

NOTE TO USERS

The original manuscript received by UMI contains pages with slanted print. Pages were microfilmed as received.

This reproduction is the best copy available

UMI

TO WHOM IT MAY CONCERN:

I, Debra A. Burnes, authorize the National Library of Canada to microfilm the following pages/graphs/charts or appendix out of the attached thesis as is: ^{Appendix A, Table 1, Table 2} Table D1, Table ~~B~~ E1, Table F1, though they may not be legible when reproduced. For reference, a bound copy of the thesis will be available at the University of Toronto's Science & Medicine Library.

Debra Burnes

Signature

Sept 12/97

Date

**QUALITY OF LIFE: EXPLORING THE PERSPECTIVE OF PATIENTS WITH
CONGESTIVE HEART FAILURE**

by

Debra Ann Bournes

**A thesis submitted in conformity with the requirements
for the Degree of Master of Science
Graduate Department of Nursing Science
University of Toronto**

© Copyright by Debra Ann Bournes 1997



National Library
of Canada

Acquisitions and
Bibliographic Services

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale
du Canada

Acquisitions et
services bibliographiques

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence

Our file Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-29300-9

ABSTRACT

QUALITY OF LIFE: EXPLORING THE PERSPECTIVE OF PATIENTS WITH
CONGESTIVE HEART FAILURE

Master of Science
1997

Debra Ann Bournes

Graduate Department of Nursing Science
University of Toronto

This study explored the experience of quality of life for persons with congestive heart failure. The descriptive-exploratory design, guided by Parse's theory of human becoming, elicited 11 participants' perspectives of quality of life. Participants spoke about limitations and losses, important relationships, comforting and not comforting experiences, hope, and yielding to change. The findings consisted of three themes of shared meaning which were joined together to form the unified description of the experience of quality of life for the participants in this study: Loss surfaces with diminishing vitality amid patterns of communion-aloneness that are consoling-not consoling while desired anticipations mingle with acceptance of what will be. The findings were discussed in relation to the participants' descriptions, Parse's theoretical principles and concepts, and related research literature. Conclusions and recommendations for professional practice and future research are offered.

ACKNOWLEDGMENTS

The author wishes to express deep appreciation to Dr. Donna Wells and Lori Simurda for their commitment, thoughtful critiques, and scholarly contributions to this manuscript. A special thank-you to Dr. Gail Mitchell whose belief in me inspired this incredible undertaking, and whose unwavering support and commitment has made finishing it possible.

Thank-you also to my friends and family who were with me through every step of this process. I could not have gotten through it without your love, support and understanding.

Finally, to the men and women who willingly shared their stories and made the most significant contribution to this work, my sincere thanks.

TABLE OF CONTENTS

CHAPTER		
I	Introduction	1
	Quality of Life: Exploring the Perspective of Patients with Congestive Heart Failure. A Study in the Quality of Life Research Program	3
II	Literature Review	6
	Cardiovascular Disease: Quality of Life Research in the 1970's	6
	Overview of Quality of Life Research in the 1980's	8
	Overview of Quality of Life research in the 1990's	9
	Summary of Quality of Life Literature Related to Cardiovascular Disease	12
	Research Specifically Concerned with Persons Living With Congestive Heart Failure	12
	Summary of Literature on Quality of Life for Persons With Congestive Heart Failure	20
	Problem Statement	20
III	Methodology	23
	Purposes	24
	Conceptual Framework and Protection of Participants	24
	Conceptual Framework	25
	Protection of Participants	28
	Research Question	29
	Study Design	29
	Research Objectives and Interview Questions	30
	Sample	30
	Data Gathering	31
	Data Analysis	33
IV	Presentation of Findings	35
	Data Analysis-Synthesis	35
	Findings	36
	Theme One: Loss Surfaces with Diminishing Vitality	37
	Theme Two: Patterns of Communion-Aloneness are Consoling-Not Consoling	41
	Theme Three: Desired Anticipations Mingle with Acceptance of What Will Be	47
	Unified Description of Quality of Life	51
V	Discussion of Findings	53
	Theme One in Relation to the Literature on Quality of	

Life and Congestive Heart Failure	54
Theme One in Relation to Other Literature on Loss and Diminishing Vitality	55
Theme Two in Relation to the Literature on Quality of Life and Congestive Heart Failure	58
Theme Two in Relation to Other Literature Linked With the Concepts Communion-Aloneness and Consoling-Not Consoling	60
Theme Three in Relation to the Literature on Quality of Life and Congestive Heart Failure	65
Theme Three in Relation to Other Literature on Hope and “Acceptance of What Will Be”	66
The Findings in Relation to the Principles and Concepts of the Human Becoming Theory	71
Principle One	72
Principle Two	75
Principle Three	78
 VI Conclusions, Recommendations, and Reflections	83
Conclusions	83
Recommendations	85
Implications for Professional Practice	85
Recommendations for Future Research	87
Reflections	88
 REFERENCES	90
 LIST OF TABLES	
Table 1: Studies Assessing Quality of Life for Persons With CHF	13
Table 2: Quality of Life Outcome Measures Used in Studies on Persons with CHF	17
Table D1: Core Ideas and Concepts in Theme One	111
Table E1: Core Ideas and Concepts in Theme Two	128
Table F1: Core Ideas and Concepts in Theme Three	146
 LIST OF APPENDICES	
Appendix A	105
Appendix B	106
Appendix C	109
Appendix D	111
Appendix E	128
Appendix F	146

CHAPTER I

Introduction

This study sought a deeper understanding of the experience of quality of life from the perspective of patients who live with congestive heart failure. Congestive heart failure is a chronic illness that influences quality of life in multiple ways and often requires frequent contacts with health care professionals. Nurses have the opportunity to participate in the care of patients with congestive heart failure in ways that make a difference to quality of life from the patient's perspective. Traditionally, nursing care has focused on assessing and diagnosing patients with the intent to fix problems identified by professionals, and to teach patients what they need to know to manage those problems; however, patients frequently say, quite clearly, that nurses are not helpful to them when they approach them with the intent to tell them what to do. What patients say is helpful is when nurses listen to them with the intent to understand their perspectives, when nurses trust patients to tell them what life is like and what would help their situation, and when nurses structure care in ways that address the patient's priorities and concerns. A deeper understanding of the details of what influences quality of life can help nurses to be more open to listening to what patients with congestive heart failure say is important, what they say would make a difference to them, and what they say should be the focus of the nursing care they receive.

