and Kreitzer (1997) interviewed 32 oncology patients to explore how health care professionals influence or inspire hope. They used a semi-structured interview tool used in previous research by Post-White et al (1996). Data were collected and analyzed by a multidisciplinary team of 10 which included oncology nurses, nurse researchers, and chaplains using manifest content analysis. Physicians (75%) and nurses (63%) were most frequently identified by participants as contributing to their hope. Participants reported that 'being present' by taking time to talk and



interact with patients was the most effective way that health care professionals inspired hope.

Wong-Wylie and Jevne (1997) reported similar findings in their descriptive study with 8 HIV seropositive individuals. Participants were asked to provide descriptive accounts of interactions, with health care professionals, that had influenced their hope. The analysis revealed that hopeful interactions with physicians were those that were 'descriptive' as opposed to 'prescriptive' in the provision of diagnosis and information related to treatment and prognosis. Furthermore, hopeful interactions were those that were perceived by the informant as connected and welcoming, versus those where there was disconnectedness with the health care professional and where the participants felt they were being dismissed. Hopeful interactions recognized the human experience of illness rather than just the treatment of signs and symptoms of disease.

### **Hope as Perceived by Nurses**

Owen (1989) attempted to develop an understanding of the concept of hope by soliciting vivid descriptions of hopeful patients from clinical nurse specialists who worked with oncology patients. Six participants were recruited and interviewed and the verbatim transcripts were analyzed using content analysis. Hopeful patients were described by nurses as those that had the ability to set goals and to redefine those goals as their changing physical status required. Hopeful patients included those individuals that

equated hope with a meaningful life and who were at peace with their situations.

Perakyla (1991) is one of the earliest researchers to have studied the concept of hope as it pertains to health care providers including nurses. She used a Grounded Theory approach to examine "hope work" (p. 407) among both patients and health care providers in a hospital in Finland. Participant observation was used to collect 1,706 pages of data during a ten-month period. Three different wards were included in her study. Perakyla found that hope was enacted through social interactions, such as conversations, that take place between patients and health care providers. Hope work was categorized into three types: curative hope work is present when the patient is defined as 'getting better'; palliative hope work is introduced when treatments are focused toward helping patients to 'feel better'; and the work of dismantling hope is manifested when patients are deemed 'past recovery'. Perakyla reported that there was a prevailing type and intensity of hope work promoted by health care providers on each of the units studied. The very existence of different types of hope work became a source of conflict between health care providers and patients and also amongst health care providers themselves.

Perakyla concluded that persons producing conversation may not always be aware of the delicate implications of their words. Consequently they may consider themselves as merely sharing 'facts' when actually their conversations are doing the work of reinforcing curative hope. If

unrecognized, curative hope work may continue even when it is no longer consistent with the patients' physical condition. Perakyla's findings are a reflection of her observations, and therefore do not address the reflexive nature of hope work and how it influences professional practice. It may be possible that health care professionals would have described the purpose of their communication, with patients and with each other, as reframing hope, rather than dismantling it.

Cutcliffe (1995) interviewed nurses to examine how they inspire or instill hope in people terminally ill with AIDS. A Grounded Theory design was chosen for this research. Data were collected by means of non-standardized, semi-structured interviews with one third of nurses working on the liaison psychiatry unit. The author never specifies the actual number of nurses who were included in the study. Among the core variables identified by the study was "Reflection in action". Nurses reported that inspiration of hope was affected by self-awareness or internal agendas brought to each interaction with patients. Cutcliffe, however, does not explore how hope was conceptualized by participants.

Landeen, Kirkpatrick, Woodside, Byrne, Bernardo, and Pawlick (1996) identified factors, which influenced hopefulness in nurses who worked with schizophrenic patients in both community and inpatient settings. Fifteen nurses participated in semi-structured interviews. Dufault and Martocchio's MMH was used as a framework for the study. Landeen et al categorized responses within either the sphere of generalized hope or particularized

hope. Nurses reported that long term relationships with patients that allowed them to share in successes with patients, and coming to know patients as people, contributed positively to their hopefulness. Participants disclosed that receiving recognition for their work from coworkers also fostered hope. Patient care rounds that focused on patients who were responding well to treatment as well as those who were not, were reported to have a positive impact on levels of hopefulness amongst the participants. Increasing resources directed toward educational activities for both patients and staff promoted hopefulness. This reinforced to nurses that their work and their patients were important to government funding bodies and to the community at large. Educational activities directed toward professional development were perceived by nurses as promoting a sense of community amongst them. This sense of community with other nurses was reported as inspiring hope for nurses who attended the educational sessions. It is interesting to note that while Landeen et al specifically asked nurses how they might define hope, their findings related to this question were not reported.

A study to examine nurses' use and effectiveness of hope engendering interventions was conducted by Herth (1995). Fifty-two hospice care nurses and 76 home care nurses participated in a descriptive survey. The questionnaire used a five point Likert scale and was developed by Herth to reflect interventions identified in the literature as promoting hopefulness. Participants rated very highly the importance of hope, with regard to

patients and their own nursing practice. Pain control and symptom management were reported by both groups as the most frequently used and most effective strategy to maintain or increase hopefulness in patients. The two groups differed significantly in how they rated the remaining items in the survey. Home Care nurses listed the development and revision of manageable goals as the second most effective strategy, whereas Hospice nurses chose the facilitation of sustained connectedness with others as the second most frequently used and effective strategy in the maintenance of hope. This discrepancy may be attributed to the fact that Hospice nurses were caring for individuals whose illness may be considered more terminal than most Home Care patients. This finding may suggest, as proposed by Perakyla (1991), that hope may be conceptualized differently, depending upon the set of circumstances that each work setting creates for nurses.

Rittman, Rivera and Godown (1997) used a phenomenological approach to study how nurses provide end of life care. Data consisted of six narratives written by experienced nurses working on an oncology unit. These participants were selected by the 'head nurse' and their peers to participate in the study because of their high degree of expertise. Each narrative was read by a team of investigators, which included the principal investigator and two experienced oncology nurses not directly involved in patient care. Members of the team then wrote and discussed descriptions of the meanings evoked by the narratives. One of the themes, which emerged as a result, was that of preserving hope. Maintaining or preserving

hope was an intervention that nurses used to help patients cope with an uncertain future. The nurses in this study approached caring for terminally ill patients as an opportunity to “participate in a life completing itself rather than only seeing the loss of shortened lives” (p. 118). Hope was maintained by finding opportunities for patients to use their remaining time in a way that was most meaningful to them.

Thulesius, Hakansson and Petersson (2003) used a Grounded Theory approach in an attempt to examine “what is happening in end of life cancer care” (p.1354). They gathered data from formal interviews with 26 nurses, 11 physicians, 11 patients and 9 relatives. Data collection also included fieldnotes related to informal interviews and from seminars and workshops conducted with professionals from hospices, palliative care and oncology departments. The results of the study indicated that imbalance was the most significant challenge related to end of life care. Patients and health care professionals are constantly attempting to regain or maintain balance between severity of illness and the resources required to deal with it. Balancing continues throughout the disease trajectory. Resources are balanced with patient needs and budget constraint. Specifically they found that patients and health care professionals continually tried to maintain or foster hope by balancing the value of every lived moment and the expected time left to live. This is expressed by the investigators as  $H = V \times T$ . They propose that hope is decreased when the amount of time left to live is decreased. Hope can be enhanced by increasing the value of assigned to

each moment lived. This approach is not always applicable and somewhat linear. Further it does not reflect the multi-dimensionality of hope.

### Conclusion

Despite its tenuous nature, "the thread of hope is woven into the fabric of each person's illness" (Nekolaichuk et al, 1999; p.591). The literature reveals that hope is an inner experience but it is influenced by, and enacted through interactions with others. There is evidence in the literature that hope is integral to the coping process. Health care professionals, including nurses, can foster hope through skilful and thoughtful communication.

Most of the research surrounding the concept of hope reflects the experience of individuals with chronic and terminal illness. Models that have been developed, thus far, to describe the phenomenon of hope have evolved from data collected from individuals who have an illness. Nurses who provide much of the care to those individuals may define hope very differently. Nurses' conception of and beliefs regarding hope, and how these relate to, and influence, their interactions with patients has not been the focus of research. Whether or not nurses themselves have hope, and what their hopes are, may affect their ability to support patients' need for hope. Given the interconnections between care-givers and recipients of care this aspect of hope should not be ignored. Further research is indicated to delineate the concept of hope as it pertains to practicing nurses.

## **Chapter III**

### **Research Design**

#### **Introduction**

The selection of a research methodology requires a good fit with the research question in order to achieve research findings that are meaningful (Denzin & Lincoln, 2000). Polit and Hungler (1993) suggest that the researcher's personal taste and philosophy should form part of the rationale for selection of research methodology. Both of these statements form the essence of my selection of a qualitative research design for studying the concept of hope as it pertains to nurses and their practice.

This chapter will discuss the research method beginning with a synopsis of the qualitative approach to research and person centered interviewing which were selected for the study. The study setting and sample are described followed by an elaboration of the data collection and analysis procedures. Ethical considerations are considered and the chapter concludes with a discussion of methodological rigor.

#### **Statement of the Problem**

The research literature increasingly supports that hope is an important aspect of coping with illness and that nurses are often involved in the inspiration of hope among their patients (Herth, 1992; Koopmeiners et al, 1997). Sharing information and exhibiting caring behaviors are among



some of the measures reported by patients that can enhance hopefulness (Raleigh, 1992). Most of the research surrounding the concept of hope reflects the experience of individuals with illness. Research regarding how hope is conceptualized by nurses and its effect on their practice is limited. Research with nurses has generally been focused toward delineating factors that can influence hopefulness among nurses or the identification of interventions that nurses can use to promote hopefulness in patients. Nurses may define hope very differently compared to their patients. Their perceptions and attitudes regarding hope may be related to and influence their interactions with patients (Simpson, 2002).

To gain further insight into the concept of hope as it pertains to nurses and their practice, further research is necessary. Two units, the Bone Marrow Transplant (BMT) unit and the Palliative Care (PC) unit were selected for this study. While these two units serve similar patient populations the purpose of the treatments provided on each unit is distinctly different. The BMT unit provides treatments focused toward the remission of cancer whereas the PC unit provides treatments related to end of life care. Several questions can be generated regarding the perception of hope among nurses working on either of these distinctive patient care units. How do nurses conceptualize and define hope? How does workplace setting influence nurses' concept of hope? How do nurses incorporate their concept of hope into nursing care and how does this manifest itself in their practice?

## **Qualitative Approach**

The aim of both qualitative and quantitative research is the generation of knowledge related to a phenomenon of interest through systematic methods of inquiry. Qualitative research has been characterized as mode of research which promotes an understanding of the human experience related to the nature of interactions between human beings and between humans and their environment (Denzin & Lincoln, 2000). It embodies a holistic approach whose methodology includes inductive reasoning, subjectivity, description and process orientation (Munhall & Oiler Boyd, 2001). The examination of hope involves solicitation and interpretation of an individual's view within a framework that explores the wholeness of the person's experience within his/her own environment. Qualitative methodology allows for an in-depth understanding of a phenomenon from each person's perspective as well as the collective experience enabling richness of data and a comprehensive view. A qualitative approach is indicated for this study to provide a better understanding of the nature of hope among nurses given that existing research is limited.

## **Person Centered Interviewing**

The purpose of this research was to develop a deeper understanding of hope as perceived by nurses within the culture of health care. Person-centered interviewing (Levy & Hollan, 1998) was chosen as the method to

gain a more profound understanding of hope as conceptualized and practiced by nurses.

Person-centered interviews engage the interviewee as both informant and respondent. The interviewee as informant affords information about culture and behavior peculiar to the group of individuals he/she belongs to. The interviewee as respondent provides aspects of "her perception and understanding of her external context" (Levy & Hollan, 1998 p. 336). As such the respondent-informant "illuminates the spaces conflicts, coherence, and transformations" (Levy & Hollan, 1998 p. 336) about the phenomenon of interest. This method is not an attempt to study individuals "primarily within themselves ... but rather ... to clarify the relations of 'individuality', both as output and input, to its socio-cultural context" (Levy & Hollan, 1998 p. 334). Person centered interviews involve the use of a mixture of open-ended and closed questions and probes to elicit informant and respondent information from the participants (Levy & Hollan 1998).

## **Study Setting and Sample**

### **Study Setting**

The study settings were selected primarily for two reasons. Firstly the two settings share some important similarities, in that they are both located in tertiary care hospitals and the majority of patients admitted to each unit were diagnosed with various forms of cancer. The objectives of

patient care, however, are fundamentally different. These factors were important because the study sought to describe differences that may be influenced by workplace settings. The Bone Marrow Transplant (BMT) unit provides aggressive forms of therapy geared toward remission of cancer whereas the Palliative Care (PC) unit provides therapies that are directed primarily toward symptom management and end of life care. Secondly the types of illnesses that are encountered by nurses in both settings are intense and provide ample opportunities for hope.

### Sample

A purposeful sample of experienced nurses was indicated for this study. Purposeful sampling proceeds from the belief that the researcher is knowledgeable about the study population and its elements. The researcher determines the type of participants or settings that will yield information rich data (Russell & Gregory, 2003). The study sought to articulate the conceptualization of hope as it pertains to nurses and their practice. This required that participants possess some experience, as a registered nurse, that had informed and shaped their perception of hope. The study included six nurses from each of two patient care settings.

The inclusion criteria for this study were:

1. English Speaking
2. Over 18 years of age

3. Registered Nurses employed within the Palliative Care (PC) unit or the Bone Marrow Transplant (BMT) unit for at least one year.
4. Full-time Registered Nurses or part-time Registered Nurses who have worked no less than a 0.5 EFT over the past year.
5. Nurses consenting to be interviewed

Following ethical approval from the University of Manitoba (see Appendix A), approval for access to each study hospital was sought through their respective Research Impact Committees. Permission was granted (see Appendix B) and subsequently large, provocative and colorful posters (see Appendix C) were placed in a prominent location on each unit. Letters of explanation (see Appendix D) were placed beneath the posters. I attended two staff meetings on each unit to introduce and explain the research topic. Participants indicated their interest by signing the letter of explanation and mailing it directly to my home. When I received the signed forms I contacted the prospective participants to ensure that they met the inclusion criteria.

Respondents were then provided with more information about how the data would be collected and how the interviews would take place. I also offered them general information about the questions that I would be asking so that they could begin to reflect their experiences surrounding hope. If the nurse indicated an interest to participate, arrangements were made so that a signed consent (Appendix E) could be obtained.

## Data Collection

Person centered interviewing requires that the investigator become the primary tool of the data collection process (Morse, 1994). This subjective stance is central to the process of seeing data and then describing their meaning. It is important to recognize personal assumptions, biases and preconceptions prior to conducting data collection (Munhall & Oiler Boyd, 2001). Thoughts, feelings and impressions need to be recorded and organized in a manner that will expose one's personal biases. Throughout the recruitment phase I maintained a journal about my preparations for data collection. I found this somewhat intimidating and unnatural in the beginning as I had not routinely engaged in journal writing. Initially I struggled to organize my thoughts in a coherent and articulate fashion but eventually this gave way to journal entries that were more spontaneous and personal. Throughout the data collection process I maintained a journal that contained my personal hunches and beliefs about the interviews. The journal entries were particularly helpful during the analysis phase of the study as they helped to provide context for statements found within the transcripts. Further they revealed some of my own biases and assumptions related to the interviews.

## The Interviews

I collected data using techniques congruent with ethnographic person-centered interviewing as suggested by Levy & Hollan (1998). Based

on Dufault and Matocchio's MMH, the research literature and my own personal observations, I developed a semi-structured interview schedule (Appendix F). The questions progressed in a manner that I thought would seem natural to the respondent. I utilized the interview questions as a guide that was adhered to, however the interviewee also provided the pace and direction for the interview to an extent.

The interview started with broader questions which were aimed at relaxing the participant (Levy & Hollan, 1998). These questions were similar to those that one might use in order to get to know someone better. I attempted to assume a stance that was sympathetic and nonjudgmental (Levy & Hollan, 1998). I listened understandingly and kept my comments to a minimum except to clarify statements. As I progressed beyond the third interview I periodically shared some of my insights with the interviewee as the opportunity presented itself. This allowed me to correct or validate my observations concurrently with data collection in order to maintain rigor (Morse, Michael, Mayan, Olson, Spiers, 2002).

Each interview lasted between one and two hours and took place in a variety of locations. Three interviews took place in the participant's home, seven occurred on site in a conference room at either hospital, and two participants came to my home. The interviews were conducted throughout the months of December 2003 and January 2004. The majority of interviews with the BMT nurses were completed prior to beginning the

interviews with the PC nurses. The interviews were audiotaped and at the end of the interview the participants were asked to complete a socio-demographic questionnaire (Appendix G). It should be noted that all six of the participants from the Palliative Care unit expressed frustration with the question requesting a declaration of religious affiliation. This was not observed with the Bone Marrow Transplant nurses. Immediately following the interviews I completed field notes which included my overall impressions of the interview as well as my reactions to specific aspects of the interview.