In addition, knowledge about quality of life is important to consumers and health care providers for a variety of other reasons. First, the number of persons living with chronic illness is projected to increase dramatically and when cure is not possible, patients and health care providers often strive for enhancement of quality of life (Holmes, 1989). Second, a wide variety of therapies and medical interventions that have similar effects on morbidity and mortality have demonstrated inconsistent outcomes when it comes to quality of life (Hollenberg, Testa, &

Williams, 1991). Third, quality of life issues are important to health care consumers who are becoming more knowledgeable and increasingly want to actively participate in the exploration of treatment options and health care planning. Finally, regulatory agencies are requesting quality of life outcome data as part of new drug or device approval (Kinney, Burfitt, Stullenbarger, Rees, & DeBolt, 1996; Wenger, 1992).

An assumption of this researcher is that the more health care professionals know about quality of life, the more they will be able to effectively participate with persons and families as they live their lives amid the changes of chronic illness. General agreement about the importance of this topic is evident when one looks at the vast number of related studies that have surfaced over the last three decades, especially those related to the study of quality of life for persons living with chronic illnesses, such as cardiovascular disease. The research has focused primarily on measuring quality of life for persons with specific types of cardiovascular problems, identifying beneficial treatments, and evaluating the impact of various treatments on quality of life (Baligadoo et al., 1990; Grady, Jalowiec, Grusk, White-Williams, & Robinson, 1992; Kubo et al., 1992). Findings from these various studies have contributed to decision-making about medical interventions, but there remain gaps in understanding the details of how persons with cardiovascular disease experience quality of life on a day-to-day basis. Further understanding about lived experiences, through the use of qualitative research methodologies, is a necessary addition to existing knowledge. Qualitative research, which focuses on specifying persons' lived experiences, can change understanding and lead to practice innovations that enhance quality of life.

Quality of Life: Exploring the Perspective of Patients With Congestive Heart Failure

A Study in the Quality of Life Research Program

This study is part of a larger nursing research program titled: Quality of Life: Exploring the Client's Perspective. The research program is guided by Parse's theory of human becoming (Parse, 1981, 1992, 1995, 1996a, 1997). It focuses on quality of life as experienced and described by patients at Sunnybrook Health Science Centre (SHSC). The purposes of the overall program are to establish a substantive knowledge base that will change practice in ways that make a difference to patient care and to provide direction for additional research. The comprehensive series of studies within the program are guided by qualitative research methodologies, including descriptive-exploratory and phenomenology. The research program includes exploration of specific phenomena already identified as important to quality of life in a descriptive-exploratory study about patients' perspectives of quality of life when living in a chronic care setting (Mitchell & Jonas-Simpson, 1995). For example, studies are in progress about the experience of living with persistent pain (Carson, 1996), and about the meaning of waiting for patients in several acute and long term care settings (V. Kolodny, personal communication, July 28, 1997).

For groups of persons where there is little known about their perspectives of quality of life a descriptive-exploratory design guides the collection and analysis of data. Researchers have explored the experience of quality of life for persons receiving inpatient psychiatric care (Fisher & Mitchell, 1997) persons living in long term care (Kolodny, 1996), persons tolerating persistent pain (Carson, 1996), and persons living with diabetes (Mitchell, 1996). Most recently, descriptive-exploratory studies investigating the experience of quality of life for persons who have had a stroke (B. Pilkington, personal communication, July 28, 1997) and for persons

diagnosed with Alzheimer's disease and related dementias (V. Kolodny, personal communication, July 28, 1997) have been added to the program.

This current study extended the quality of life research program at SHSC by exploring the experience of quality of life for persons who have congestive heart failure. Persons with congestive heart failure often have frequent, and in some cases prolonged, contact with the health care system. The quality of their lives during those times is influenced by the relationships they develop with nurses. It has been the experience of this author that when nurses are able to listen to and articulate the person's perspective of quality of life issues, plans of care change to integrate the patient's wishes, concerns, and routines linked to quality of life. Patients report enhanced quality of life and healing when nurses are with them in ways that convey understanding and concern about their unique life situations. Findings from qualitative research studies can provide the understanding that helps nurses convey understanding and interest, as well as a commitment to participate in enhancing quality from the patient's perspective.

The story of an elderly woman with end-stage congestive heart failure provides a vivid example of the power a patient's perspective of a situation has to influence quality of life. Mrs. G had been a patient on an acute care unit for several weeks. From a medical perspective there was nothing further that could be done. Unfortunately, Mrs. G was unable to return to her home because she was too weak to care for herself. Alternate arrangements were discussed with Mrs. G who did not want to participate in making plans for long term placement.

Nursing staff were angered by the situation and their relationship with Mrs. G deteriorated. When someone finally went and spoke to Mrs. G about what she hoped would happen she spoke about how she hoped her suffering would soon be over. She talked about seeing herself as garbage and about being treated like garbage by the staff. She also spoke about how much it hurt to know that all the staff were interested in was getting rid of the old garbage

who was wasting the hospital's money. She said: "They just come in and do what they have to and leave. Sometimes they laugh and that makes me very angry. I think, why do I deserve this? How will they like being treated like this when they're old and sick like me?" She said she would really like to be able to go home, but home no longer existed because her husband had died and there was no one to help her. She said that a nursing home wouldn't be too bad but she didn't want to bother having all the forms filled out because she would die before she ever made it off the waiting list for placement.