### **Data Analysis**

Although described separately, aspects of data collection and analysis should occur simultaneously (Morse et al, 2002). I used a process of reflection within a journal format and examined field notes, typed verbatim transcripts and listened to audiotapes to facilitate ongoing interpretation of findings. I also verified observations with participants at opportune moments in order to remain responsive to the data. Categories gradually emerged as the interviews progressed.

Extensive interpretation of the data occurred throughout the data collection phase and immediately afterward, through the process of basic content analysis (Ryan, & Bernard, 2000). I became immersed in the data through reading, and re-reading of transcripts, as well as listening to taped interviews and referring to my field notes. The process of coding raw data



into meaningful units enables the recognition of group patterns. Patterns discovered in one interview are compared with another interview until the category or theme is identified. Through this process data is abstracted into a more generalized mode of description (Morse, 1994). Data analysis proceeded from a concrete literal description to a more abstract conceptualization.

An open coding system similar to that described by Denzin and Lincoln (2000) was used. The coding process was completed for the BMT nurses first and then repeated for the PC unit. The process of developing categories assumes that themes or commonalities are apparent with the transcriptions of conversations. The categories at this point were literal reflections of the content expressed within the transcripts. The typed transcripts downloaded into my computer where a font color was assigned using word processing tools. Word processing edit tools such as copying and pasting were also used to process the raw data. Using different colored fonts for each transcript allowed a very graphic method of monitoring the prevalence emerging categories and themes among the participants.

Single words or phrases were used at this initial stage to create categories. These data were then examined literally to develop and articulate levels of meaning within categories as the symbolic nature was explicated. Categories were then derived from the underlying meaning of the words or phrases. Almost all of the data were accounted for within this

process. Fieldnotes were integrated to support these categories at this time in the process. Data not included in these categories mainly consisted of irrelevant information that did not enhance the understanding of nurses and hope.

The next step of coding involved collapsing the existing categories into broader and more inclusive categories containing similar information. At this stage, categories developed for each patient care unit were compared and analyzed for differences and similarities. The transcripts and fieldnotes were reviewed and compared to the original and subsequent categories to ensure that data were appropriately and reasonably accounted for within the coding system.

Research findings were then examined and interpreted in contrast to Dufault and Martocchio's Multi-Dimensional Model of Hope (1985). The comprehensive nature of this model permitted its application to nurses' experiences pertaining to hope within their practice. Dufault and Martocchio's incorporation of cognitive, affiliative, affective, behavioral, temporal and contextual dimensions provided a useful framework to describe the concept of hope as it pertains to nurses.

### **Ethical Considerations**

According to Canada's Tri-Council Policy Statement (2003) on ethical conduct there are seven principles which ensure the principle of respect for

human dignity and guide research on human subjects. These include: respect for free and informed consent, respect for vulnerable persons, respect for privacy and confidentiality, respect for justice and inclusiveness, balancing harms and benefits, minimizing harm and maximizing benefit. These principles guided ethical considerations for each step of the research process. Formal ethical approval was sought and obtained from the Education/Nursing Research Review Board (ENREB) at the University of Manitoba. There were no recommendations received from this committee. Subsequently, the access committee of each hospital was approached for permission to gain access to nurses on the BMT and PC units. Recommendations from these committees were incorporated into the research protocol. The ENREB was notified of and approved the changes to the protocol.

Respect for free and informed consent requires that "dialogue, process, rights, duties and requirements" (Tri-council Policy Statement, p.ii6) be provided to the participant prior to engaging in research. I provided the participants with comprehensive information about the nature of the research project and what their role would be. I stressed that participation was voluntary and that they could terminate their involvement at any time during the research process. Furthermore they could refuse to provide information when they felt the need to do so. Questions at any stage in the process were encouraged. The terms, and ongoing nature, of

the consent was reviewed with each participant prior to starting each taped interview.

Several mechanisms were used to ensure the principle of respect for privacy and confidentiality. The text of the transcripts was saved in a specific color and the participants name was removed and replaced by the color assigned to the text. When names are mentioned in the tape recording, I entered a generic title or term such as "husband" or "BMT" unit. Only I have access to the tapes which contain the identifying information.

The tapes, the record of participant names and accompanying identification codes (see Appendix H), the socio-demographic questionnaires, and the signed consent forms are stored in a locked filing cabinet in my home. I am the only person who has access to these original tapes and documents stored in a secure filing cabinet in my home office. These will be retained for a period of seven years at which time a company that is bonded and specializes in confidential waste disposal will destroy them as confidential waste. In the findings chapter, I have removed any identifying information and have assured anonymity by disguising scenarios where indicated.

The principles of balancing harms and benefits, minimizing harm and maximizing benefits were intended to ensure that knowledge advanced by research is worthwhile and beneficial. Further the research process should

minimize harm while maximizing benefits to the participants. The nature of this research did not offer obvious benefits or harms. Potentially the participants may have benefited from the opportunity to reflect upon the meaning of hope within their practice. Conversely reflecting upon interactions with patients during face-to-face interviews may have evoked difficult emotions such as sorrow or regret related to those interactions. The majority of participants found the interview process to be stimulating and a positive experience. Two participants became tearful during the interview at which point I offered to stop the interview. Both declined, however, and we proceeded to complete the interviews.

### **Limitations**

There were some limitations related to this study. These were linked directly to procedures designed to maintain the feasibility of the study as a Master's thesis. The limitations are listed below:

- There was only one male participant included in the study. The study, therefore was more likely to reflect a gender bias in the manner that hope was conceptualized by nurses.
- The study did not include field work observations and therefore reflects only thoughts and reflections of the participants about the concept of hope.
- There was only one interview conducted with each participant. The data therefore reflects the thoughts and

perspectives of the participants at one point in time and may not have captured the dynamic and fluid nature of the concept of hope.

### **Methodological Rigor**

Reliability and validity are terminology most readily associated with quantitative research. Many qualitative researchers have argued that “reliability and validity were terms pertaining to the quantitative paradigm and were not pertinent to qualitative inquiry” (Morse et al, 2002). Guba and Lincoln (1981) described four criteria that permit a meaningful appraisal of qualitative work. They suggested that reliability and validity can be assessed through an examination of truth-value, applicability, consistency and neutrality. Guba and Lincoln suggested that credibility, fittingness, auditability and confirmability could be utilized as criteria to determine the trustworthiness in qualitative research. The trustworthiness of this research will be examined using the criteria set forth by Denzin and Lincoln (2000). These include credibility, transferability, audibility and confirmability. Several strategies are recommended to ensure trustworthiness such as negative cases, peer debriefing, member checks, and audit trails.

Morse et al (2002) cautions that the rigor of a study is determined by “mechanisms woven into every step of the inquiry to construct a solid product” (p. 6). These include investigator responsiveness in the utilization

of verification strategies such as methodological coherence, sampling sufficiency, developing a dynamic relationship between sampling, data collection and analysis and thinking theoretically. Morse maintains that rather than consigning rigor to the end of the study it should be attended to throughout the research process. Evidence of rigor will be reflected in the "quality of the text" (Morse et al, 2002, p. 9).

### Credibility

Credibility is judged by the degree to which the researcher is able to convey the reality of the participants. It is a measure of how well the qualitative research is able to provide the reader with an account that is readily recognizable as his or her own experience. This study addressed this issue throughout preparations for the interview process through ongoing interaction and collaboration with my thesis chair. Furthermore I submitted to my thesis chair the transcripts of the interviews along with my analysis on an ongoing and episodic basis. I also shared some of my preliminary analysis with participants as I progressed past the third interview. This allowed for concurrent verification of my analysis during the data collection process.

Progressive subjectivity refers to the process of monitoring the immersion of the researcher (Denzin & Lincoln, 2000). This aspect was managed through the continual process of reflection and journal entries as described under data collection and analysis. Member checking is a

strategy which involves returning to the participants for verification of the study findings. Member checks can be problematic as suggested by Morse et al (2002). Participants may perceive the findings as unflattering and therefore pronounce them as inaccurate. Furthermore, as stated earlier, the findings have been synthesized, decontextualized, and abstracted and therefore individuals may not be able to distinguish themselves or their experiences. In recognition of these challenges, collective member checking was not solicited. Rather a presentation of the findings was arranged for all of the nursing staff of each unit, where lunch was also provided for those who chose to attend. The presentation lasted approximately twenty-five minutes. An opportunity for response to the categories was afforded and feedback was solicited afterward. The feedback from the nursing staff was generally positive and supportive of the findings. The participants identified no concerns at that time. The study participants were offered an executive summary of the completed study within the process of consent. This summary will be mailed out accordingly.

### Transferability

Transferability is the ability to apply research findings in a broader context, outside of the study situation. This should be facilitated by clear descriptions of the sample, setting and data collection procedure (Denzin & Lincoln, 2000). In reporting the findings, categories and themes were



supported by the textual data. A summary of themes were developed and presented which allowed the research findings to be compared with current literature. The findings of this study are congruent with other similar research related to the concept of hope, but also reveal different aspects of the concept that are specific to nurses.

### Auditability

Auditability may be compared with consistency within quantitative research. Although exact replication is not the goal of qualitative research, a type of replication is possible in other patient care settings. Further exploration of the nature of hope as perceived by nurses and the themes derived from this research could be achieved by the comparison of contextual variables present in other patient care units.

A decision trail, which can be easily followed by other researchers to achieve similar results, is the hallmark of auditability (Denzin & Lincoln, 2000). Each step of the research process has been detailed within this chapter. Chapter four provides a rich description underpinning the categories and themes through the use of textual data.

### Confirmability

In order to achieve confirmability or neutrality of the research findings, interpretations and analysis were rooted in the data and the realities of the participants (Denzin & Lincoln, 2000). Actual examples of

the participant's own words were used to substantiate my interpretations of the data. In the final analysis the reader will judge the quality of the research as it corresponds with his or her own worldview. If confirmability is achieved then they will be able to follow the approach taken even though they may disagree with my findings.

### **Conclusion**

This chapter has provided a discussion of the appropriateness of person-centered interview methodology to answer the research questions. This methodology enabled a richer appreciation with which to explore the concept of hope as perceived by nurses in two different work settings. The procedures used to collect and analyze the data have been detailed along and the strategies utilized for verification and analyses of the data were discussed. Research findings have been interpreted within the broader context of Dufault and Martocchio's Multi-dimensional Model of Hope (1985).

## Chapter IV

### Findings

#### Introduction

Chapter four includes a summary of the participant demographic data, and a description of the research findings of this study. The findings will be presented in relation to the framework of the Multi-Dimensional Model of Hope. The themes which emerged from the study are organized under the headings of generalized and the particularized spheres of hope as well as their six dimensions including the cognitive, affiliative, affective, behavioral, temporal and contextual dimensions. While the model was a helpful tool for data collection and analysis, it is important to note that the findings did not arise purely from the model but rather from the actual data. Some findings were not addressed by the model or did not correspond directly to the model. The concept of hope is explored from the various perspectives of the individuals participating in the study.

Findings are presented and substantiated by means of verbatim quotations from fieldwork notes and interview transcripts. Pseudonyms for the participants are used throughout the chapter. All names have been changed to the first two letters of the colors that were assigned to each participant to facilitate analysis and to protect the anonymity of all participants.

### Demographic Data

Twelve nurses participated in this research project and they were evenly distributed between the Palliative Care and the Bone Marrow Transplant Units. All six of the registered nurses from the Palliative Care Unit were women whose ages ranged between 37 and 60 years. The mean age was 49.5 years. Four of the participants from Palliative Care were either married or partnered, one participant was divorced and one was single. All of the nurses were graduates from a nursing diploma program and none were working toward a degree. The years of professional nursing practice on the Palliative Care Unit ranged from 10 to 33 years, with a mean of 19.4 years (Table 1). All of the nurses were working in part-time positions, as there were no full time, direct care nursing positions on the Palliative Care Unit. The number of years worked on the Palliative Care Unit ranged from 2 years to 20 years with a mean of 10.25 years (Table 2). Generally these nurses were older and more experienced than the nurses from the Bone Marrow Transplant Unit.

Table 1

#### Years of Nursing Experience of Participants from Palliative Care Unit

Years of Nursing Experience	Participants
Less than 5 years	0
5-10 years	2
11-15 years	0
16-20 years	2
21-25 years	0
Greater than 25 years	2

Table 2

Years Working on Palliative Care Unit

Years of Nursing Experience On the Palliative Care Unit	Participants
Less than 5 years	1
5-10 years	1
11-15years	2
16-20 years	2

The six participants from the Bone Marrow Transplant Unit included one man and their ages ranged from 24 to 55 years. The mean age was 37.3 years. Three of the participants from the Bone Marrow Transplant unit declared themselves to be single and the other three stated they were married. The number of years in professional nursing practice for the nurses on the Bone Marrow Transplant Unit ranged from 1 year to 34 years (Table 2). Three of these nurses possessed a baccalaureate degree in nursing sciences, one nurse had a baccalaureate degree in political science as well as a diploma in nursing. Two nurses had a diploma in nursing. Five of the nurses worked full time and one nurse was working part-time. The number of years spent working on the Bone Marrow Transplant Unit ranged from 1 year to 25 years with a mean of 10.5 (Table 4).

Table 3  
Years Working on the Bone Marrow Transplant Unit

Years of Experience	Participants
Less than 5 years	3
5-10 years	1
11-15years	1
16-20 years	0
21-25 years	0
Greater than 25 years	1

Table 4  
Years of Nursing Experience of Participants from Bone Marrow Transplant Unit

Years of Experience	Participants
Less than 5 years	3
5-10 years	1
11-15years	1
16-20 years	0
21-25 years	0
Greater than 25 years	1

As discussed earlier, religiosity has been linked in the literature to hopefulness. Religiosity may influence the manner in which hope is conceptualized and it correlates positively with levels of hope (Benzein et al, 1998; Hall, 1994; Mickley & Soeken, 1993). The nurses in this study were therefore asked to declare a religious affiliation. Three nurses from the Palliative Care unit reported a religious affiliation and all three stated that they were practicing members. Three nurses from the Bone Marrow Transplant Unit declared a religious affiliation but only one stated that he/she was practicing.

In summary the participants from the Palliative Care Unit are older and more experienced nurses. The nurses from the Bone Marrow Transplant (BMT) unit are generally younger and newer to the profession of nursing (Table 5). Although there is no significant difference in the average number of years the nurses have worked on their respective units, the range is much greater among the BMT nurses than among the Palliative Care (PC) nurses. Generally the PC nurses have worked for a longer period of time on their unit.

Table 5

Demographic Data Palliative Care Nurses versus Bone Marrow Transplant

Nurses

Age of Nurses on the Palliative Care Unit		Age of Nurses on the Bone Marrow Transplant Unit		Years of Nursing Experience Palliative Care Unit		Years of Nursing Experience Bone Marrow Transplant Unit	
21-25 years	0	21-25 years	2	0-5years	0	0-5years	4
26-30 years	0	26-30 years	0	6-10 years	0	6-10 years	0
36-40 years	1	31-35 years	2	11-15 years	2	11-15 years	1
41-45 years	0	35-40 years	0	16-20 years	2	16-20 years	0
46-50 years	3	41-45 years	0	21-25 years	0	21-25 years	0
51-55 years	1	46-50 years	0	26-30 years	0	26-30 years	0
56-60 years	1	51-55 years	2	31-35 years	2	31-35 years	1

### Themes related to the Generalized and Particularized Spheres of Hope

In this section themes that reflect the two spheres of generalized hope and particularized hope will be discussed. They are listed below.

	<b>Bone Marrow Transplant Nurses</b>	<b>Palliative Care Nurses</b>
<b>Themes Related to Generalized Sphere of Hope</b>	<b>Approach to Nursing Practice:</b> I want a challenge  Generally I hope for: Health and Long Life  Hope is important for the Journey	<b>Approach to Nursing Practice:</b> This is a calling  Generally I hope for: A life well lived  Hope is important for the Journey
<b>Themes related to Particularized Sphere of Hope</b>	<b>Object of Hope:</b>  Hope for a cure	<b>Object of Hope:</b>  Hope for a Peaceful Death

#### **Generalized Sphere of Hope:**

##### **Approach to Nursing Practice**

Nurses from the Bone Marrow Transplant (BMT) unit and from the Palliative Care (PC) unit each expressed a distinct worldview with which they approached their nursing practice. Their primary motivation in choosing their area of nursing practice was reflected throughout their statements about hope.



The BMT nurses affirmed a strong need to be 'challenged' in their work with patients. These nurses articulated a desire for profound relationships, with patients that were further intensified by the acuity of their illness. This intensity was heard in the conviction of the nurses' voices and observed in the vigour of their body language.

Re. (leaning forward with hand gestures): I thought it would be extremely challenging, in every area, not just task-wise and learning-wise but just putting your best foot forward.

Bl. (switching positions and leaning forward): The challenge. I like, I learn every day that I am here. I learn something new, something is re-emphasized, um, it's an ongoing learning process and I enjoy that challenge.

Bl.: When I first started working here it was similar to what I said before in terms of the challenges that it would provide, with the level of acuity... that was the initial reason. The care that they would need, the things I would need to learn, you know in the area, in the specialty, that was the initial reason that I chose the area

Ma. (shoulders tense and clasping hands): ... I wanted to counsel patients, I wanted to... psychosocial nursing is big to me and yet (the BMT unit) had the challenging, um, it's an acute medical unit, so I was challenged medically and I just felt I could offer everything that I wanted to.

The nurses from the BMT unit unanimously stated that part of the motivation for working with bone marrow transplant patients was that they could make a difference in the lives of these patients. They wanted to have a meaningful part in the lives of patients who must face the sometimes, overwhelming adversity of cancer.

Pi.: I really wanted to make a difference and to really do something that I felt was rewarding.

Ma.: I just really wanted to be able to make a difference.

Or.: Because I couldn't imagine being anywhere else.... when I started a lot of the diseases that we are now controlling and sometimes curing weren't controllable or curable and so I have a historical perspective.

Nurses from the PC Unit each expressed a calm assurance that the provision of end of life care is what they had always been meant to do. There was no real reason that they could identify for working in palliative care other than an intuitive sense of 'homecoming'. They viewed the PC Unit as their home and the place where they 'fit'.

Te.: Well, for one thing, I needed a home... it was a fit, that's all I can say. It wasn't a big heart-rushing, this is the place I need to be... it was a real...it was a lot of peace, you know.

Ye.: When people ask me how I like it here, I say 'it's, like this is where I was meant to be'. My whole life, I've been working towards being here'... It's my heart and my soul.

Most of the PC nurses viewed their work as a calling. One sensed that they did not necessarily choose this area of nursing practice but that it chose them. End of life care allowed them to attend to the spiritual needs of their patients and this was an aspect that was also significant in their own lives.

Aq.: I believe that this is my path and so, that's my passion and I am going to do this and that's it...It's a calling first, I know this is what I am supposed to do.

Co.: I get so much; it's just a very rich experience. Extremely rich ... I have always been on a very tense spiritual path, questioning for decades. Um, and this is a perfect fit.

Ye.: My whole life, I've been working towards being here'; and I said 'it's like being a real nurse'. I say, 'I get to do all of it, not part of it'.

### Generally I Hope for...

When asked to discuss hope from a very general perspective, nurses chose to reveal their own personal hopes rather than those related to their patients. They described their hopes in a very general sense. Once again the BMT nurses and the Palliative Care (PC) nurses provided very distinctive viewpoints that were pervasive throughout the discussion on hope.

### Good health and a Long Life

Nurses from the BMT unit all responded that at a very global level or in a more general sense their hopes were focused toward good health. These nurses wanted to live and they wanted to be healthy while they live. These nurses viewed life as fragile and precious. Good health was essential to living a full and productive life and they valued it. They did not assume that good health as a given but they hoped for it none-the-less.

Ma.: In a very general way...(I hope for) health, a long life um, healthy family. I think health is a really big thing.

Or.: To remain healthy, and if not healthy to be o.k. with whatever happens... most people on Oncology don't, don't assume good health... because they know it can change just like that.

Ma.: I can't count the number of times that I have driven home in my car and cried. I walk outside and I just feel privileged to be able to feel my lungs with the air. You know, I really do, I just...and my family, I come home and I just want to hug my family and ..... I am a happier person because I, I value everything that I have and I am reminded every day ...

This perspective was salient throughout the discussion about hope and hoping with the BMT nurses. It formed the basis for hopes particular to their patients and to their nursing practice.

## A Life Well Lived

Nurses who worked in Palliative Care presented a somewhat different outlook related to generalized hope. Quality, and not quantity, of life factored significantly into their hopes. Good health was not viewed as a necessary precursor to a good quality of life. These nurses hoped for a life that is well lived. They did not view illness as a barrier to a good life. PC nurses desired spiritual well-being equally to physical and social well-being.

Ye.: I don't worry about the future. I take it sort of as it comes and I don't know, where that came from and when it started, but I am very content in my life, whatever it brings, I use it as a learning tool and I hope that the good things will stay, of course... my hope is that each person that I touch, will teach me something and will go away with something as well.

Li.: ...Hope doesn't necessarily mean good health. I could be in a wheelchair, but as long as everything is o.k. around me and that sort of thing, and yeah, I think um, I'm ready for whatever...

Li.: I suppose I just hope for good things or that everything comes out all right and everyone is on the same page in everything.

These nurses expressed a certain type of serenity and acceptance toward the challenges of life, in their approach to hope. They acknowledged that illness creates hardships but it is by no means always an indicator of poor quality of life. A good life is one that encompasses meaningful relationships, opportunities for learning and spiritual growth. This perspective was woven throughout their comments about hope.

### Hope is important for the Journey

Nurses from both the BMT unit and the PC unit found the initial part of the interview difficult. When they were invited to describe the concept of

hope in general terms, they struggled to find words and sometimes needed prompting. The nurses had a general appreciation that hope was significant particularly as it related to their nursing practice. There was an expectation that one must have hope to practice as a professional nurse. Hope was woven into many of their nursing activities but they were not usually aware of it. They all stated that, while hope was not part of every conscious thought or action, it was an important element of life which underlay their nursing practice.

Fi.: (I)don't think you could do what we do without hope. Um, I think that would be very discouraging and I think you would be almost in despair. Like if there was no hope, and you came to work and you just did your job, I don't think there would be much point to it.

Li.: I don't know if it helps me, it's just always there. I suppose I have not been not hopeful... If you don't have it (hope), it'll drag you down. It's, it's kind of like ah, air and water and all of that and oxygen... If you don't have that hope and that positive outlook, or a different outlook, um, then you never get ahead, it's like you are spinning your wheels

Ye.: I mean, how can you live your life without hope? You know, you have to have it and how can you be effective in your job without hope... life is so much easier with hope... Hope is important because without hope, what do you have.

Ye.: If I didn't have hope, I couldn't work here. Because I have to hope that these people, I'm using people, you know, as patients, um will get what they need and they are here, in my life the same as I am in their life for a purpose.

Participants spoke of life as a journey and hope as that which keeps us engaged in those activities which are important for the journey.

Achievement of what is hoped for, or objects of hope, was not as significant as the process of hoping and staying engaged in living.

Re.: It's (hope) never disappointed me, and that's the same in private life too. I mean things hurt, things go bad, things go good, things are great, no, no ... because I don't think achieving them is the deal... Just hoping, just always being positive, always trying to get there because we won't always get there. It doesn't matter, it doesn't matter.

Or.: It is more important to hope. We don't all achieve our hopes...It's the journey, achieving is the end, the destination. The journey is important. Sometimes, by the time you get to the destination it no longer is.

Co.: ...I don't know if the bird experiences hope or faith. But whether, to live out that reality, it doesn't need to ponder whether it should have hope or faith, it just lives...Maybe that is true hope or true faith in the sense that it doesn't wonder, it just does. It gets it or it doesn't get it, and then it keeps trying.

Pi.: I think when I was in Nursing School and if we had talked about hope and I think I would have thought about it being a positive outcome at the end. You know, long time survival or remission and that, but I think that working on (the BMT unit) has shown me that it doesn't have to be always a good outcome in the end, that there can be hope and sort of a positive outcome from just the process of either, the process of dying or the process of living through the illness.

Each of the participants interviewed also expressed a certain awe and gratitude that they are allowed to be a part of the patient's journey.

Te.: But you really think that it's a journey that uh, you have been graciously allowed to participate in.

### Particularized Sphere of Hope

Two different perspectives emerged once again in the responses about specific or particularized hopes. Nurses did not struggle with their responses as they had earlier in the discussion. Hopes specific to patients

and nursing practice were very distinctive and clearly related to the kind of work that each group of nurses was involved with on their respective units.

### Hope for a Cure

The nurses from the BMT unit unanimously stated that hope related to patient care was focused toward a cure. These nurses wanted their patients to live. Much of their energy both mental and physical was directed toward this possibility. The high degree of uncertainty related to some of the therapies provided seemed to intensify this hope. Conversely these nurses also hoped for the personal courage to acknowledge when therapy had failed. They did not want patients to suffer unnecessarily but giving up on treatment meant that they can no longer hope for life. If a cure was not possible then they could only hope for a good death, but that was not their primary hope.

Bl.: For transplant aspects you hope that, you hope that it cures them ...Speaking statistically only, 5 to 7 years for an... antilogous transplant it can be expected for, you know a continuation, and that in itself is certainly a hope, because what is the alternative.

Re.: You just hope that these people....you hope that they will make it, you hope that they will live because of course, that is what we all want to do, you want to get better but I hope that if they die, they die well. That they are ready to die and that they die in faith. That's my hope.

Or.: You know, you hope that everything goes well, that they get cured and they go on to live the lives they want to live. If it isn't curable, then what I hope for them is that they will be able to deal with whatever it is that they are going to be going through.

## Hope for a Peaceful Death

The object of hope, for nurses on the PC unit, was a peaceful death for their patients. They hoped that patients could achieve an understanding of the dying process that would allow them to accept their physical reality and to surrender the fight for life. Conversely, these nurses hoped that patients would live their lives until they died. Their hopes were directed more toward the spiritual well being rather than simply the physical well being of patients. Patient care was structured in such a manner so as to allow patients to maximize and focus their energies toward those activities that would enrich the 'end of life experience'.

Te.: We don't look for a cure, we are looking for a peaceful, that they are comfortable, that the family is able to cope, all these are little hopes, it's the reality of a peaceful, comfortable death...

Aq.: Peaceful, comfortable deaths, you know, where there is that calming, that inner peace that you see. You know, like that woman... She came in, you know, thrashing around and everything, but not at the end... it was o.k. because that hope had fulfilled and now it was o.k., it was o.k.

Li.: I hope that ah, people understand death and dying. I um, hope I always do a good job to bring that across to them, to explain how it happens... Sometimes it can be in a minute that they die, but where everyone, totally understands the dying process, you know.

Co.: ...they get the best care because as far as they know and I know and it's the only kick you are going get at death, so why not try and make it a good one.

## Summary

There were areas of convergence and divergence among the findings from the two groups of nurses. The BMT nurses articulated a need to be challenged at work. Generalized hope was associated with good health and



a long life. They did not assume good health but they valued it and hoped for it. Particularized hope for BMT nurses was directed toward a cure for their patients. They wanted their patients to live for as long as they possibly could but they did not want them to suffer for it.

PC nurses professed a calling for their work. Working in palliative care provided them with a sense of homecoming and that this was the kind of work that they had always been meant to do. When PC nurses spoke of hope in a general sense they alluded to hoping for a life well lived. Good health was not considered necessary for a good life. Rather they valued a life rich with experiences and relationships. Particularized hope for PC nurses was related to a peaceful death for their patients. They hoped that their patients would live fully and comfortably until they died.

Both groups of nurses agreed that hope is an important element of life that keeps people engaged in living. There was cognizance that hope was important to their practice and they expected to have hope in order to be an effective nurse.

### Themes related to Dimensions of Hope/Hope Work

The themes discussed in this section reflect dimensions or the work of hope. These are statements that describe processes of hope that the nurses engaged in.

	<b>Bone Marrow Transplant Unit Nurses</b>	<b>Palliative Care Unit Nurses</b>
<b>Themes related to Cognitive Dimension</b>	<b>Truth vs. Possibility</b> <b>Switching Gears</b> <b>Moral Judgments</b> <b>Imbalance and Isolation</b>	<b>Truth vs. Possibility</b> <b>Switching Gears</b> <b>Moral Judgments</b> <b>Imbalance and Isolation</b>
<b>Themes related to Affiliative Dimension</b>	<b>Building Trust and Connecting</b> <b>Connected</b> <b>Humor</b> <b>Providing Context</b> <b>My patients give me Hope</b>	<b>Building Trust and Connecting</b> <b>Connected</b> <b>Humor</b> <b>Providing Context</b> <b>My patients give me Hope</b>
<b>Themes related to Behavioral Dimension</b>	<b>Fight</b>	<b>Surrender</b>
<b>Themes related to Affective Dimension</b>	<b>Energized</b> <b>Conflicted</b>	<b>Peaceful</b> <b>Acceptance</b>
<b>Themes related to Contextual Dimension</b>	<b>People come here to be cured</b> <b>Difficult Illness (self or family)</b>	<b>People come here to die peacefully</b> <b>Difficult Death in the Family</b>
<b>Themes related to Temporal Dimension</b>	<b>Life is Day to Day</b> <b>Milestones</b>	<b>Live in the Present</b> <b>Milestones</b>

### Cognitive Dimension:

Nurses from both the BMT unit and the PC unit described similar thinking surrounding the concept of hope. They described hope as similar to 'wishes' or 'dreams' that may or may not be grounded in the truth as perceived by these nurses. Hope is a noun but more importantly to these nurses it is also a verb. It is a positive or good energy that encompassed many activities but it also energized and motivated people to act. Hope was seen to evolve with life circumstances and it was dynamic. Hoping was goal and future oriented.

#### BMT Nurses

Or.: "I think, hope is the way you want the future to be."

Re.: Truth is not always positive... but I think hope is what you are going to do with the truth... they go hand in hand.

#### PC Nurses

Li.: Hope is an energy, of course, it's a positive energy, um, if you don't have hope, then you are dragging down, you know.

Co.: When I think of hope, I think of ah, you know, if I am going to be cynical, when I think of hope I can think of almost hope is about a blind faith, hope is about wishing, hope isn't necessarily realistic, probably  $\frac{3}{4}$ s of the time.

Fi.: It's purposeful, it gives you a purpose I think. I think we all work towards some goals, even if they are just small.

Te.: Hope is part of dreaming and your dreams sometimes change and mutate as you go along.

### Balancing Truth and Possibility

The cognitive dimension played a prominent role in how both groups of nurses hoped, particularly as it pertained to their practice. It formed the

basis for all of their interactions with patients. More specifically how nurses thought about hope influenced how they communicated with, and inspired hope in, patients. Hoping from a cognitive perspective was the result of balancing truth with possibility. This involved an ongoing, complex set of assessments and decisions around truth and possibility. Truth and possibility were contrasted in an attempt to understand and focus hopes. Nurses examined and evaluated medical truths, personal truths and the truth that their patients owned.

#### Medical Truths:

BMT Nurse

Bl.: Look more medically, at some of the statistics, um, things like is their disease refractory ... All those things play a factor in terms of really how much hope there is. As long as all of those options and potentials are given to them.

PC Nurse

Li.: Prognosis in the chart and then their physical – what they look like and all of that, their bloodwork and all of that so that kind of – you put the two together and then you have an answer.

#### Nurse's Personal Truth:

BMT Nurse

Or.: "Um, they always want to know odds and they will say to me you know, 'what are my chances of cure or control' or whatever and my usual response to that is for every individual person, the odds are 100% or 0 and if you have a disease that is only 20%, a 20% response rate or a cure, why not you, because it's the truth."

PC Nurse

Fi.: "I think that's legal, if it's to help them put things into perspective, right, um, and sometimes it means being really honest, you know. I once had a man hemorrhage all over me, a young man, he wasn't much older than me and he said 'am I dying' and I said 'yeah, you are, you really are and you need to make your peace' and he closed his eyes and he had a few minutes of whatever that was and he was dead, like very shortly after that. And I don't think it is the time to fool around..."

### Determining the Patient's Truth:

BMT Nurse

Or.: Well a lot of patients look to me to give them hope. Ah, I think my job is to find out what exactly they mean by that. Um, I would never....and to figure out, you can't ever tell somebody 'you aren't going to live'.

Ma.: You know, I like to pull up a chair, or sit on the bedside so we are face-to-face and um, and I like to ask people 'how do you feel about how things are going, how do you feel about all this stuff', depending on, you know and then I sort of play off what they want.

PC Nurse

Li.: We ask them over and over again, that's one of our...we don't use the term hope, it's like 'overall, how are you feeling, what's your outlook, how has it changed'

Ye.: Hum, very often it's determination, you know, that's a big one. If they are determined and they are not taking 'no' for an answer, they usually will get their wish.

Nurses went on to consider the possibilities that existed from a medical or scientific perspective, a personal perspective and also from the patient's perspective. Each truth and possibility achieved a certain weight of influence in decision-making. Each possibility was contrasted with the nurse's own 'held truths' and brokered to the patient and his/her family.

BMT Nurse

Bl.: To me hope, partly it's being honest. Honest with the patient and the family member, but it is also being able to provide them a sense that, you know, there is a possibility, there is a chance that this will work, that this will help, you know...