When Mrs. G's perspective was shared with the staff caring for her it transformed the way they viewed her and interacted with her. They recognized the pain and suffering she was enduring and had a better understanding of her reasons for not wanting to pursue long term placement. When the staff realized how Mrs. G viewed her situation and what options were there for her, they were able to let go of much of their anger and to be with her in a different, perhaps more meaningful, way. Mrs. G died two days later. This is only one story. There are countless others that remain untold that have equal potential to influence nurses' understanding of the experience of persons living with congestive heart failure. Qualitative research, such as the descriptive-exploratory study conducted here, seeks to enhance understanding about the meaning of human experiences as they are lived by the persons experiencing them so that others will have opportunity to learn from the increased understanding and to integrate it into their practices in ways that make a difference to quality of life.

CHAPTER II

Literature Review

This literature review demonstrates the importance of the study described here by providing an historical overview of quality of life research. The first three sections of the review highlight the gradual changes in research methodology that have occurred since the 1970's as researchers have recognized the importance of including subjective measures of quality of life for persons with cardiovascular disease. The author discusses the absence of clear agreement on what is to be regarded and measured as quality of life, describes shortcomings of the extant literature, and reviews literature addressing quality of life for persons living with a broad range of cardiovascular problems. In the fourth section, a review of research directly related to quality of life for persons living with congestive heart failure shows the importance of the descriptive-exploratory study that was conducted. Finally, gaps in the literature relevant to the importance of this study are summarized and a problem statement is offered.

Cardiovascular Disease: Quality of Life Research in the 1970's

Interest in quality of life research first surfaced in the cardiovascular literature in the mid 1970s. Rapid advances in medical science had led to development and evaluation of a wide variety of interventions for persons with cardiovascular disease. For example, coronary artery bypass surgery (CABS) was established as a form of treatment for angina pectoris. It offered most patients symptomatic relief with low operative and perioperative mortality; however, the degree to which patients were able to lead a life considered normal by medical researchers following surgery was not well documented (Wallwork, Potter & Caves, 1978). Thus, research about quality of life began to surface.

Several studies evaluating the effectiveness of CABS as a treatment for angina also included data about the effect of CABS on outcomes believed to indicate an improvement in

quality of life (Brown & Rawlinson, 1979; Mathur et al., 1975; Wallwork et al., 1978; Westaby, Sapsford, & Bentall, 1979). Improved quality of life was defined as increased exercise tolerance, lack of disease progression, and decreased frequency of symptoms (Mathur et al.). In several studies, improvement in quality of life was equated with successful reintegration of patients into their family and social roles. One index of successful reintegration into roles was the patient's ability to return to and maintain gainful employment. Thus, in addition to mortality rate, symptom relief, frequency of hospital admissions, and change in drug requirements, work capability was also used as an outcome measure for quality of life (Wallwork et al.; Westaby et al). Return to work was not, however, always a complete picture of what quality meant from the patient's perspective. For example, in one study the researchers captured whether or not the person returned to work on a questionnaire and conducted interviews which explored the person's ability to work in more depth. Some patients who had returned to work reported they were very dissatisfied, usually because they had switched to less interesting, and often less well paid work with lower pensions and loss of promotion chances (Mayou & Bryant, 1987).

Recognition of the importance of patients' perspectives of quality of life in the cardiovascular research literature was first noted in a study comparing the social and psychological function of patients randomized to surgical or medical intervention for angina. In addition to multiple measures of physiological, psychological, and social adjustment, Brown & Rawlinson (1979) used a series of cantril ladders to assess patients' perceptions of their current health status and their satisfaction with life. Results of Rawlinson's study showed objective measures of quality of life did not necessarily correlate with patients' subjective assessments of quality of life. For example, persons viewed their health as decidedly better after treatment and they reported overall satisfaction with their health, work performance, and income levels. In contrast, objective measures indicated patients in the study, as a group, were not able to fulfill

their work roles, had a median income level lower than the national average, and physiologically could not be considered healthy.

The discrepancies between subjective and objective measures of quality of life that have surfaced in the cardiovascular literature highlight the importance of research that includes patients' perspectives of quality of life. For example, Evans (1984) reported that when patients believed they had an improvement in physical function, ratings of health care professionals did not support this improvement. Mayou and Bryant (1987) interviewed 79 patients before and after CABs. One out of every five patients interviewed rated their quality of life as no better, and sometimes worse, following their surgery; yet this information was not closely related to objective measures of physical function. In some cases there were differences between subjective reports and objective measures of improvement in activity level. Even persons who felt there had been no improvement in their symptoms said that their operation had been worthwhile and believed it had improved their expectation of life. Conversely, patients who appeared to have no physical cause described poor social outcomes associated with lack of confidence about physical activity. These examples emphasize the importance of methodological pluralism in research. Research must be carried out in a variety of ways so that knowledge includes what can be learned and understood by studying phenomena from different perspectives. Use of research methodologies that generate objective and logical data in some circumstances and interpretive and reflective data in other circumstances, reveals patterns of health and illness that aid explanation as well as understanding (Wells, as cited in Gortner, 1993).