Ma.: I need to find out if they realize exactly the possibilities and then if they still want to be hopeful, fine, that's fine with me. But I need to, as a nurse, I need to make sure that they understand the weight of the situation and what.

PC Nurse

Te.: Sometimes I think um, I think of myself, almost, you know as in a plug, the grounding, so when they express hopes that I don't think

are realistic, um, I think I am grounding them. I'm, I'm balancing things and I find myself doing that quite often.

Aq.: Well it depends on how well you know the patient to begin with and that um, that usually, you get signals all the way looking through looking after people. They give you different signals, but again, if you spend time with them, then that sharing leads on to other conversations usually. You can get little hints of things.

As truths and possibilities emerge or evolve and change the nurses adjusted their thinking and refocused hope. For the BMT nurses the wide varieties of treatment options constantly offered new possibilities that in turn needed to be balanced with new truths. PC nurses had to refocus and balance hopes in response to the patient's loss of physical and cognitive abilities. The heavy weight of new truths may have needed to be balanced by many smaller possibilities each with less weight. This was stressful for nurses and could become a source of tension.

BMT Nurse

Or.: But, you know, if we have done our jobs well and things don't go well for the patient, then our job then becomes helping the patient deal with that and refocusing what it is that is happening to them, refocusing their, perhaps what their hopes for the future are.

Re.: You drill into them hope, hope, hope, realistic hope, you know because until you are told, 'this is it, that's all we can do', there is always hope. 'You failed this treatment, we will try another one, this didn't work, we will do this', you know.

PC Nurse

Co.: let's say on a day-by-day basis, abilities are taken away on a day-by-day basis...they will slip to a lower level of hope or it's the same hope, as far as, maybe yesterday got up. I remember this one patient very clearly ... and he said, you know 'tomorrow I really want to get out of bed and sit in the chair' and it was just so poignant, that's what his total hope had been reduced to and it was all meaningful to him.

Fi.: Um, I think sometimes, it's, it's putting things into perspective, um, maybe helping someone realize that using other energy to get to the bathroom is not a good use of their energy because maybe they have family coming in, in the afternoon. Where, o.k. you are giving up some independence and you are now having a foley, but you are not using up your energy to get to the bathroom and now you can get up in the chair in the afternoon and visit with your family.

### Switching Gears

All of the nurses spoke of 'switching gears'. This typically occurred when there were undeniable and irrevocable changes in the patient's physical condition, which drastically altered possibilities. Difficult truths had to be broached. The weight of some of these truths were challenging to balance with possibility. BMT nurses referred to 'switching gears' when they spoke of situations where all treatment options had been exhausted and patients had failed to respond. They had to change their thinking about hope as it pertained to a cure and refocus it toward hopes for a peaceful death. 'Switching gears' on the PC unit usually occurred when the patient's death was imminent. The nurses, patient, and the family all possessed an awareness that the patient was living through the last stage of life. However, when the patient began to 'actively die' the raw truth of that one reality had to be acknowledged and the list of possibilities had to be minimized to that of a peaceful death.

BMT Nurse:

Re.: That's what we always do, always say, always say (*hope for a cure*) and then all of a sudden... what else can we do' and the doctor says 'nothing, nothing' (quietly). Then usually the next question is 'how long do I have'. Usually at that point it's... then the focus changes.

Ma.: For us... it's difficult because you are hoping, you are fighting with patients, with families for long periods of time, year... two years and then one day you switch, that same person that same patient and usually... it just comes to a halt. It's just, yeah and it's um, you are switching gears, with care. And the same things that you would have said to a family a week before, you won't say then.

PC Nurse:

Fi.: There is nothing hidden, you're, you're at a really vulnerable time in life and you get to be part of that and make it somehow be better. Yeah, it's really raw, there is no covering up on anything, it's out there.

Te.: Sometimes they 'say isn't he doing well today, he did so well yesterday, things are getting better' and you look at them ... and say 'they are dying, we need to move along'... and they look, they look in your eyes and it is just like, um, it's like horror, they have just seen something so horrendous and then the tears come and the tears aren't even hard to deal with, it's, it's... you know reality can really smack you in the face.

#### Imbalance and Isolation

Overly focusing on truth or possibility without giving due consideration to one or the other created a tensions in relation to decision-making. This could result in miscommunication and may have had the effect of creating distance between the nurse/health care provider/family member and the patient. Patients may have become isolated as a consequence.

Pi.: "I still try to support what she wanted and what her husband wanted, even though I didn't really believe that they were going to have anything positive come out of it... Like, I still tried to support what she wanted, um, without sort of, like me being a little more reserved.

Ma.: "...and I remember... her and her husband, they had just received the news that day... about there being this 3% chance that she would survive. And to me, if I had received that information, I would have thought 'oh, it's over', but they, they were telling me that, they kept saying '3%, she has 3%'. They were from (city) and she said 'that means out of a 100 (people from her home city), 3



would survive and I know that's going to be me, I know it'... At that point I had hoped that she would sort of accept the information that we had given her and she was hoping right to the very end that she wouldn't die. That was really hard for me to care for her in those last hours because, there was so many things I wanted to do for her. I wanted to...have her cat come to the hospital and see her, but she was so against believing that she would die. Not only that, her family, were from (city) and they didn't make it in time, she didn't want to speak on the phone with them or talk to them. I just felt as though there was so much that we could have done..."

### Morality Judgements

Throughout the process of appraisal and balance nurses were also making moral evaluations about truths and possibilities. These judgments often overrode other assessments with regards to their decisions about hope and how they communicated with patients. There was recognition that they had the power to harm patients by encouraging or discouraging hope. Nurses struggled to balance their need to be truthful with the patients need to remain hopeful.

#### BMT Nurse

Gr.: She was finally going to a home for palliation and they were taking her, the ambulance was taking her, transported and she was like 'oh you just see, I'll be back', you know. 'I'll get over this, I'll be back' and what are you supposed to say to that? You can't say, 'no, you are not coming back, this is the last time I am going to see you', you know... that was really hard and uh, because you say to her 'well I hope so'. Because you do hope so.

Bl.: "You know, you don't think, you don't say, good-bye in the sense of...o.k. I realize this is the last time I am ever going to see you alive. You don't look at it that way or you don't focus on that for them that way, it was you have a safe flight home and go be with your family was the way that I focused on it for her on that day.

Ma.: He was 18 years old-a young guy, you know. And I just felt that would never happen and it hurt me, it hurt me to have that...But at

the same time I know how wonderful and important that was for him to have that hope.

PC Nurse

Aq.: They are telling me, is it wrong to maybe hope for a cure - No, I don't think it is wrong to hope for that at all. Miracles happen everyday, unfortunately we are just not use to seeing them.

### Summary

Nurses described several cognitive activities when speaking about hope and their practice. Hope was defined as including aspects of wishing and dreaming and it was focused toward the future. Nurses' thinking, surrounding hope, involved a complex set of assessments where truths and possibilities were evaluated. Truth and possibilities from various perspectives including, a personal and medical perspective as well as patients' perspectives were considered. Significance or weight was assigned to each perspective. Nurses sought to maintain a balance between truths and possibilities for themselves and their patients. This could become a source of tension for nurses. Overly focusing on either truth or possibility created distance between nurses and their patients. Patients, who concentrated too heavily on truths, or only on possibilities associated with their illness, were perceived to be isolated from others. There were events which necessitated that nurses refocus or redirect their hopes for patients. Nurses referred to this as switching gears. Finally all decisions related to influencing hope in patients were filtered through a process of moral assessment. The decision to inspire hope was based upon what was determined to be good for patients.

### Affiliative Dimension

Nurses believed that they could influence or inspire hope in their patients through their interactions with patients and by developing relationships that were trustworthy. Trustworthy relationships evolved from interactions that were mutually revealing to a certain extent. These nurses wanted to understand their patients as individuals or persons so that they could inspire hopes that were meaningful and helpful. This was an aspect of nursing practice that they viewed as tremendously satisfying.

BMT Nurse

Or.: You do develop very strong relationships that may or may not happen to the same degree in other places. I think the evolution is really important. It provides you with opportunities for that kind of intimate relationship as the, as time passes.

Ma.: Knowing that people trust in me and can confide in me about how they are feeling about the way things are going and I think I try to establish that right off the bat.

Re.: I was always sort of taught 'you can't get too involved, you have to step back, you know, you just can't...you'll burn out, but I think that you burn out if you don't get involved and it hurts to get involved sometimes, it's very hard'. But otherwise you are just going to work and collecting a pay cheque, I can't.

PC Nurse

Te.: That's why I am always thankful that you can see a little bit of that person's personality... I don't even care as they deteriorate, that ability to um interact always recedes. You know, sometimes they pull away, but you knew what they were like... when there personality was really intact. If you can see that it makes it easier to care for them.

### Establishing Trust and Connecting

The establishment of trust was fundamental to the process of inspiring or influencing hope. Nurses needed to demonstrate trustworthiness so that

patients could believe them when they offered them help. Patients would allow their hopes to be influenced by nurses who showed themselves to be sincere, knowledgeable and caring. Trust had to be present between nurses and their patients, particularly during those episodes referred to by the nurses as 'switching gears'. If the nurse were to renegotiate and help patients and their families refocus hopes they must have their trust.

#### BMT Nurse

Ma: Just things to show that I care for them. They are tired, they are overwhelmed, telling them, you know 'maybe we can, maybe we can put a little do not disturb sign on your door for two hours this afternoon and you can get some rest'. Sort of showing them that I am here to protect them, I'm not here to invade their lives.

Or.: It is never an event, but through the course of going in and just being there and explaining things and establishing a relationship of trust, because I always do what I say I am going to do, at least 99.9% of the time, I do what I say I am going to do. So if I say I'll get back to you with that, I do. Or I will say remind me about this. If I say I am going out to find somebody, I will. So, just little bits, like little, just like building a house, brick by brick.

#### PC Nurse

Te.: (I)want to have a real good relationship...with them so you can be really honest because you know at some point in time the honesty, that's what's going to mean a lot then. And you want to have a real trusting... I don't want it to be an issue of trust...I want to get in there so I can say to them and (they) are going to believe me when I say 'we need to move things along', or when I say 'I think we can get this pain under control, I think if you give us a couple of days, you are going to feel a lot better and we will be able to get you home'. I want them to believe it. So whether I am giving them good or bad news, I hope that they know that I am sincere.

Te.: I want them to say when I do something with them, it's going to be because I really do have their best interests at heart, whether it be something that is difficult for them or something that is joyous, you know.

Te.: You say things like 'I know you have been telling me you are ready for your death but when it happens, it's going to come fast and

you are going to be amazed, it's never the right moment, it's never' and um, 'but I'm going to be there with you and ...you know you want to provide a little comfort.

Fi.: Sometimes I think you just connect if you are able to get them through a real rough spot and they see you as that person who helped them through that, you know and I think there is a connection.

In order to be seen as trustworthy a connection must have been established between nurses and their patients. This involved interactions where the nurse shared something, of a personal nature, with a patient. The relationship evolved beyond that of nurse-patient to that of person-person. There was an affirmation of the patient's personhood as a result. A better understanding of each other was achieved and the nurse gained more credibility with his/her patient.

BMT Nurse

Bl.: Her and I had a similar personal situations, children in custody and those kind of divorce issues that her and I were able to, I guess, connect on that level, outside of a nurse providing care ... was able to directly empathize with her in terms of wanting the best for your children, the feeling powerless to do that and I think that both of us talking helped give each other hope that maybe things will turn out for the best."

Or.: Being myself because I don't try to be 'a nurse', or 'the nurse'... Um, sometimes our conversations are about their lives, usually, I...ask people 'what do you do'. Not 'what did you do' but 'what do you do'. Um, I take my cue from them, ah...

PC Nurse

Li.: "And sometimes when they ask, you know, 'are you married, do you have kids, what do they do' and I am telling them my story and thinking 'why do you really....' It's not important to you... and I think 'well maybe that's their way of hanging on and participating still'. Being connected and that's fine and I'll share..."

Aq.: But that gets back to spending time with them. Everyone likes you to tell them your story, they like to hear your story and they like to tell you theirs. Because I believe that time is telling those people they are worth being with and that you care about them and that's when they share with you, of themselves.

Co.: "I'm hoping to bring them something about myself that allows them to feel that this is a safe thing."

Aq.: She was one of my connections... and I used to bring my fairies in and show her my ... collection. She had collections too. . I use to take about an hour and go in there, if I wasn't busy. I'd just spend time talking to her about the kids and what was happening, you know, she would share with me a lot about, you know, her worries about her kids and her daughter who is just turning 13 and her boy is younger, you know the worries, things she worried about and things she hoped about her kids...

### Connected

Nurses reported feeling more hopeful about patients with whom they could 'connect'. They described hopeful individuals as those who remained connected to friends and family and to the life that they had outside of the hospital setting. Conversely nurses found it difficult to 'connect' with patients whom they perceived as hopeless. Hopeless individuals were depicted as disengaged, isolated, and empty.

#### BMT Nurse

Pi.: People who have more hope for returning to their lives, stay really involved in their outside lives and their families outside lives. Sort of not giving up that connection. Often a patient who is sort of despairing and negative will sort of withdraw from other people and not be as interacting with their family and friends as others.

Bl.: Feelings of hopelessness ... it is harder to make a connection, you know, to be there for them, you know, for listening, as well as direct nursing care and things of that nature. Even the things how to connect and when is humour appropriate...somebody who, speaking for myself personally, that you really connect with patient-wise and family-wise, it is easier to provide that sense of hope.

PC Nurse

Li.: And they are more connected...and they are the ones that have family members coming in all the time.

Aq.: Cause I think people who don't have hope are often isolated... I think it makes me feel, it can bring down, but, I think it just makes you feel that you need to be in there more, you need to be spending more time with them, you need to really get them talking and establish a bond, establish something, somehow connect with them.

Fi.: (No Hope)I think really withdrawn, with a kind of flat affect, uh, just wanting to be left alone... It's hard to connect. It's hard to, it makes you feel (pause). I think caring for them you feel a little bit weighted, it's a bit of a burden... Well, I'm just thinking, yeah, if you are not hopeful, you are a bit of a shell aren't you?

You've got to Laugh

Nurses viewed humor as an important element of their interactions with patients that help to inspire hope. It allowed the nurse a glimpse of the people that their patients were. Nurses felt more connected to their patients if they could share laughter with them. It provided patients with a sense of normalcy and that perhaps 'things will turn out right'. Life was still good if it was still providing opportunities for laughter.

BMT Nurse

Bl.: Um, I guess hope, for me sometimes comes in the form of humour, providing that sense of release being that not everything is that overburdening sense of finality, as well as the sense of being o.k.

PC Nurse

Li.: Whether you have no breasts or no nose or whatever, you can still laugh and be crazy and you are just normal. You are just like everybody else only you have this diagnosis.

Te.: But probably the best thing is to use a little humor and it makes them feel like....when you can see them laugh, even smile, their day is brighter and they are relating like a normal person... If you can get them at the bedside within a couple, even days, and either they or

the family member laughs, I have really achieved something then. There is a little bit of normality even though the situation isn't normal...

Li.: ...You know, we will go in and someone is dying there and they are all talking about good times and laughing and joking... it almost seems out of place but it isn't, it's a, that's life right, it does go on after someone dies.

### Providing a Context

Inspiring hope in patients often involved providing them with a frame of reference. The illness experience needed to be placed within the context of patients' lives so that they could gain an understanding of this new aspect of their lives. Nurses stated that providing context allowed patients to feel safe and less overwhelmed. It created a sense of 'normalcy' by finding a place for the new reality of their illness. Nurses maintained that providing this context inspired confidence that possibilities still existed in the changed lives of their patients. They viewed this as one of the more satisfying components of nursing practice.

#### BMT Nurse

Pi.: So I really like that whole process of having someone newly diagnosed and being able to teach about the disease and the treatment. I really, I get satisfaction of them being sort of ...feeling more confident about their treatment and their care. Lots of people will come and sort of be very scared and very overwhelmed by the new experience and I really like being able to sort of be there for them during that time.

Ma.: You know, initially people hear leukemia and they think 'it's all over for me and that's it', it's overwhelming and .... Um, as far as when I am teaching families and patients about living with leukemia, I try to help them to have hope by, I guess I try and normalize things for them ah. Because I know, and I actively tell them that 'you know, you are still the same person, but you are going to be living



with leukemia. It's a chronic illness, you know. You are still the same person.

Ma.: I try to help people find a place for it (cancer) in their lives and I try to suggest to them that perhaps this could be, this is a project right now, this is a project, it's a very important project but when you are finished your project you know, you will be able to....and I try and focus and ask them questions about their plans for the future, you know. Things will change, what do you think?

I get Hope from...

Nurses were inspired to hope by the very people whose hope they were trying to nurture. Patients who remained positive and persevered in spite of devastating illness were powerful sources of hope for nurses.