Overview of Quality of Life Research in the 1980's

Most quality of life research linked to cardiovascular disease during the 1980's included both subjective and objective outcome measures. To evaluate various treatments, researchers incorporated quality of life as a complimentary end point to traditional outcomes of morbidity

and mortality (Dodek, Hooper, & Kiess, 1988; Evans, 1984; Fletcher, McLoone, & Bulpitt, 1988; Kay, Bubien, Epstein, & Plumb, 1988; Kornfeld, Heller, Frank, Wilson, & Malm, 1982; Mayou, Sleight, MacMahon, & Florencio, 1981; Mickley, Peterson, & Nielsen, 1989; Peduzzi, Holtgren, Thomsen, & Detre, 1987; Walden et al., 1989; Weinstein, & Stason, 1982). Although many claims about quality of life surfaced, investigators did not establish a precise definition or a specific tool to measure the concept. Instead, there was emerging consensus in the literature that quality of life must be viewed as a multidimensional concept requiring complex analysis using multiattribute measurement techniques (Kinney et al., 1996). Quality of life was most often represented by four dimensions: symptoms and side effects, physical functional status, social functioning, and psychological status (Aaronson, 1988). A wide variety of generic, rather than disease-specific, tools were used to measure multiple factors believed to contribute to quality of life. The reliability and validity of the tools used were not reported by any of the above researchers. This observation is supported by the results of an integrative review and meta-analysis of quality of life research published from 1987 to 1991 (Kinney et al., 1996). The meta-analysis found 35 generic measures used in 84 descriptive studies, and 82 generic measures used in 84 experimental studies. Little is known about the validity, reliability, and sensitivity of these instruments because more than 75% of the reports of the descriptive studies and 71% of the experimental studies failed to address these issues (Kinney, 1995; Kinney et al., 1996). What this means is that different studies cannot be replicated and findings cannot be compared.

Overview of Quality of Life Research in the 1990's

The use of multidimensional, generic tools to quantify quality of life remains a common strategy in research reported since 1990. Instruments frequently used in studies of cardiac patients include the Nottingham Health Profile (DeCampi, Luikart, Hunt, & Stinson, 1995; Chocron et al., 1996; Ekeberg, Klemsdal, & Kjeldsen, 1994; Permanyer-Miralda, Alonso, Anto,

Alijarde-Guimera, & Soler-Soler, 1991), the Sickness Impact Profile (Arteaga & Windle, 1995; Lau, Tai, & Lee, 1995; May, Smith, Murdock, & Davis, 1995; Miranda, 1994; Page, Verhoff, & Emes, 1995; Waller, 1991), the Duke Activity Scale (Harlan, Sandler, Lee, Lam, & Mark, 1995; Hlatky, et al., 1995; Mark et al., 1994; Pilote et al., 1995), and the Psychological General Well-being Index (DeCampi et al., 1995; Kummel et al., 1993; Nissinen et al., 1991; Strauss, Fortin, Hartigan, Folland, & Parisi, 1995). There have been a small number of investigators who have developed, tested, or used disease-specific measures of quality of life with cardiovascular patient populations (Cleary et al., 1991; Dracup, Walden, Stevenson, & Brecht, 1992; Gorkin et al., 1993; Grady et al., 1995; Grady, Jalowiec, Grusk, White-Williams, & Robinson, 1992; Hillers et al., 1994; Hixon, 1992; Kubo et al., 1992; Lim et al., 1993; Rector et al., 1993; Rukholm & McGirr, 1994; Searle & Jeffrey, 1994; Spertus, Winder, Dewhurst, Deyo, & Fihn, 1994; Walden et al., 1994). Others have focused on psychometric evaluation of generic tools with cardiac patients (Duquette, Dupuis & Perrault, 1993; Visser, Fletcher, Parr, Simpson, & Bulpitt, 1994).

Despite the more recent use of valid and reliable tools, such as those listed above, many findings continue to be inconclusive when it comes to definitive practices that enhance, or diminish, quality of life. For instance, Walden et al. (1994) used the Heart Failure Functional Status Inventory to compare quality of life for patients living with end-stage heart failure who received medical therapy with quality of life for patients who received a heart transplant. At the time of follow-up, no significant differences in quality of life were found between the two groups. In another study, investigators used the Nottingham Health Profile to look at the effect of enalapril on quality of life for patients who recently had a myocardial infarction (Ekeberg et al., 1994). Quality of life scores did not differ significantly between those treated with enalapril and those treated with placebo. In addition, a meta-analysis of studies of quality of life in cardiac patient populations suggests the positive effects of treatment on quality of life are significant but

small, regardless of the form of treatment; and, even though many interventions are accompanied by undesirable side effects, no negative effect of treatment on quality of life was seen in any of the 84 studies included in the meta-analysis (Kinney et al., 1996).

Recently, investigators are recognizing the limitations of standardized measures of quality of life and many are looking for ways to compliment these measures in ways that contribute to a deeper understanding of patients' experiences of their health and illness situations. Several investigators have reported results of research in which at least a part of their data regarding quality of life was collected from patients using methods other than self-administered questionnaires. For example, Lau et al. (1995) asked patients being treated for a cardiac arrhythmia to list five of their most prominent worries or concerns regarding their illness before and after they had received treatment. Patients reported fear of: strenuous activity; going on long trips; potential impact on their work; having tea, coffee, or other stimulants; and psychological burden. Most patients who received treatment reported their concerns about the fears listed above had been rectified.

In other studies evaluating the effect of particular treatments on quality of life, various data gathering strategies were used to collect subjective accounts. For example, patients were asked to: write freely about their positive and negative experiences during the previous two months (Linde-Edelstam, Nordlander, Unden, Orth-Gomer, & Ryden, 1992); to take part in semistructured interviews (Borghetti-Maio et al., 1994; Blackwood, Mayou, Garnham, Armstrong, & Bryant, 1990); to keep a diary of activities interrupted or limited by symptoms; and to rate specific indicators of quality of life on visual analogue scales (Blackwood et al., 1990). In one example, participants were asked how many years of their life they would be willing to give up in exchange for returning to full health. Seventy-six percent of them did not think it would be worthwhile to forego any time (Glasziou, Bromwich, & Simes, 1994).