PC Nurse

Aq.: The families and the patients. They give... hope...Yeah, they do. My colleagues too. They give me a lot of hope.

BMT Nurse

Ma.: Hopeful patients give me hope because when they believe in the possibilities then that makes me believe in the possibilities. It's kind of infectious that way I think.

Re.: So you go in there and here they are for the fifth day in a row and they have such a bad mucositis, that they can't even talk to you and they are up brushing their teeth. You know, I don't know if you have ever seen bad mucositis, but it is a very, you know, it hurts and there they are, or they are sitting up looking at you and they are just trying, they are just trying to walk the halls and I just think, 'well isn't that a hopeful thing'.

Significant relationships with other nurses also served to nurture hopefulness in nurses. Nurses needed the support of other nurses who shared similar experiences and who could offer encouragement and empathy when required.

BMT Nurse

Pi.: There are a lot of nurses on (*the BMT unit*) who have been there for quite a while and even after seeing all the death and all the

suffering that has gone on in our ward, they still have a positive attitude and still feel that um, that we are doing some good and are accomplishing what we are trying to do

Gr.: I think that people who you work with factor in hugely. I know there is a group of people I mostly work with all the time and I think without having them, having them as resources or to even talk to about patients or to have to fall back on, even like psychologically, you know, without that group of people, a good group of people it would be very hard to do the work.

### Summary

Much of how nurses enacted hope in their practice was included in the affiliative dimension. Nurses inspired or influenced hope in patients by interacting with them in a meaningful way. Sharing information with patients about disease and treatments would not inspire them to hope unless it was provided by a person who was deemed trustworthy. Nurses established trust by seeking to know their patients and be known by their patients as the persons that they were. They tried to connect with patients not only as a nurse but also as the person that they were. This usually involved revealing an element of their personal lives. Patients, who remained connected to their friends and family throughout their illness, were perceived by nurses as more hopeful. Nurses found it easier to connect to patients who they perceived as more hopeful. Nurses also used humor to connect with their patients. Humor was used to create intimacy between nurses and their patients so that they could connect with them on a more personal level. Humor also assisted patients in maintaining a lighthearted perspective that prevented them from becoming overwhelmed.

Finally nurses tried to create a context for illness so that patients could make sense of it and find a way to hope.

### Behavioral Dimension

Nurses from the BMT unit and from the PC unit each adopted a very different stance when describing behaviors that were hopeful or that inspired hoping. These perspectives were reflective of earlier statements about hope.

#### Fight

BMT nurses observed that individuals who were hopeful were engaged in the 'fight' for life. BMT nurses saw themselves as fighting along side of their patients. They were 'pushing' and they were 'dragging' them to persevere mentally and physically and to get up and move. There was an expectation that patients coming to the unit were willing and wanted to fight for their survival.

Ma.: On (*the BMT unit*), we are an active treatment unit um, we have, you know, we take care of patients from diagnosis and usually ... you know, many cycles of chemotherapy; you get to know the patients and the family and you are hoping, you are fighting together

Gr.: I told her 'you know, you have to do your best to get up, even if you are super-tired, you have to push yourself, you always have to push yourself'. Sometimes people think, like that, you know, you are telling someone to push themselves ...

Re.: It's people are fighting for their lives. Fighting for their lives...they sort of lose will you know, and that's when you have to kind of ... push them a little bit and get them moving and doing all those things and when they start fighting with you, I love that, I love that, you know I said to one patient 'oh you're feisty again, that's good, you're back'. You know. Looking at those things and not being

feisty is a negative. To me that's a positive, their fighting. It might be with you, but that's o.k. you know.

Re.: We have a patient right now who ah, is very sick, 'I can't do this anymore'; and I say to him well, 'why can't you, is it because you are just to, you're throwing up and you are too physically sick, because you are tired, because you don't want to fight anymore, why? Why? Why?' So he told me 'I'm tired, I'm sick' and I said 'if I can try and make you less sick, do you, do you want to live or do you want to die'. Well he said, 'I want to live'; and then I said, 'well, then I'll help you and I am going to push you, but there is a time when it is o.k. to give up, but are you, are you really ready to give up'. He said 'no', and then I said 'well o.k., then I'm going to push you' and he said 'o.k.'. And it was hard, hard days, but he said to me, said to me 'I'm back' and I said 'yes you are

The BMT nurses sometimes described themselves as fighting to remain hopeful when they were challenged by the loss of patients. There were times when their own survival as nurses was at risk and hope was difficult to maintain.

Or.: I walked onto the ward one day and there was my family physician and he has since died. Um, so you can't. Those are situations you just have to live through. But on a day-to-day basis, you have to figure out a way to survive... And thrive.

Ma.: That's why I didn't know if I would be the right person for your study. I thought, you know, I saw the topic, I thought, 'gosh, am I hopeful' and I really questioned whether I was or not. Um, in the beginning I sure was, but we have had so many losses and I've suffered... I'm struggling, I'm struggling...

#### Surrender/Resignation and Acceptance

PC nurses described hopeful behaviors as those that facilitated resignation. Surrendering the fight for a cure and surrendering hopes for physical health in favor of emotional and spiritual healing. PC nurses considered symptom management crucial to this process of resignation. They considered pain control an urgent matter that needed to be attended

to very quickly. When physical pain was managed effectively patients could more easily ignore their ailing bodies and focus their energies on experiences that provided emotional healing and spiritual growth. They tried to facilitate those experiences that would provide peace and contentment to their patients.

Te.: Sometimes hope is giving up the fight and graciously and in a gracious manner, you know. Hope can sometimes be resignation. You know...as we say, it's kind of black, but when somebody stops breathing, that's a good thing on this ward sometimes.

Te.: Hope seems to be, it's one of those elusive things, if you haven't dealt with the daily comfort, decreased anxiety, enough food, decreased pain, hope isn't part of it... hope doesn't come in when the basics haven't been dealt with.

Aq.: Hope can be a healing of the body, but from the inside out... somebody's body can completely deteriorate but the hope of that healing from within, it doesn't matter about the body, as we see it. It's a healing of the person from within, their spirit. And it comes with a calm.

Fi.: I think hope when you are dying is ah, how do I put this, it doesn't include any of the frivolous hopes that we have otherwise. I think it's the true hope that you really hope for whether that be life after this or connecting with your family before you go.

Te.: And there she is skinny and dying with these little artificial breast and she had a wig that she wore all the time, and we would go through, make her look good, put her make-up on and I spent 6 weeks with this woman, full time.

Aq.: All the things that really count, all those human things, they can't do because they can't get past the symptoms.

## Affective Dimension

### Conflicted

The nurses from the BMT unit described conflicting emotions when they speak of hope. They all reported feeling energized and happy as result of hoping, however the emotions were that of uncertainty and anguish were equally prominent. The BMT nurses were conflicted about hoping too much for patients in their care. They feared for their patients. Hope could be the source of joy but also disappointment and pain.

Re.: The struggles, the pain, pain and then they still carry on, it's very sad. But it is uplifting too, it, it is both those things, you just feel like crying for them but then they do it and it's awesome really.

Pi: You feel, like happiness and you feel um, like you have something to look forward to, that there is something good to come.

Gr.: It energizes actually. That was the first thing that came to my head...when you do feel hopeful, at least you, it pushes you a little bit more.

Or.: It's good. It's an uplifting experience. As you watch people, you can learn.

Ma.: I do have hope, but it's um...(laugh), it's painful hoping. It hurts me when I hope for people, it hurts me and every time we have a newly diagnosed patient, I'll say to one of my colleagues, 'oh I hope he does well', but it hurts, it is a hurtful hope, it's not, 'I know he's going to do well' or 'I know it', it's not that, it's ah...it's an uncertainty, but a large fear.

Pi.: When you are hoping for something you always want the good to come out of it, but you are never really knowing what is going to happen.

## Peaceful

The nurses from the PC unit associated feelings of peace and contentment with hope. They experienced feelings of warmth and joy when they were hopeful. Like the BMT nurses they felt energized when they were hoping but they did not report uncertainty or pain to the same extent. There was not the same sense of inner conflict as conveyed by the BMT nurses. Some of the PC nurses described feeling guilty about what they hope for related to their patients' deaths, however this is not a prominent emotion.

Li.: Hope is an energy, of course, it's a positive energy.

Aq.: I think it is a very calming thing. I think it is a very calming thing. It's a serenity.

Aq.: It (hope) gives you that inner peace to keep doing what you want to do.

Fi.: (Hope) you can have a contentment I think. I think it can bring you peace.

Ye.: there is joy, there is laughter, there is peace, there is contentment, there is, it is endless right.

Te.: Almost, that sense of comfort when you get sitting in a warm, in the warm sun and you can feel that just complete peace, but also in a good happy sense. On the beach with a good group of friends, you know, feeling warm and comfy, almost to the point of sleep and then something just brightens you up, that's the way hope is it encompasses warmth, a sense of security, a calming, it should bring you peace and um, at times just laughter with the peace, I guess.

Te.: Well, you know sometimes when you are hoping that the death will come easily and quickly, there is a little bit of guilt involved.

## Summary

As mentioned earlier the BMT and PC nurses provided very different perspectives when describing behaviors associated with hope. The BMT nurses adopted a fighting stance when they engaged in hopeful behaviors while the PC nurses chose to surrender or resign the fight in favor of acceptance. The BMT nurses were more likely to describe feelings associated with hope as conflicted whereas the PC nurses described feeling peaceful and content when they hope.

## Contextual Dimension

Each workplace provides a unique set of circumstances where hope can be enacted. This factor influenced what nurses were hoping for related to their patients. Nurses also came to their work with their own set of life situations which had helped to shape their ideas of what could be hoped for. The nurses' own life situations affected the context of their hope and influenced how and what they hoped for their patients.

### People Come Here to be Cured

The BMT nurses stated that their patients were admitted to their unit because they wanted to live for as long as possible. The workplace activities were concentrated toward extending their patients lives and so the nurses' hopes were also focused in that direction.

Pi.: Sort of, on (the BMT unit) it's considered a very active aggressive treatment and I guess that people being there will always have more hope (of a cure)... sort of they don't have that finality of something, um...



Gr.: And um, so they were hoping to survive and beat leukemia and to fight leukemia because they are a fighter, you know, we have a lot of people who want to fight.

Pi.: Often our physicians are so geared towards active acute treatment that it is really hard to make that switch to something palliative.

### There was Serious Illness/Injury in my Family

When discussing life circumstances which had contributed to their perception of hope most of the BMT nurses described incidents of personal or family illnesses or injury. These were situations where the nurses or a significant person in their lives had experienced an injury or illness and which had created a crisis in their lives. The crises were generally resolved in a positive fashion often with the assistance of a nurse.

Gr.: Well, my father had, he had a tumor in his um, a sarcoma and he had that taken out and everything like that and he actually spent some time on (the BMT Unit). Just because he had an infection so he had to be isolated and he was there for a week. I, I didn't really realize (the BMT Unit) was there, I wasn't nursing then either... It kind of intrigued me to want to work there, and also when I was 19 I had a friend who died of cancer. It was pretty traumatic and the nurses who worked with her were pretty amazing and I just, um...

Or.: I was in a car accident when I was 16 which sort of set me on the road to becoming a nurse. Um, in those days, women became mostly nurses, teachers and stewardesses (laughter). But two things happened out of that. There was a nurse at the scene who I was very impressed with regardless of, I wasn't really hurt that badly, other than shock. But, the second thing that was, because two people were killed in it, I was, I never, ever assumed that, after that anyway, I never had the assumption that adolescents have that nothing bad will ever happen to them.

### People Come Here to Live until they Die

Nurses on the PC unit understood that patients who came to their unit were living through the last stage of life. Their workplace activities were focused on supporting patients so that they could live through this stage comfortably and in a manner that was satisfying to them. Consequently the PC nurses' hopes were focused more toward patient comfort and, to the extent that they could, facilitating activities that were important to their patients. These nurses were committed to assisting patients and their families through this last stage of life in a manner that was positive and supportive.

Aq.: But when I come to work I just feel that this is it for a lot of these people and you know what, I've just got to make it the best I can, that's all.

Aq.: I just hope that I can get them to where they need to be and I can't project, particularly where they should be because I am not them, but, I hope I can get them there somehow.

Fi.: Because when, o.k., when you are first diagnosed or something, your hope is mostly to cure this, to get better. You are in palliative, that really isn't your hope anymore, your focus maybe...

Li: I think um, whatever your hopes are, we will try and help you achieve that, yeah.

Aq.: I can help them in plugging things in and being there but I can't get them to that spot, we all have to get there on our own and there is a lot of different things that play into that, you know.

Li.: I suppose going with their theme, you know and going, not necessarily their wishes, but their hopes and the way they are thinking that kind of thing. You get on their wagon...

Te.: Like I said, it's just to achieve a peaceful and sometimes comforting death for both the patient and the family and a lot of times it's being able to provide, whether it's putting in a intrathecal

line or something that they can go home with their medications. That they can, you know, do as much living as they can in the short time they have.

### I Lost Someone in my Family

Almost all of the nurses from the Palliative Care unit stated that they had lost someone very close to them earlier in life. They expressed dissatisfaction with the end of life care that their loved one had received. These nurses conveyed a determination that their patients should not experience the same hardships on the Palliative Care Unit.

Ye.: I always go back to my Mom. I was 17, my Mom was 44 when she died. That was very difficult and I never really got past that until I was in nursing school and I was 40ish.

Te.: I didn't have that (good) experience with my father's death.

Co.: So much was left unfinished, um, it (father's death) created so much suffering for me, because everything was left completely unfinished between him and I, um it created more of a sense of urgency about my own life.

### Temporal Dimension

#### Life is Day to Day

Nurses on the BMT unit tried to keep their own hopes for patients focused on short term goals and this is what they tried to communicate to their patients as well. At times this was a daily challenge for both the nurse and the patient. There was too much variability in long term goals. Focusing on challenges and accomplishments that presented themselves on a daily basis allowed nurses to keep hopes at a level that was manageable.

Bl.: One of the things that I like to talk to and teach patients is... it is very overburdening, overwhelming if you try to look at the long picture, take one day at a time, you have to. You have to take it one day at a time, because if you look at the whole course of events, anybody would be overwhelmed

Ma.: I try to help people focus on the day-to-day aspects and um, even if they have had a terrible rotten day, at the end we say, 'well there is one down and tomorrow is a brand new day.

Re.: Still they.....they plod on, they just keep going. They just hope, they just think, 'I'll hopefully get past this, hopefully I'll be o.k., hopefully this will work'.

Bl.: Focusing on small goals gives them the hope that eventually they will be at that end where they will be going home

#### Living in the Present

The PC nurses kept hopes focused on the present or the 'right now' and the 'right here' of each situation. There was an awareness that their patients were dying and that their future was very limited. Their hopes were focused on daily moments that provided their patients with comfort and peace. These moments could be the last ones that their patients experienced and so there was a sense of urgency around the provision of care. Symptoms were dealt with quickly and effectively.

Te.: You don't say 'I know you have only got a month to live'. That doesn't even enter your mind, you are busy dealing with their living, right at that point in time.

Li...: The present, that's the word, that first got me ... I don't think of tomorrow, I think of now and the present and do what I can for now. I never think of tomorrow because, with our people, tomorrow doesn't always come.

Te.: But it is more like when you see a symptom, you control it, we are right there in their face with the doctors and the patients. It's not 'I'll get your pain under control in two or three days', it's 'I'll get

it under control in a couple of hours'... Our hopes are very limited, they are not long term and working with people who are dying.

Aq.: When you come onto the ward, you are dealing with that day and it is very much what encompasses that day... I think you have to have that ability to just deal in the present, because there are a lot of people who can't deal in the present.

### Milestones

All of the nurses interviewed mentioned achieving milestones as an important part of hoping. Milestones were a source of hope for both the nurse and the patient. It helped nurses and their patients to keep life in perspective. When patients were able to achieve milestones that were meaningful to them it provided nurses with a sense of accomplishment. Nurses felt rewarded that perhaps on a very small scale they were able to help.

BMT Nurse

Or.: But she said 'this is the day the doctor told me I would be dead', and I said 'well... if you see that physician, mention it to him' (Laugh).