Summary of Quality of Life Literature Related to Cardiovascular Disease

The literature on quality of life and cardiovascular disease provides both subjective and objective data about the quality of life of persons who have cardiovascular disease. Objectively, mortality rate, physical functional status, a variety of symptoms, social functioning, and psychological status are all considered related to, and indicative of, quality of life. As noted earlier, techniques for assessing the above noted variables are not always valid and reliable measures; nor do they consistently produce significant findings.

What is known is that numerous multidimensional tools are frequently used to assess the quality of life of persons with cardiovascular disease. Many of the tools require the research participants' subjective ratings of some combination of their overall functional status, the frequency and type of symptoms they live with, as well as evaluation of their emotional, psychological, spiritual, and social status. From the results of such investigations it is known that persons with cardiovascular disease report being concerned about issues like fatigue, breathlessness, impaired leisure interests, limited social lives, anxiety, and difficulty sleeping (see Blackwood et al., 1990; Glasziou et al., 1994).

Research Specifically Concerned with Persons Living With Congestive Heart Failure

Several researchers have reported studies which investigated quality of life in groups of patients living with congestive heart failure. The purpose and results of each study are summarized in Table 1, and the outcome measurements researchers used to assess quality of life are summarized in Table 2. Although there are limitations in the reported results which will be considered later, there are insights that emerge which are useful in developing a deeper understanding of the experience of quality of life for persons living with congestive heart failure. Patients reported some of their most frequent and upsetting concerns were those related to the future, family (Muirhead, 1992), and health status (Grady et al., 1995; Muirhead et al.). Good

quality of life was associated with patients' satisfaction with sources of emotional support and with relationships with their partners (Grady et al., 1995). Conversely, quality of life was diminished by negative changes in patients' relationships with friends and extended family (Dracup et al., 1992). The most frequent, and the most distressing, symptoms reported about patients' experiences included: tiredness (Grady et al., 1992; Mayou, Blackwood, Bryant, & Garnham, 1991); fatigue (Muirhead et al., 1992); decreased energy level (Grady et al., 1995); decreased physical strength (Muirhead et al., 1992); whole body weakness (Grady et al., 1992); anxiety and apprehension (Dracup et al., 1992; Grady et al., 1992; Walden et al., 1994); breathlessness (Grady et al., 1992; Mayou et al., 1991; Muirhead et al., 1992); fluid retention (Muirhead et al., 1992); difficulty with sexual performance and difficulty sleeping (Grady et al., 1992).

TABLE 1: Studies Assessing Quality of Life for Persons With CHF

Study	Purpose	Results
Dracup, Walden, Stevenson, & Brecht (1992)	To determine the quality of life of patients with advanced heart failure who were evaluated for possible heart transplantation	<p>Overall, patients' quality of life was found to be significantly compromised.</p> <p>Patients described themselves as moderately anxious and hostile and moderately to severely depressed.</p> <p>The most negative changes described were in relationships with friends and extended family, and in emotional state.</p> <p>Calculated correlation coefficients between subjective and objective measures:</p> <ul style="list-style-type: none"> • No significant correlation between ejection fraction and any quality of life measures. • Significant correlations between self-reported functional status (in MET) and the 6-minute walk test ($r=-0.60$), NYHA classification ($r=-0.46$). • Psychosocial adjustment correlated with depression ($r=0.56$) and hostility ($r=0.50$).
Muirhead, Meyerowitz, Leedham, Eastburn, Merrill, & Frist. (1992)	To describe the psychosocial difficulties faced by patients awaiting heart transplantation.	<p>Physical Symptoms & Functional Status:</p> <ul style="list-style-type: none"> • 78% indicated their current health is poor and their physical condition had disrupted their lives. • Nurse rated an even higher proportion (97.8%) as being in poor health. • Fatigue, problems with physical strength, shortness of breath, and fluid retention were among the most frequently reported symptoms. <p>Psychological Difficulties</p> <ul style="list-style-type: none"> • Moderate levels of psychiatric symptomatology and

	<p>mood disturbance reported by patients.</p> <ul style="list-style-type: none"> • Most frequent and upsetting concerns were those related to the future, health, and family. • Maintained positive attitude towards medical treatment • Most reported having confidence in treatment efficacy, anticipating leading a healthy life, and anticipating at least 5-year survival. • Acceptance, confrontation, and escapism relatively uncommon. <p>Social Support</p> <ul style="list-style-type: none"> • Most experienced good social support but 53.7% reported they regularly had to "put up a front and pretend things are better than they are in order to protect others." <p>Overall Quality of Life</p> <ul style="list-style-type: none"> • On average patients rated their quality of life as negative: 34.1% reported a poor quality of life; 26.8% reported a good quality of life. • 78% reported having a positive outlook on the future. • Nurse coordinator rated 90.9% of the patients' quality of life as poor. 	
<p>Grady, Jalowiec, White-Williams, Pifarre, Kirklin, Bourge, & Costanzo. (1995)</p>	<p>To assess life satisfaction. To examine correlations between life satisfaction, demographic, physiologic, and psychosocial variables. To identify predictors of quality of life in patients with advanced heart failure awaiting heart transplantation.</p>	<p>Life Satisfaction</p> <ul style="list-style-type: none"> • Patients reported being most satisfied with health care, emotional support, children, family's health, and relationships with partners. • Patients reported being least satisfied with current health status, ability to travel, energy for daily activities, and ability to do things around the house. <p>Significant Correlates of Life Satisfaction</p> <ul style="list-style-type: none"> • Older age ($r=0.13$); lower NYHA class ($r=-0.16$); fewer daily medications ($r=-0.16$); overall functional disability ($r=-0.42$); less overall symptom distress ($r=-0.44$); less stress overall ($r=-0.49$); coping well ($r=0.31$); better health perception ($r=0.40$) <p>Multiple Regression Analysis</p> <ul style="list-style-type: none"> • 11 of 19 variables in the regression were significant predictors of quality of life. <p>Accounted for 49% of variance in quality of life.</p>
<p>Walden, Stevenson, Dracup, Hook, Moser, Hamilton, & Fonarow, (1994)</p>	<p>To compare the quality of life of patients with end-stage heart failure receiving maintenance medical therapy with patients who had heart transplantation.</p>	<ul style="list-style-type: none"> • Both groups had similar quality of life and clinical features at baseline. • Over time, feelings of anxiety, depression, psychological adaptation, and perceived functional capability improved in the transplant recipients. • Transplant group reported more weakness after surgery. • No significant differences were found in quality of life over time between the two groups.
<p>Grady, Jalowiec, Grusk, White-Williams, & Robinson (1992)</p>	<p>To examine symptom frequency and distress in heart transplant candidates.</p>	<p>Most frequent symptoms reported were:</p> <ul style="list-style-type: none"> • tiredness, difficulty breathing with exertion, difficulty sleeping, whole body weakness, sleepiness, feeling restless, anxiety and apprehension, irritability,

		nervousness, difficulty breathing when lying down, and leg weakness
		Most distressing symptoms:
		<ul style="list-style-type: none"> tiredness, difficulty breathing on exertion, difficulty sleeping, whole body weakness, difficulty in sexual performance, anxiety & apprehension
		More Symptom distress correlated with:
		higher overall stress ($r=0.34$); more total functional disability ($r=0.58$); more physical disability ($r=0.50$); more psychosocial disability ($r=0.63$); less life satisfaction ($r=-0.44$); lower quality of life ($r=-0.34$)
Mayou, Blackwood, Bryant, & Garnham (1991)	To examine associations between exercise capacity, symptoms, and specific aspects of quality of life in subjects participating in a trial of the treatment of heart failure.	<ul style="list-style-type: none"> Most common symptoms were: tiredness, breathlessness, chest pain, and palpitations. Symptoms limited extent and speed of physical activities, restricted social, leisure, and family life, and were associated with emotional distress. Association between baseline exercise capacity and quality of life
Blackwood, Mayou, Garnham, Armstrong, & Bryant (1990)	To compare xamoterol and digoxin in patients with mild to moderate heart failure. To evaluate methods of assessing changes in symptoms and quality of life.	<ul style="list-style-type: none"> Improvements in experimental and control groups on quality of life and exercise capacity measures with no significant differences between groups. Statistically significant positive relationships found between quality of life scores on physician-rated Likert scales and chest pain ($r=0.24$), palpitations ($r=0.16$), ease of walking ($r=0.27$), pace of walking ($r=0.22$), difficulty with daily tasks ($r=0.36$), speed of daily tasks ($r=0.31$), mood ($r=0.22$), and sleep ($r=0.23$) and a non significant correlation between physician scores and confidence ($r=0.14$). For VAS scores there were significant relationships between exercise duration, and breathlessness.
Kubo, Gollub, Bourge, Rahko, Cobb, Jessup, Brozena, Brodsky, Kirilin, Shanes, Konstam, Gradman, Morledge, Cinquegrani, Singh, LeJemtel, Nicklas, Troha, & Cohn, (1992)	To determine the efficacy and safety of pimobendan on exercise tolerance and quality of life in patients with heart failure.	<ul style="list-style-type: none"> Trend was toward improvement in scores with certain doses. Change only significant at 5 mg dose.
Baligadoo, Subratty, Manraz, Tarral, Maiti, & Murday, (1990)	To assess whether an inotropic agent may affect quality of life in severe heart failure.	<ul style="list-style-type: none"> No significant change in quality of life scores. Significant changes only in mean daily NYHA score and in duration of walking test in treatment group.

Rogers. Johnstone. Yusuf, Weiner. Ahn, Schron. Shumaker, & Sheffield. (1994)	To assess the quality of life of patients with left ventricular dysfunction for up to two years following randomization to enalapril or placebo.	<ul style="list-style-type: none"> • Among the 14 scales of quality of life, better scores at one or more of the follow-up intervals were noted in the treatment trial (patients with symptomatic CHF), and in 1 scale in the prevention trial (asymptomatic participants) among patients receiving enalapril. • Noted consistent superiority in the enalapril group in the treatment trial for social function and dyspnea but for no scale in the prevention trial.
Rector, Johnson. Dunkman. Daniels, Farrell. Henrick, Smith. & Cohn. (1993)	To determine if the patient's perceptions of the effects of enalapril on their daily activities and sense of well-being were different than the group treated with isordil and hydralazine.	<ul style="list-style-type: none"> • Both groups showed progressive decrease in quality of life as measured by the questionnaires. • No significant differences between groups on the questionnaires or on peak O₂ consumption, ejection fraction etc. • When asked if they thought the study drugs were helping their heart condition, the patients' responses did not agree with the changes in the questionnaire scores, and did not show a progressive deterioration in quality of life.
Cowley & Skene. (1994)	To determine the effects of enoximone on mortality and quality of life in patients with severe, end-stage heart failure.	<ul style="list-style-type: none"> • Trial ended because of increased mortality in treatment group. • Quality of life questionnaire showed clinically, but not statistically, significant increase at week 2 in the treatment group.
Linde, Gadler. Edner. Nordlander. Unden. Rosenqvist, & Ryden. (1995)	To investigate if A-V synchronous pacing with an individually optimized A-V delay is beneficial in patients with severe CHF.	<ul style="list-style-type: none"> • Somatic symptoms and emotional state improved after 3 months. • After 3 months only improvement in emotional state significant. • No clear evidence of benefit of treatment on any of the outcome measures.
Acanfora . Lanzillo, Papa. Longobardi. Furgi, Rengo. Melillo, & Rengo. (1995)	To compare use of delapril and captopril on symptoms and quality of life of elderly patients with CHF	<ul style="list-style-type: none"> • No significant changes in either group in exercise duration or left ventricular function. • Clinical symptoms of CHF significantly better with both drugs. • Significant increase in quality of life with both drugs as measured by the Symptom-Activity Scale.
Walden , Stevenson, Dracup, Wilmarth, Kobashigawa, & Moriguchi, (1989)	To compare quality of life for patients who survived at least 6 months after heart transplantation with patients clinically similar at baseline who survived at least 6 months with sustained medical therapy.	<ul style="list-style-type: none"> • MAACL scores: no significant differences between groups in general feelings of anxiety, depression and hostility. • Psychosocial adjustment: no significant differences between groups except in the domain social functioning. • Differences existed in functional status with transplant group having fewer limitations related to shortness of breath.