PC Nurse

Aq.: She would start knitting and she would say to me, she would hold it up and she would look at me like this (raising her arms) and she would say 'I'm knitting this for him for Christmas' and I would go 'ah ha'. This was in September... and I would say 'he'll like that'; and she would say 'do you think I'm going to get it finished?' and I say 'I think you will. Do you want to get it finished for Christmas?' 'Yeah'... and she would knit some more and every night she would hold it up to me and show me... Well she said, 'I want to make it to Christmas'. So she was doing some bargaining there. I said 'well, you've got the sweater made, he will have it and have to open it on Christmas'... Anyways, she did make it to Christmas and on Christmas day... kids stayed overnight and they opened all their gifts and that was her hope, to make it to Christmas, and she made it ...when I left

Christmas day at 3:00, she put the light on and I went into the room and she said to me 'something is happening to me right now'... I said 'I'll just stand with you for about 10 minutes' and she said 'o.k.'. I said 'do you want to have a cold cloth on your head?' She said 'yeah' and I said 'quiet?' 'Yeah'. And that last thing I said to her, because she died...I leaned over and I said to her 'yeah, but you made it to Christmas' (whispering) and she said 'yeah'. And her husband passed me in the hallway and... he stopped and he said 'she made it to Christmas' and that was her hope and she made it. And he had the sweater and he wore it.(Nurse weeping).

### Summary

Each patient care unit provided a very different context for the manner in which nurses viewed hope. The BMT unit was focused toward remission of cancer whereas the PC unit was more concerned with symptom management and patient comfort. The nurses each came to work, however, with their own personal contexts which influenced how they hoped. Nurses from the BMT unit were more likely to have experienced an event where they or a loved one came close to dying but thankfully recovered. Many of the PC nurses had suffered the loss of someone close. These deaths were generally perceived very negatively by the PC nurses.

Finally nurses incorporated the dimension of time into their concept of hope. Nurses on the BMT unit focused their hopes, related to patient care, toward short-term goals that were achieved one step at a time. The PC nurses directed hopes toward the 'right now' of each moment and each day. Achievement of milestones was important for both groups of nurses. It provided them with a sense of accomplishment and helped to sustain their hope.

## Chapter Summary

Each group of nurses offered a distinct perspective of hope that was related to their own worldview and their approach to nursing practice. The BMT nurses who sought challenges in their nursing practice also adopted a fighting stance when describing behaviors related to hope. Further they were more likely to describe feelings associated with hoping that were conflicted. They struggled or fought to remain hopeful. Conversely the PC nurses who viewed their practice as more of a 'calling' espoused a stance of surrender or acceptance when they described behaviors associated with hope. The feelings that they linked to hope were those of serenity, peacefulness and warmth.

Consensus was found between the two groups in the findings related cognitions and interactions related to hope. These two dimensions were more prominently exhibited during the interviews than were the other dimensions. Generally both groups described thoughts and decisions, related to hope, that involved balancing truth with possibility. Hopelessness was equated with isolation, and resulted when there was an over emphasis on either the truth or the possibility of each patient care situation. Decisions related to hope were also clearly linked to judgments about the morality of hope. In other words decisions around fostering hope were always filtered through an examination as to whether or not doing so would help

patients. Finally interactions related to hope involved those where nurses were able to 'connect' with their patients. These interactions involved affirmation of personhood for the patient, which was achieved when the nurse exposed something of his/her personal nature. These interactions engendered trust which was seen by the nurses to be the foundation of hope.



## Chapter V

### Discussion of the Findings

#### Introduction

In this final chapter I discussed the findings of the study. The concept of hope as described in the literature was compared with the findings of the study. Discussion of the research objectives was arranged under the questions as posed in the opening chapter. These included:

1. How do nurses conceptualize and define hope and how does workplace setting influence their concept of hope?
2. How do nurses incorporate their concept of hope into nursing care and how does this manifest itself in their practice?
3. How useful is Dufault and Martocchio's Multidimensional Model of Hope for the study of hope as it pertains to nurses?

Sample demographic data was incorporated into the discussion of the first question.

#### Discussion of Research Question # 1

**How do nurses conceptualize and define hope and how does workplace setting influence their concept of hope?**

The answer to this question is captured within the description of the findings in the previous chapter. Dufault and Martocchio's Multidimensional Model of Hope (MMH) provided the framework for a discussion

of the prevailing themes. These were organized under the spheres of generalized and particularized hope and their dimensions which include the cognitive, affiliative, affective, behavioral temporal and contextual dimensions.

### **Generalized and Particularized Spheres of Hope**

#### **Approach to Nursing**

The BMT nurses and the PC nurses exhibited dissimilar approaches regarding their nursing practice. This was an incidental finding related to a question, at the beginning of the interview, that was intended to put the participant at ease. It was interesting to find that each participant consistently responded in a manner that was peculiar to his or her respective group. The BMT nurses sought a challenge in their work whereas the PC nurses described their work as a calling. This finding cannot be linked to other studies related to nurses and hope found in the literature. It is mentioned however because it provides insight into the worldview of the nurses and seems to permeate their concept of hope as well as their activities related to hope and their patients. It seems plausible that each worldview may have influenced their choice of workplace setting. The differences related to the conceptualization of hope may be more a factor of the type of individual choosing to work in certain workplace settings rather than the workplace setting shaping and influencing the conceptualization of hope. In other words individuals with similar

conceptions of hope may share similar perceptions related to workplace settings, which are considered desirable.

#### I hope for Healthy and Long Life versus I hope for a Life Well Lived

Each group of nurses presented a distinct perspective when asked to describe hope in very general terms. Generalized hope has been described in the literature as a large intangible umbrella which protects the hoping individual by providing them with a sense that a good life is possible (Dufault & Martocchio, 1985). It is the belief that life holds some future good. It imparts an overall motivation to carry on with life's responsibilities and it is reflected in one's worldview.

Both groups chose to discuss hope in general terms from a very personal point of view. The BMT nurses described their general hope in terms of a long and healthy life whereas the PC nurses referred to a life well lived. Both of these viewpoints have been reported in the literature in relation to individuals with illness (Herth, 1992, 1993; Hall, 1994), however, neither has been distinguished or linked to a particular group of individuals.

#### I Hope for a Cure versus I Hope for a Peaceful Death

Particularized hope is concerned with specific hopes. Particularized hope was related to the nurses' practice given the nature of this study. Once again there was divergence between the two groups of nurses. Not surprisingly the BMT nurses hoped for a cure or remission for their patients, while the PC nurses hoped that their patients would live comfortably until they died peacefully. Given the focus of each patient care unit, one would

expect to find some diversity related to this sphere. This finding is consistent with Perakyla (1991) who reported that different forms of hope were espoused by health care professionals depending upon the ward that they worked on. Interestingly Perakyla (1991) defined the prevailing type of hope on an acute medical unit as curative, whereas health care professionals on the palliative care unit were described as dismantling hope.

It is clear that particularized hope for the BMT nurses is focused toward a cure similar to the nurses on the acute medical unit in Perakyla's study. The PC nurses in this study, however, could not be characterized as dismantling hope. Rather, their hopes were focused toward patient care goals that are consistent with end of life care. These nurses expressed hopes related to their patients' quality of life and spiritual well being. Hope was not dismantled but rather it was framed differently than curative hope.

#### Hope is Important for the Journey

The importance of hope in their own lives and in the lives of their patients was stressed by both groups of nurses. Many of them referred to life as a journey and hope was viewed as an important element for that journey. Hope was seen as a factor that keeps people engaged in life. This finding is reflected in much of the research on hope particularly as it pertains to individuals with illness (Cohen and Dawson, 2000; Ersek, 1992; Hall, 1994). Miller (1989) reported one of the prevailing themes among

survivors of critical illness was the belief that hope is "an intrinsic element of life" (p.24). The objects of hope were not deemed to be as significant as the process of hoping. This finding has been established by other research with individuals who are ill (Dufault & Martocchio, 1985; Hall 1994) but it has not been noted within the research conducted with nurses.

Most nurses asserted that they could not continue to practice if they did not have hope for their patients. Hope was viewed as central to nursing practice and indeed this was considered an expectation of practicing nurses. This finding was also noted by Herth (1995) when she reported that 75 home health and hospice care nurses consistently rated the importance of hope to their practice as very high.

### **Cognitive Dimension**

The cognitive dimension was prominent in the manner that nurses conceptualized hope. When asked to define hope all of the nurses used language such as wishes or dreams. Hope was viewed as a positive and purposeful energy which functioned to motivate individuals toward a desired goal. Most significantly hope was considered to be dynamic and evolving as life circumstances changed. These descriptors are frequently reported in the literature with individuals who are ill (Dufault & Martocchio 1985; Morse & Doberneck, 1995) but as yet have not be noted in research involving nurses.

More importantly nurses identified several cognitive activities related to hoping for their patients. These included, balancing truth with possibility, switching gears, and moral judgements.

### Balancing Truth and Possibility

Decisions surrounding hope involved complex and ongoing assessments of truths and possibilities. Nurses incorporated several sources of information to determine 'truths' as they relate to hopes for their patients. These included medical truths, personal truths and the truth that each patient brings to the illness experience. A similar appraisal of possibilities was conducted concurrently. Significance or weight was assigned to each truth and possibility. The value assigned to medical truths was particularly noticeable among the BMT nurses, whereas this was not such a significant factor for PC nurses. Nurses sought to maintain a balance between truth and possibility. Balancing truth with possibility was most encumbered by the number and frequency of additional truths and possibilities that arose throughout patients' disease trajectories. The greater the number of treatment options that were offered the more challenging that balancing truths with possibilities became. This created stress for nurses on both units and could become the source of tension between nurses and their patients as well as between nurses and other health care professionals.

Thulesius, Hakansson and Petersson (2003) reported a similar theme of balance in their research on end of life care. A grounded theory

approach was used to collect data from 64 participants, including nurses, physicians and patients. They suggest that hope, for terminally ill individuals, is the result of balancing the value of each moment with the time that one has left to live ( $H = V \times T$ ). Health care professionals can influence hope by helping patients assign greater value to each moment lived. This equation, and its variables, is perhaps not as pertinent to the nurses in this study but the theme of balancing is a parallel finding. Further, Thulesius et al reported that continually balancing patient care needs with available resources was the source of great stress for health care providers and patients. The constant assessment and reassessment of treatment options vis a vis available resources and the desires or expectations of patients and families were difficult to manage particularly during times of profound change in the physical status of patients.

#### Switching Gears

Significant events related to their patients' condition sometimes necessitated rapid and profound adjustments of hope. This required that nurses refocus hope by balancing new truths with different possibilities. Several small possibilities may be offered to patients in order help them maintain hope in the face of devastating truth. This was a challenging and stressful task for nurses particularly for the younger nurses on the BMT unit. It could become a source of tension for nurses if patients, or other members of the health care team, were not able or prepared to 'switch gears' along with them.

This finding was also noted by Perakyla (1991) when she described the tensions that manifested related to transitioning patients from 'curative hope work' to 'palliative hope work'. Herth (1990) found that when patients described hope hindering factors they were usually associated with periods during their illness when there were significant changes in their physical condition. Thulesius et al (2003) noted that there were cyclical periods of 'shifting' throughout disease trajectory of terminally ill patients. They state that these occur related to changes in the physical status of patients. Shifting creates a crisis for patients but also taxes health care providers as they struggle to rebalance "resources, communicational skills, and empathy" (p.1360).

#### Imbalance and Isolation

Imbalance between truth and possibility often created a distance between nurses, in this study, and their patients. Patients who were perceived as overly focused on possibility or conversely preoccupied by the truth of their situation were assessed by nurses as "not hoping". Nurses found it challenging to communicate with them in a meaningful way. They felt that they held back from these patients. It was more difficult to walk into the room of one of these patients and they considered them more of a burden to work with.

Abandonment and isolation has been described in the literature as hope hindering factors (Ersek, 1992; Wong-Wylie & Jevne, 1997). Herth (1990) in her research with terminally ill adults described the emotional



distancing that occurs between patients and nurses during situations when negative or profound changes in physical status developed. Research conducted with individuals who are ill indicates that they feel misunderstood and isolated during these episodes and consequently abandoned and hopeless (Koopmeiners et al, 1997; Miller, 1989).

Nurses in this study recognized that situations such as these often required additional resources or involvement of another nurse who could provide a different perspective. Circumstances such as these created tension and additional strain for nurses. As mentioned earlier Perakyla (1991) also observed increased tensions between health care providers and their patients during periods of transition from curative care to palliative care.

#### Morality of Hope

Throughout the process of appraisal and balance, nurses were also making moral evaluations surrounding truth and possibility. These moral judgments functioned as a filter for decisions related to inspiring hope in patients. Dufault and Martocchio's model does not include this aspect of hope. Their model was developed from data collected with chronically and terminally ill adults who probably did not question the ethics of their hope. Nor was this finding captured in the research conducted by Herth (1993) with family members of terminally adults. Research conducted with nurses has not previously described this characteristic of hope. It may that this finding is unique to health care professionals.

Nurses are in a position of power relative to their patients. They have the power to influence hope either by nurturing or discouraging it (Koopmeiners et al, 1997; Wong-Wylie, 1997). It may be that nurses hope in a fundamentally different manner than patients and their families, because of the moral obligations that are espoused by their profession. By and large nurses adhere to a code of ethics that obligates us to help and not harm. Furthermore nurses have a duty be truthful with their patients. The nurses in this study believed that they also had a moral obligation to foster hope appropriately. All of these considerations were factored into their decisions with regard to fostering hope in their patients.

It was not clear how the nurses in this study processed these moral decisions. In many instances they felt that they were required to respond in a very rapid manner and moral appraisals were conducted almost instantaneously. Simpson (2002) noted that enabling hope in patients can create moral dilemmas for nurses in some instances. She provides an ethical analysis of hope using a feminist care ethics framework. This perspective acknowledges the importance of power differentials in any social relationship. 'Caring about', 'taking care of', 'care giving' and 'care receiving' are suggested by Simpson as four steps that can assist nurses in resolving moral dilemmas related to hope. This process involves assessing and recognizing the hope needs of patients and provides a method for responding morally to the significance of hope in the lives of individuals

with illness. In essence Simpson states that the process involves simple recognition and affirmation of personhood of those requiring care.

### **Affiliative Dimension**

#### **Connected and Sources of Hope**

The affiliative dimension describes aspects of hope that are related to interactions with others. This dimension will be more fully discussed in relation to the second question posed for this study which examines how nurses incorporate hope into nursing care. The MMH defines hope as a phenomenon that can be influenced or inspired. Research with adults who are ill has found that family members, health care professionals and a faith in God are listed as sources of hope (Dufault & Martocchio, 1985; Nekolaichuk, Jevne, Maguire, 1999). Nurses in this study indicated that patients largely inspired them to hope. Patients who remained engaged in their lives outside of the hospital setting and maintained connections with family and friends were assessed by nurses as more hopeful. Nurses affirmed that they had stronger relationships with and felt more connected to patients that they perceived as hopeful.

Hope was also influenced by colleagues who shared experiences and who offered encouragement. This finding is consistent with Landeen (1996) who reported that hope in nurses was positively affected by long term relationships with patients and being supported by colleagues.

While spiritual well being was highly valued, particularly in relation to the PC nurses, a faith in God was not perceived by most nurses as a

significant source of hope as it relates to their practice. It could be that a faith in God is a factor that is linked to hopes of a personal nature and is not as prominent when describing hope as it pertains to professional practice. This could also have been influenced by the hospital culture, in which these nurses practice, that is heavily influenced by the biomedical model.

### **Behavioral Dimension**

#### **Fighting versus Resigning**

The BMT nurses and the PC nurses used very divergent language when describing behaviors that were related to hoping. Not surprisingly the BMT nurses, who seek to be challenged in their nursing practice, perceived themselves as engaged in the fight for life. They also recognized determination as an important behavior related to hope. Ersek (1992) and Saleh and Brokopp (2001), noted in their studies with bone marrow transplant recipients, that participants adopted a fighting stance as a strategy to maintain hope. Cohen and Dawson (2000) reported that bone marrow recipients perceived themselves as fighting for survival. Survivors of critical illness reported that nurses who conveyed a mental attitude that was determined inspired them to remain hopeful. It is clear that the BMT nurses in this study sought to inspire hope in their patients by encouraging them to fight against their disease.

The PC nurses described hopeful behaviors as those that facilitated resignation. Surrender involved giving up the fight for a cure and in turn

acknowledging all of the possibilities that still remain in life, even as it comes to an end. Hope was linked to activities which promoted peace and contentment. Terminally ill adults in Herth's study (1990) included "purposeful pausing" which allowed inner feelings of tranquility, as a factor which fostered hope. Pain and discomfort were viewed by the PC nurses as barriers to hope and therefore symptom management and pain control were considered to be central to the inspiration of hope. Herth (1990) noted that pain was a hope hindering factor reported by terminally ill adults. Herth (1995) asserted that hospice nurses and home health nurses listed pain control and symptom management as the intervention most commonly used in the maintenance of hope.

### **Affective Dimension**

#### **Conflicted versus Peaceful**

The affective dimension includes aspects of hope which are related to feelings. Feelings of anxiety and fear as well as those of joy, peace and contentment have been described in the literature as co-existing within the hoping individual (Dufault & Martocchio, 1985; Morse & Doberneck; Herth, 1990, 1993;). These feelings were also described by all of the nurses in this study but there were certain feelings that prevailed more significantly among each group of nurses.