TABLE 2: Quality of Life Outcome Measurements Used in Studies on Persons With CHF

Study	Quality of Life Outcome Measurement(s)
Dracup, Walden, Stevenson, & Brecht (1992)	NYHA Functional Classification Ejection Fraction Six Minute Walk Test Heart Failure Functional Status Inventory Multiple Affect Adjective Checklist Psychosocial Adjustment to Illness Scale
Muirhead, Meyerowitz, Leedham, Eastburn, Merril, & Frist. (1992)	Profile of Mood States Dyadic Adjustment Scale Derogatis Symptom Checklist-90-Revised Folkman & Lazarus' Ways of Coping Checklist Questionnaire designed by Investigators to assess symptoms, functional status, social support, compliance, and attitudes Global Adjustment to Illness Scale Nurse rated patients on: level of physical symptoms, social support, quality of life and adherence to medical regimens
Grady, Jalowiec, White-Williams, Pifarre, Kirklin, Bourge, & Costanzo. (1995)	Quality of Life Index (modified for this study) The Heart Transplant Symptom Checklist Sickness Impact Profile Heart Transplant Stressor Scale Jalowiec Coping Scale The Heart Transplant Intervention Scale Social Support Index Rating Question Form
Walden, Stevenson, Dracup, Hook, Moser, Hamilton, & Fonarow. (1994)	Multiple Affect Adjective Checklist Heart Failure Functional Status Inventory Psychosocial Adjustment to Illness Scale
Grady, Jalowiec, Grusk, White-Williams, & Robinson (1992)	Heart Transplant Symptom Checklist Heart Transplant Stressor Scale Heart Transplant Intervention Scale Jalowiec Coping Scale Social Support Index Assessment of Compliance With Transplant Regimen Rating Question Form Sickness Impact Profile Life Satisfaction (Quality of Life) Index Heart Transplant Chart Review Form Study Termination Form
Mayou, Blackwood, Bryant, & Garnham (1991)	Likert Scales: physician rated answers given by patients re: tiredness, breathlessness, chest pain, palpitations, difficulty walking, pace of walking, difficulty with daily tasks, pace of daily tasks, mood, confidence, and sleep. Profile of Mood States Semi-structured Interview (replies rated & categorized by

	interviewer) Diaries (patients recorded activities and degree to which symptoms limited them)
Blackwood, Mayou, Garnham, Armstrong, & Bryant (1990)	NYHA classification Treadmill exercise test Likert Scales (rating by physician) Visual Analog Scales (re: breathlessness, anxiety, depression, irritability, tiredness, energy, concentration, sleep, and limitation of activities) Profile of Mood States Detailed, Semistructured Interview Diaries (as above) Cognitive State - Weschler Adult Intelligence Scale
Kubo, Gollub, Bourge, Rahko, Cobb, Jessup, Brozena, Brodsky, Kirlin, Shanes, Konstam, Gradman, Morledge, Cinquegrani, Singh, LeJemtel, Nicklas, Troha, & Cohn. (1992)	Minnesota Living With Heart Failure Questionnaire
Baligadoo, Subratty, Manraz, Tarral, Maiti, & Murday, (1990)	Developed a protocol to measure symptoms that commonly limit quality of life including: visual analogue scales re: fatigue and dyspnea NYHA Classification Graded Exercise Test
Rogers, Johnstone, Yusuf, Weiner, Ahn, Schron, Shumaker, & Sheffield, (1994)	Developed own questionnaire with 14 scales excerpted from previously validated instruments- addressed components: physical function, ADLs, emotional distress, social health, intimacy, life satisfaction, hopefulness, perceived health, general health perception and job performance. 308 patients underwent detailed psychosocial, physical, and intellectual assessment by a psychologist
Rector, Johnson, Dunkman, Daniels, Farrell, Henrick, Smith, & Cohn, (1993)	Living With Heart Failure Questionnaire Heart Condition Assessment Form
Cowley & Skene, (1994)	Quality of Life Disease-Specific Questionnaire (not described; no reliability/validity/sensitivity reported) Nottingham Health Profile NYHA classification Frequency of Hospital Admissions Changes in Other Drug Requirements
Linde, Gadler, Edner, Nordlander, Uden, Rosenqvist, & Ryden, (1995)	NYHA classification Quality of life questionnaire (designed by investigators with no psychometric testing) (measured somatic symptoms, emotional state, physical activity, life satisfaction, sleep dysfunction)
Acanfora, Lanzillo, Papa, Longobardi, Furgi, Rengo, Melillo, & Rengo, (1995)	Clinical symptoms of heart failure NYHA Classification Symptom-Activity Scale (to measure quality of life; no description given; noted it was suggested by other investigators)

Exercise tolerance
Left ventricular function (echocardiogram)

Walden . Stevenson. Dracup.
Wilmarth. Kobashigawa. & Moriguchi.
(1989)

Multiple Affect Adjective Checklist
Psychosocial Adjustment to Illness Scale
Questionnaire developed by authors to measure
functional status in this patient population

As in the wider body of literature addressing quality of life for patients with cardiovascular disease, the studies reviewed concerning quality of life for persons with congestive heart failure reveal there is some agreement that the concept of quality of life needs to be explored from both subjective and objective views. All but one study (Kubo et al., 1992) used multiple instruments to assess quality of life. In most cases a combination of disease-specific and generic measures were administered to elicit the participants' subjective reports of quality of life. Only 4 of the 15 studies (Grady et al., 1995; Rector et al., 1993; Walden et al., 1989; Walden et al., 1994) reported the reliability, validity, and sensitivity of the instruments used. Even researchers convinced of the need for a standardized approach to measuring and defining quality of life would question the accuracy and reproducibility of results generated when reliability, validity, and sensitivity are not explicitly stated.