The BMT nurses described feelings related to hope that were polar opposites. They described feeling joy and pain simultaneously when they hoped. The BMT nurses often described feeling conflicted about hope as it

pertained to their patients. Bone marrow transplant procedures are difficult for patients to tolerate and they are risky. Fear was a prominent theme reported by Cohen and Dawson (2000) in their study with bone marrow transplant recipients. Hope was used by the participants to minimize the effects of fear. Post-White et al (1996) found that there was a significant relationship between harm appraisal and levels of hope in their study with cancer patients. Participants who had higher hope scores were more likely to appraise risk of harm as lower. The BMT nurses may similarly have utilized hope as a mechanism for controlling fears and anxiety related to the difficult procedures which they must nurse their patients through.

Hope was linked to feelings of warmth, peace and contentment by the PC nurses. They did not report feelings of anxiety and pain, to the same degree as did the BMT nurses, when they hoped. Certainly they expressed feelings of anxiety related to patient care issues but this was not a salient feature when they spoke of feelings connected with hope. Terminally ill patients included in Herth's (1990) study, reported feelings of inner peace in relation to hope which allowed them to transcend the present and move toward a new awareness of life and its possibilities. Researchers have not, to date, investigated how nurses feel in relation to hope and therefore this finding is not reported in the literature.

It is possible that the BMT nurses felt more conflicted about hope because of the variability involved in the bone marrow transplant procedure. The objectives of patient care change more frequently than

with patients who are palliative. The BMT nurses were far less assured about the outcomes of patient care than were the PC nurses. Patient care objectives seemed more clearly defined for PC nurses and they were more certain about the outcomes that could be expected as a result of therapeutic interventions.

### **Contextual Dimension**

People Come Here to be Cured versus People Come Here to Die

Each workplace provides a context or opportunity for nurses to hope. The context for hope usually involves actual or potential gains and losses (Dufault & Martocchio, 1985; Morse & Doberneck 1995). Thus far our discussion has focused on the similarities and differences in the perception of hope as exhibited by two groups of nurses. It is apparent that hope is conceptualized differently by nurses depending upon the nature and objectives of their work. The BMT nurses affirmed that patients admitted to their unit were hoping for a cure or remission of cancer and that is what they hoped for as well. The PC nurses acknowledged that the majority of patients on their unit were living through the last stage of life and were hoping to live as productively and comfortably as possible until they died peacefully. This parallels what the PC nurses hoped for their patients as well.

Context appears to have an influence on the conceptualization of hope. This phenomenon was described by Morse and Doberneck (1995) when they examined how hope was conceptualized by three different

groups of adults each diagnosed with a different type of illness. They reported distinctly different patterns of hoping for each group. Perakyla (1991) also reported that there was a prevailing type of hope work adopted by health care professionals on each of the three units that she observed.

### There Was a Serious Illness in my Family versus I Lost Someone in my Family

Nurses also come to their work with their own set of life circumstances which have helped to shape their perceptions of what can be hoped for. The nurses' own life situations influenced their concept of hope as it pertained to their patients. When asked about circumstances that had shaped their perception of hope, most BMT nurses described events where they, or a family member, had experienced a difficult injury or illness from which they had recovered successfully. The majority of PC nurses shared that a close friend or family member had died and this experience had been problematic for them. Dufault and Martocchio (1985) state that hope can be influenced by previous successful achievement of desired goals. Individuals are more likely to hope again when past hopes have been met. Past experience has perhaps reinforced for BMT nurses that difficult illnesses can be overcome whereas the PC nurses' dissatisfaction with end of life care has energized them to hope for a better experience for patients.



## Temporal Dimension

### Life is Day to Day versus Living in the Present

The dimension of time was incorporated into the experience of hope for all of the nurses involved in this study. Time was integrated into each group's perception of hope in a slightly different manner. The BMT nurses stressed the importance of hope within short term goals whereas PC nurses focused hopes on the 'right now' of each situation. Each approach had a significant impact on how nursing care was provided. The BMT nurses focused hope on goals that were manageable in effort to prevent their patients from becoming overwhelmed by the challenges of their therapy. The PC nurses expressed an urgency related to the provision of patient care as they sought to create a milieu that would permit contentment and comfort for patients at the end of life. Each moment could be the last for their patients and therefore was considered precious.

Both findings have been described by other research conducted with persons diagnosed with illness. Ersek (1992) and Saleh (2001) both reported that bone marrow transplant patients sustained hope by focusing on short term goals one day at a time. Hall (1994) and Herth (1989) found that terminally ill patients maintained hope by developing a new awareness of the present and celebrating life in each moment. Thulesius et al (2003) also noted that the value assigned to each living moment could compensate for the limited amount of time remaining in the life of terminally ill patients and allow them to maintain hope.

## Milestones

Milestones were important for all of the nurses in this study. The nurses experienced a sense of accomplishment when patients achieved milestones that were meaningful to them. They used these milestones to offer their patients encouragement. The nature and use of milestones was slightly different for each group of nurses. The BMT nurses described milestones that demonstrated that patients were moving closer to remission. Conversely milestones depicted by the PC nurses included dates or events that their patients wanted to live long enough to experience. These findings are frequently reported in the literature particularly in studies related to bone marrow transplant recipients and terminally ill individuals (Ersek, 1992; Saleh, 2001; Herth, 1990; Morse & Doberneck, 1995). Herth (1995) also reported that the nurses in her study utilized milestones as a strategy to maintain and foster hope in oncology and terminally ill patients.

## Demographic Data

The differences in each group's demographic data may explain some of the variations found in the manner that hope was conceptualized by each group. Most significantly was the fact that nurses on the PC unit had significantly more years of nursing experience (19.4) than did the nurses on the BMT (9.75) unit. While there was little difference in the average number of years worked on each unit, the range of years between the shortest and longest years of service was much wider on the BMT unit (1-34)

then on the PC unit (2-20). Only half of each group reported a religious affiliation. Three of the BMT nurses described themselves as practicing members of a religion whereas only one nurse from the PC unit indicated that she was practicing her faith. It is interesting note that all of the PC nurses expressed frustration with that particular question on the socio-demographic questionnaire. Most felt that religion was generally too constraining for the expression of their own spirituality.

Nursing experience is a factor which impacts many aspects of nursing practice (Benner, 1984) and therefore probably has implications for the manner in which these nurses conceptualized hope. Nurses with more experience may have encountered more patient care situations that linked hope to quality of life rather than cure or remission of disease. Length of nursing experience cannot account for all the differences described in this study but it should be considered to be a contributing factor. Nursing demographic data has not been included in previous studies with nurses and therefore has not been reported in the literature. Finally while religiosity has generally been linked with high levels of hope (Fehring, Miller, & Shaw, 1997; Mickley & Soeken, 1993) this was not a significant factor found in the demographic data.

## Discussion of Research Question #2

**How do nurses incorporate their concept of hope into nursing care and how does this manifest itself in their practice?**

The response to this question is revealed within the findings described in the affiliative dimension. Essentially the findings of this study reveal that nurses incorporate their concept of hope into their interactions with patients. Hope is fostered through skillful communication which affirms personhood and builds trust. The themes of connecting and building trust, providing a context and humor were revealed by the data and will guide the discussion of the second question related to this study.

### Connecting/ Building Trust

Nurses in this study described fostering hope in patients as a process of communication which commenced with building trust. Trust was essential so that they could be perceived by patients as able and willing to provide help. Nurses sought to be assessed by their patients as sincere, caring and trustworthy. In order to accomplish this they needed to connect with patients at a personal level. This was achieved through interactions where nurses revealed something of their personal nature as they solicited personal information about the patient. This allowed nurses to be revealed as a person who was also a nurse and it also resulted in an affirmation of the patient's personhood.

There is support in the literature for the idea that nurses' communication behaviors can foster hope in patients. It has been described in research involving individuals who are ill and also in research that included only nurses. Herth (1990) identified strategies such as interpersonal connectedness and affirmation of worth as communication strategies that assist in maintaining hope in patients. Wong-Wylie and Jevne (1997) also noted that individuals with HIV described hopeful interactions with health care professionals as those where they were 'known as human' and where the health care providers allowed themselves to be 'known as human' as well. Furthermore the participants in Wong-Wylie and Jevne's study reported that feeling connected to health care professionals allowed them to also feel understood and cared for. This, consequently, led them to feel more hopeful.

In his study with nurses who provided care for terminally ill HIV patients Cutcliffe (1995) identified affirmation of worth and creation of a partnership as strategies that were utilized by nurses to foster hope in patients. These communication strategies were preceded by a process of reflection in action which Cutcliffe describes as the application of self awareness to interactions between nurses and their patients. Herth (1995) examined the use and effectiveness of hope inspiring strategies among home health and hospice nurses. The home health nurses rated the facilitation of sustained connectedness as the fourth most effective strategy

for inspiring hope in patients while the hospice nurses designated it as the second most used strategy.

### Humor

Humor was also used as a strategy to maintain and foster hope in patients by the nurses in this study. Humor was a form of communication that was used to establish intimacy in order to further connect with their patients. Humor allowed both the nurse and patient to interact as any other two people might in the course of a conversation. Personhood was conferred to both patients and nurses. Nurses believed that sharing laughter created a sense of lightheartedness for patients and prevented them from becoming too overwhelmed by the demands of their illness.

Humor is reported in the literature as a hope fostering strategy. It was listed as the second most commonly used strategy by home health nurses who participated in Herth's study (1995). The hospice nurses in that study used humor less frequently and only rated it as the eighth of fifteen strategies most frequently used to inspire hope. Cutcliffe (1995) noted that nurses who participated in his study included 'playfulness' as a factor that promoted hope. Cutcliffe concluded that humor was part of holistic care that recognized the totality of the person and was an important aspect of maintaining hope in patients. Participants included in Herth's (1990) study with terminally ill adults stated that lightheartedness created sense of release from the present moment and provided a "communication link between persons" (p.1255). Finally, Dean (2003), in her study involving the

use of humor in palliative care, reported that humor was used by both staff and patients as a means of survival. Humor was used in order to survive difficult aspects of the dying process itself more so than ultimate physical survival. Further Dean also noted that humor was also used to preserve dignity and acknowledge personhood rather than merely being seen "within the context of their illness" (p. 211).

### Providing a Context

All of the nurses in this study recognized the importance timely and appropriate information as an effective strategy to maintain and foster hope in patients. When information about illness and treatments was presented to patients, it was offered within a context that was individualized and meaningful for each patient. Information was structured to provide facts but also included possibilities related to illness and therapies. The provision of information was conveyed in a manner that was paced so as to prevent patients from becoming overwhelmed and feeling hopeless.

Hall (1994) reported that the maintenance of hope was enhanced by information that was not only accurate but also offered within an appropriate context. Individuals with cancer who participated in a study by Koopmeiners et al (1997) also stated that the manner in which information was shared affected hopefulness. Information that was imparted in a manner that was focused on both facts and possibility was perceived by participants as more honest and compassionate and inspired them to remain

hopeful. Wong-Wylie and Jevne (1997) reported a similar finding in their study involving HIV sero-positive people. Participants in their study affirmed that hopeful interactions with health care professionals included those where information was offered in a descriptive rather than the prescriptive fashion. Information provided in a descriptive format included choices for participants whereas prescriptive information assigned directions.

### **Discussion of Research Question #3**

**How useful is Dufault and Martocchio's Multidimensional Model of Hope for the study of hope as it pertains to nurses?**

Similar to fossils that are deeply imbedded within the earth's crust, the concept of hope is buried deep within our human psyche. Archeologists require tools that are robust enough to dig down to the outer edges of a fossil but once these are exposed instruments that are more sensitive and delicate are needed to expose the full extent of the fossil. Dufault and Martocchio's Multidimensional Model of Hope can be considered a robust tool for examining the concept of hope. The strength of the theory lay in its broad focus and application to the concept of hope. It provided a useful framework to organize and structure an array of observations resulting from the study. The cognitive, affiliative, behavioral, affective, contextual and temporal dimensions were supported with the words of the participants.



Recognition of these aspects enabled a deeper appreciation of the complexity of hope as perceived by nurses.

The limitations of this model became more apparent as I became immersed in the data. Dufault and Martocchio define hope as always related to realistic possibility. This feature was not always present in the manner that hope was conceptualized by nurses. Hope seemed more strongly linked to possibility than to truth and it was not usually related to reality. Further the component of morality surrounding hope is not included as a component model's cognitive dimension. Further Dufault and Martocchio maintain that the spheres of generalized hope and particularized hope are distinctly separate from each other and do not interact. This does not seem consistent with the findings of this study where statements related to generalized hope seemed to permeate and influence thoughts, feelings and interactions related to particularized hope.

In keeping with Dufault and Martocchio's model I did note that both spheres and all six dimensions were present in the manner that hope was conceptualized by nurses. Dufault and Martocchio suggest that all six dimensions may overlap and change in emphasis which characterizes the process of hoping. I found that the cognitive and affiliative dimensions featured much more prominently in how nurses perceived hope than the other dimensions of the model. This could be related to the nature this study which was focused toward nurses and their work as it relates to hope. Nurses routinely make decisions about patient care which require use of

knowledge and processes of cognition. Further the nature of nurses' work is grounded within their interactions with patients in their care.

The component parts of each dimension are not necessarily limited to that dimension within the MMH model. Thinking about hope is considered to be a component of both the behavioral and cognitive dimensions. This created some challenges during the analysis and discretion had to be used to make determinations about optimal fit with the data. This issue is related to the very dynamic and complex nature of the phenomenon of hope which is deeply imbedded into our thought processes as well as our behaviors.

In summary, the use of this model provided a robust tool for exposing the outer edges and larger aspects of the phenomenon of hope. The spheres of hope and its six dimensions were well supported by the data. Similar to the smaller bones of a fossil, however one would need an expanded model more sensitive to the components of each dimension so that they could be more clearly delineated.

### **Reflexivity**

Reflexivity refers to the degree that the researcher becomes immersed in the setting being studied and in turn is affected by it (Koch, T., Harrington, A., 1998). It requires the researcher to actively incorporate both views of the insider and the outsider to data collection and analysis. This provides a new dimension that reflects an ethnographic picture. My

research did not incorporate fieldwork in the true ethnographic sense, however, I was able to observe certain responses and behaviors during and after the interviews that further revealed the culture of each unit and something of my own nature as well.

It became apparent as the interviews progressed that each nurse came to the interview eager to speak about hope. They were however unprepared for the types of questions that were posed. After each interview I asked the participants what they thought of the questions and universally they responded that the interview questions had been difficult requiring them to think about aspects of their practice that were assumed or accepted as 'a given'. Many nurses stated that they needed to go away and think about 'this'. Both groups of nurses assumed that hope was a given for nurses and therefore not in need of research. Many nurses wanted to talk about 'false hope' and thought that the interview would be focused in that direction even though there had been a concerted effort on my part, not to refer to false hope during the recruitment phase.

The body language of each group of nurses was most revealing and it was during one interview with a palliative care nurse that I noted how her posture was so different than that of the nurses from the BMT unit. For the most part the PC nurses sat back in their chairs with arms at their sides and appeared more relaxed. The BMT nurses were intense and leaned forward during much of the interview. It was then that I noted the difference in stances adopted by each group as either surrender or fight.

Reflexivity affected my interpretation of the data. It was common for me to awaken at night thinking about the data. The data seemed to consume my every waking moment and I started to perceive the concept of hope as an object deeply imbedded in the earth that I was trying to extricate with a pulling force and which the earth would not let go. I felt that I was trying to pull the concept of hope from the data but that because it was so deeply imbedded the data would not surrender it. As I progressed with the analysis I realized that it was much better to delicately remove the data like the loose sediment which surrounds a fossil so as to allow the nurses' concept of hope to reveal itself. This required me to be more persistent and to trust myself to make the right decisions about the data.

Finally I developed a true fondness for the participants of this as I analyzed the transcripts of the interviews. I was deeply moved by their wisdom, their inner struggles and the poetry of their words. It reinforced once again for me the complex thinking involved in the provision of nursing care. Nursing interventions appear simple and straight forward at times but they are rooted in sophisticated and elegant thought processes.

### **Reflection**

The process of reflection entails an examination of fieldwork to develop specific self images during the data collection process. It requires that one engage in self examination surrounding details that previously were difficult to see (Lauterbach & Becker, 1996). Reflection was accomplished primarily through the use of personal journal entries and also

fieldnotes, but only to a certain extent. These self images portray a novice researcher who felt like an imposter during the initial phase of the research project. Journal writing had not been a habit of mine and this further added to my sense of insincerity. There were elements of uncertainty and bewilderment about the initial interviews. My journal entry after the initial interview with a BMT nurse states "I don't know if this interview was any good. Will it give me what I need to know" (p.5). As the interviews progressed I grew more confident with my interviewing skills and more natural in my journal writing.

Interviewing the PC nurses created a new type of anxiety. At this point I was more relaxed with the interviews but I had difficulty understanding their responses. I note my journal entry after the first interview with a PC nurse states "Qu'est que what c'est ca!" which aptly reflects my profound bewilderment. In retrospect I found that I had quickly gained an appreciation for the BMT nurses' perspective because it was more similar to my own experience. The PC nurses offered a very different viewpoint that was difficult for me to comprehend initially. As I progressed with the interviews the responses from the PC nurses started sound more familiar and made more sense to me. I commented on this to one of the last participants interviewed and she stated "You either get it or you don't" (p.15) and I wondered in my journal how she would categorize me.

The combination of reflection and reflexivity enabled a greater appreciation of the true nature of research. Further a greater

understanding of hope emerged which incorporated my own beliefs as a nurse.

### **Recommendations**

Recommendations in the areas of nursing practice, nursing education, nursing administration and nursing research are included based on literature review and the implications of this study.

#### **Nursing Practice**

Hope is an important aspect of coping with illness. Patients are more likely to appraise illness and stress as manageable if they are hopeful (Hirth & Stewart, 1994; Post-White et al, 1996). Through skillful interactions with patients that affirm personhood, nurses can build trust and foster hope. Nurses need to recognize the importance of assessing hopefulness in their patients. Additional resources and time may be required for patients who are assessed as lacking hope in order to prevent them from becoming further marginalized and isolated.

Nurses may experience tension related to decisions surrounding how or when to foster hope in patients. Thus they need to develop a process for ethical decision-making surrounding hope such as that suggested by Simpson (2002). Further nurses need to recognize the importance of religiosity for some patients in the maintenance of hope. Nurses need to become more comfortable in assessing for religiosity so that proper resources can be put

in place for patients to express themselves in manner that is religiously significant to them.

### **Nursing Education**

New nurses coming into the work force must be prepared in programs that recognize hope as an important element of coping with illness. It must be emphasized that hope need not only be linked with cures and good health. It should be stressed that cures are frequently not forthcoming. Rather curricula should emphasize the importance of assessing hope from the patient's perspective as part of developing a relationship that is helpful. Finally students should be encouraged to discuss situations that create ethical dilemmas as part of their clinical experience. This would encourage them to begin to develop a process for moral decision-making.

### **Administration**

Fostering hope in patients requires skillful interactions that allow nurses and patients to connect in a meaningful way and to develop trust. These types of interactions require time. Patient assignments need to be reasonable in order to afford nurses the time to establish trusting relationships with patients. Further nurses who are new to the profession must be mentored and supported throughout their transition into the workplace. Institutional support is necessary to assist nurses with moral dilemmas surrounding their own hopes and those of their patients.

## Nursing Research

More research is required to further delineate the concept of hope, as it relates to nurses, its dimensions and its component parts. Hope is a complex phenomenon and it needs to be researched as such. Further research could include the following:

- Further ethnographic research, that includes fieldwork, could reveal decision-making processes involved in the inspiration of hope and how the patients that they affect view these decisions.
- Longitudinal ethnographic research could examine if and how nurses' conceptualization of hope is influenced as they evolve from novice to expert practitioners.
- A combination of qualitative and quantitative methodologies could examine interventions that foster hope in patients. Well-developed hope scales could be used in combination with ethnography to examine the efficacy of such interventions.



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**Appendix A**



UNIVERSITY  
OF MANITOBA


RESEARCH SERVICES &  
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244 Engineering Bldg.  
Winnipeg, MB R3T 5V6  
Telephone: (204) 474-8418  
Fax: (204) 261-0325  
www.umanitoba.ca/research

### APPROVAL CERTIFICATE

12 September 2003

**TO:** **Eliette Allec** (Advisor D. Gregory)  
Principal Investigator

**FROM:** **Stan Straw, Chair**   
Education/Nursing Research Ethics Board (ENREB)

**Re:** **Protocol #E2003:070**  
**"Exploring the Concept of Hope among Nurses Working on Palliative  
Care and Bone Marrow Transplant Units"**

---

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note that, if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.**



UNIVERSITY  
OF MANITOBA


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### AMENDMENT APPROVAL

24 November 2003

**TO:** Eliette Alec  
Principal Investigator

**FROM:** Stan Straw, Chair   
Education/Nursing Research Ethics Board (ENREB)

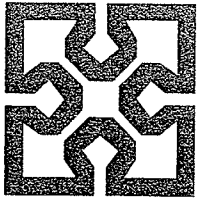
**Re:** Protocol #E2003:070  
"Exploring the Concept of Hope among Nurses Working on Palliative  
Care and Bone Marrow Transplant Units"

---

This will acknowledge your memo dated November 20, 2003 requesting amendment to the above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.

**Appendix B**



# Health Sciences Centre

OFFICE OF THE DIRECTOR OF RESEARCH

MS7 - 820 SHERBROOK STREET  
WINNIPEG, MANITOBA R3A 1R9

DIAL DIRECT (204) 787-4514  
FAX (204) 787-4547

October 3, 2003

Ms Eliette Allec  
Principal Investigator  
3137 Assiniboine Ave.  
Winnipeg MB

Dear Ms Allec

**RE: THE PHENOMENON OF HOPE AS PERCEIVED AND PRACTISED BY  
NURSES.**

**ETHICS #: E2003:070 RIC #: R103:135**

The above-named protocol, has been evaluated and approved by the HSC Research Impact Committee.

The Department of Research wishes you much success with your study.

Sincerely

Ms Karen Shaw  
Research Protocol Officer  
Health Sciences Centre

cc: Director of Research  
Ancillary Services, Finance Division





Hôpital  
général

**St-Boniface**

General  
Hospital

Room N1004 - 409 Tache Ave.  
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## Research Review Committee

### Approval Form

**Principal Investigator:** Ms. Eliette Allec

**RRC Reference Number:** RRC/2003/0508

**Date:** December 9, 2003

**Protocol Title:** Exploring the Concept of Hope Among Nurses Working on Palliative Care and Bone Marrow Transplant Units

The following is/are approved for use:

- Protocol submitted to October 1, 2003 meeting
- Socio-Demographic Questionnaire and Interview Questions included with Protocol submitted to October 1, 2003 meeting
- Explanation of Study document submitted with November 20, 2003 response memo
- Research Participant Information and Consent Form submitted with November 20, 2003 response memo

The above was approved by Ms. A. Hughes, Acting Chairperson, Research Review Committee, St. Boniface General Hospital, on behalf of the Committee. As the recommendations by the Research Review Committee have been met, final approval is now granted.

Sincerely yours,

Ms. A. Hughes  
Acting Chairperson, Research Review Committee  
St. Boniface General Hospital

**Please quote the above reference number on all correspondence.**

Inquiries should be directed to the RRC Secretary

**Telephone:** (204) 789-3255 **Fax:** (204) 237-9860

409 Taché, Winnipeg, Manitoba, Canada R2H 2A6  
Tel (204) 233-8563 Fax (204) 231-0640

**Appendix C**

# LET HOPE FLOURISH IN THIS PLACE

( Title from the Health Sciences Centre Annual Report )

## Is there hope in this place?

Patients have told researchers that hope is an important aspect of coping with devastating illness and that nurses are a significant source of that hope. There is very little research about how nurses view hope.

- What do you think about hope?
- Is it something that you think is an important part of your practice?
- Is it important for your patients?
- Is it important to you?

If you think you could spare an hour and a half of your time, and you'd like to participate in my research, please read and complete the attached

'Explanation of the Study'

Mail it to me in the self-addressed stamped envelope included.

You may also call me at (204) 889-3087.



**Appendix D**

## Explanation of Study

My name is Eliette Allec. I am a graduate student with the Masters of Nursing Program at the University of Manitoba. As partial fulfillment of this program I am conducting a research study entitled "Exploring the Concept of Hope among Nurses Working on Palliative Care and Bone Marrow Transplant Units". Existing research exploring the concept of hope among nurses is limited.

I would like to interview approximately 20 nurses to explore their personal experiences and perceptions related to the concept of hope. Should you agree to participate, I will arrange an interview at your convenience, and at a location of your choice. This interview will last about one hour and it will be audio taped. A follow-up phone call lasting about 20 minutes will also be required to clarify some information. You will also be asked to complete a short sociodemographic questionnaire at the end of the interview. All nurses agreeing to the interview process will be asked to sign a consent form. The interview will last about one hour.

There is no obligation on your part to participate in this study. Should you decide to participate in this study you are free to withdraw at any time with no explanation required and no negative consequences will result. Your name will never be used. No information will be shared in any manner that can be traced to your name.

There is no known benefit to you should you agree to participate. However, indirect benefit may occur for nurses working on Palliative Care Units and Bone Marrow Transplant Units as more becomes known about this concept

and how it relates to nursing practice. Participating nurses will be asked to provide feedback during the research process and when the results are compiled. Each participant will receive a summary of my preliminary analysis and this will be followed by a discussion, either by phone or in person, whichever is most convenient for you. This discussion will last about 30 minutes.

If you have any further questions regarding this research study please feel free to contact me at (204) 889-3087 or (204) 787-3274. You may wish to contact my Thesis Committee Chairperson, Dr. David Gregory, at (204) 474-9201.

By providing your name and phone number, you are indicating an interest in participating in the study. This means that I will contact you to further pursue this interest.

Name \_\_\_\_\_  
Print \_\_\_\_\_

Phone Number \_\_\_\_\_

**Appendix E**

## **Research Participant Information and Consent Form**

### **Exploring the Concept of Hope among Nurses Working on Palliative Care and Bone Marrow Transplant Units**

**Researcher:** Eliette Allec

*Supported in part by a research grant from the Health Sciences Centre Research Foundation.*

**This consent form, a copy of which will be left with you for your records and reference is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

#### **Purpose of Study**

This research study is being conducted to study the concept of hope as it is perceived and practiced by nurses working in Palliative Care and by nurses working with Bone Marrow Transplant patients. A total of 20 nurses will participate in this study.

#### **Study Procedures**

If you take part in this study you will be interviewed about your perception of hope in the care of patients on the Palliative Care/ Bone Marrow

Transplant Unit for approximately one and one half hours, on off duty hours. This interview will be tape recorded and later typed word for word. A follow-up phone call lasting about 20 minutes may be necessary to clarify specific points or information. The location and timing of the interview will be your choice. You will be asked to complete a short one page, socio-demographic questionnaire at the end of the interview. You will be provided with a preliminary analysis of the study and called for feedback during the research process and when the results are compiled. The research staff will obtain your feedback by calling you on the phone at a time that is convenient for you. The phone call will last no longer then 30 minutes.

In this study you will be considered in one of two study groups, which include the Palliative Care Unit group or the Bone Marrow Transplant Group. Your placement will be determined by the workplace setting that you currently occupy.

### **Risk and Discomforts**

There are no known direct risks for participation in this study. If you become upset or troubled during the interview the following steps will be taken:

- a. The interview will be stopped and you will be allowed to compose yourself.
- b. You will be offered reassurance and clarification as necessary.
- c. You will be consulted as to whether or not to continue or reschedule the interview.

You will be offered the number of the Employee Assistance Program so that the further counseling and support can be obtained.

**Benefits**

There are no known direct benefits to you for taking part in this research study. The findings of the study may indirectly affect current nursing practice through the acquisition of new information about the concept of hope and how it relates to nursing practice.

**Costs**

There are no costs associated with this study other than the time that you take to participate in the interview.

**Payment for Participation**

You will receive no payment or reimbursement for any expenses related to taking part in this study.

**Confidentiality**

Information gathered in this research study may be published or presented in public forums, however your name and other identifying information will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. The only people that will have access to the interview transcripts will be the members of the thesis committee including Dr. David Gregory, Dr. Susan McClement from the Faculty of Nursing at the University of Manitoba, Jill Taylor Brown MSW, RSW from Cancer Care Manitoba, and a typist. A code number will identify these transcripts.

The tape recordings, the transcripts, the sociodemographic questionnaires, and the consent forms will be kept locked and separate from each other in a secure location. After a period of seven years, the tapes will

be erased and the transcripts, questionnaires, and consent forms will be destroyed.

### **Voluntary Participation/Withdrawal for the Study**

Your decision to take part in this research study is strictly voluntary. You are free to withdraw from this study at any time, without question or untoward effect. During the interview any question can be refused and/ or the interview can be terminated, at any time. During the interview, you are free to request that no tape-recorder be used, or that the tape recorder be turned off at any time.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

**Eliette Allec(204) 889 3087**

**This research has been approved by the Nursing/Education Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.**



**Participants Signature :** \_\_\_\_\_

**Print :** \_\_\_\_\_ **Date** \_\_\_\_\_

**Researchers Signature** \_\_\_\_\_

**Print** \_\_\_\_\_ **Date** \_\_\_\_\_

If you wish to receive a summary of the research findings you will write your name and permanent address below. A copy will then be forwarded to you upon completion of the study.

**Name** \_\_\_\_\_

**Address** \_\_\_\_\_

**Appendix F**

## Interview Questions

Generalized Hope: sense of some future beneficial but indeterminate developments.

1. How did you come to work on the Palliative Care/ Bone Marrow Transplant Unit?
2. What have been your major sources of satisfaction and enjoyment in nursing on the Palliative Care/ Bone Marrow Transplant Unit?

Particularized hope: concerned with a particularly valued outcome, good or state of being.

3. Please complete the following sentence: I chose to work on the Palliative Care or Bone Marrow Transplant Unit because I believe I can contribute by ...
4. What are some of your hopes?
5. What do you hope for as you provide nursing care to your patients?

Cognitive Dimension: Focuses on the processes by which individuals think, learn, generalize, judge and perceive in relation to hope.

6. How would you describe what hope is or what you mean when you talk about hope as it pertains to your nursing practice?
7. How would you define hope as it relates to your practice as a nurse?
8. What kinds of things do you look at or consider when deciding the likelihood of attaining certain hopes related to patients in your care?
9. How does having hope help you as a nurse? How does having hope hinder you?

Behavioral: actions taken to directly effect the desired outcome or to achieve a hope.

10. What are the behaviors that a hopeful person engages in?
11. How do you incorporate hope into your practice as you provide care to patients?
12. Tell me a story about when you think you accomplished this most effectively. Do you have any stories whereby this was not accomplished effectively?

Contextual Dimension: focuses upon those life situations that surround, influence and are a part of persons' hope. The circumstances that occasion hope.

13. What are some the factors that shape your hopes and determines the limits of hope as it relates to nursing practice and the provision of nursing care.
14. How does working on the Palliative Care/Bone Marrow Transplant Unit affect or influence what you hope for your patients.

Affective Dimension: sensations and emotions that are part of hoping process

15. What are some of the feelings (good and bad) that you experience as nurse and that you associate most closely to hopefulness?
16. How does it make you feel to work with patients and or nurses who, you think, exhibit a high degree of hopefulness/hopelessness?
17. Have are suffering and hope related?

Affiliative Dimension: the hoping person's sense of relatedness or involvement beyond self. It includes components of social interactions,

attachment and intimacy. It is characterized by relationships with people, both living and dead and also with God and other living things.

18. What have been your major sources of hope as you provide nursing care to patients on the Palliative Care/ Bone Marrow Transplant Unit?
19. Describe an interaction with a patient that you found particularly hopeful. What factors contributed to that interaction?
20. Have there been occasions where you and the patient/family were hoping for different outcomes related to treatments you were providing? If so can you describe the event? How did this change your practice?

Temporal Dimension: the hoping person's experience of time in relation to hopes and hoping.

21. How does your past experience as nurse affect what you hope for your patients presently in your care?
22. How do hopes surrounding future outcomes of patient care affect how you interact with you patient in the present time?

Further Questions:

23. Why is hope important?
24. How is truth and hope related?

**Appendix G**

## Sciodemographic Questionnaire

Please answer the following questions:

### Circle the applicable answer

1. Gender ..... Male / Female
2. Marital Status ... Single; Partnered; Married; Divorced; Separated;  
Widowed
3. I work on the .....Palliative Care Unit / Bone Marrow Transplant Unit

### Please Complete

- a. Religious affiliation \_\_\_\_\_
  - i. Practicing
  - ii. Non-practicing
- b. Age \_\_\_\_\_
- c. Number of years of professional practice \_\_\_\_\_
- d. Number of years experience working on this unit  
\_\_\_\_\_
  - i. Full time
  - ii. Part time
- e. Educational background (diploma / B.N. / M. N.)
- f. Are you presently working toward another degree? \_\_\_\_\_
  - i. Nursing \_\_\_\_\_
  - ii. Non- Nursing \_\_\_\_\_

Thank You

**Appendix H**



**Participant Identification Codes**

01	-----	Green
02	-----	Blue
03	-----	Red
04	-----	Pink
05	-----	Teal
06	-----	Coral
07	-----	Aqua
08	-----	Fiusha
09	-----	Yellow
10	-----	Mauve
11	-----	Lime
12	-----	Orange