In one study (Muirhead et al., 1992) a nurse rated 97.8% of the participants' health as being poor. In the same study only 78% of the patients considered themselves unhealthy. In another study (Rector et al., 1993), quality of life for participants was shown to be decreasing; however, when asked about this, patients did not support the changes in the questionnaire scores. Further, patients' scores did not show a progressive deterioration in quality of life. Differences in patient-reported and researcher-reported data add to this current author's questions about quality of life issues. Even in studies reporting significant correlations among quality of life and other indicators, the correlation coefficients are very low and explain only a small percentage of the

variance (Blackwood et al., 1990; Grady et al., 1992; Grady et al., 1995). It is proposed here that patients' evaluations of quality of life are influenced by many issues such as their symptoms, worries, hopes, and dreams.

Summary of Literature on Quality of Life for Persons With Congestive Heart Failure

The literature on quality of life and congestive heart failure provides the knowledge that patients with congestive heart failure report being concerned about the future, their health, and their families; however, it does not reveal specifically what their concerns are. The literature also reveals that, at times, negative changes in quality of life have been associated with relationships with friends and family. In one study (see Muirhead et al., 1992), participants reported they experienced good social support but also described how they regularly had to put up a front and pretend things were better than they were in order to protect others. In other instances, positive changes in quality of life have been associated with health care, emotional support, and relationships with partners. What is not known from the literature reviewed is what contributes to relationships being positively, or negatively, associated with changes in quality of life. In addition, patients with congestive heart failure have reported restrictions in their social, leisure, and family lives, as well as dissatisfaction associated with: being unable to travel; having decreased energy; feeling tired; and being unable to do things around the house. Participants reported that maintaining a positive attitude and seeking social support helped them live with their physical condition (Muirhead et al., 1992). What is not known are the details of what it means for these persons to live, day-by-day, with the restrictions and symptoms they report, or what is meant by maintaining a positive attitude.

Problem Statement

Until now, investigations about quality of life for persons living with any type of cardiovascular disease have primarily been concerned with the effect of a variety of symptoms

and treatments on social functioning, psychological status, and physical function. Research methodologies that have focused on assessing and categorizing subjects with preestablished questions and answers have been the dominant mode of inquiry. The research reported has provided a wealth of information about the many quality of life issues studied; however, there are gaps in what has been learned about quality of life for persons living with congestive heart failure. These gaps were made evident throughout the literature review and include lack of precise measures of quality of life and discrepancies between researcher and participant definitions of quality of life.

In nursing, quality of life has been defined as the “whatness” of life. It is the way life is (Parse, 1994). Parse (1994) wrote:

“One’s lived experiences incarnate quality of life; thus, only the person living the life can describe it. Quality of life as the incarnation of lived experiences is the indivisible human’s view on living moment to moment as the changing patterns of shifting perspectives weave the fabric of life through the human-universe interconnectedness” (p. 17).

While there has been research which expands knowledge about quality of life from the perspective of the persons being studied, thus far the information given by research participants with congestive heart failure has been limited to what they can share by filling in questionnaires with predetermined answers, giving answers to semi-structured interview questions that were rated on a predefined scale, and rating their symptoms on Likert scales. There is a gap in what is known about patients’ perspectives of what life is like for them, and of the meanings and the consequences of living with frequently reported and upsetting concerns such as: changing relationships, feeling tired, being out of breath, and having difficulty sleeping. This author was not able to find any published studies that sought to understand the details of what it was like to live day by day for persons who have congestive heart failure. In addition, no other studies using

either the descriptive-exploratory method guided by the human becoming theory, or the Parse research methodology (Parse, 1987, 1990b, 1995, 1997) were found which explored quality of life from the perspective of this group of patients. The position taken in this study was that nurses require understanding and knowledge of patients' experiences if they are to participate with individuals in ways that are helpful and that contribute to quality of life. The descriptive-exploratory study conducted here attempted to clarify what life was like for individuals with congestive heart failure, as well as the areas persons living with congestive heart failure found most important in day to day living. To address the critical need to enhance understanding of the complexity and depth of quality of life issues for persons with congestive heart failure, participants were able to discuss whatever they felt was important.

CHAPTER III

Methodology

The experience of quality of life, as described by persons with congestive heart failure, was the phenomenon of concern for this research project. A descriptive-exploratory design, guided by Parse's theory of human becoming (Parse, 1981, 1987, 1992, 1995, 1996a, 1997) was used to obtain participants' perspectives of quality of life. Individual stories and descriptions of quality of life were elicited by this method, so that universal, or shared, meanings embedded in the descriptions could be extracted, forming the major findings of this study.

The theoretical assumptions underpinning the theory of human becoming specify humans as unitary, open beings who are free to choose meaning in situations and who exist with, influence and are influenced by others at multidimensional realms of the universe (Parse, 1981, 1992, 1996a). The assumptions underpinning research consistent with the human becoming theory flow directly from the philosophical assumptions of the theory itself. For example, the human becoming theory postulates that humans are unitary beings in dynamic interrelationship with their temporal, historical and cultural worlds, and that unitary human beings are more than and different from the sum of their parts. As such, research consistent with this perspective must focus on indivisible human experiences within the lived context. The research approach is necessarily qualitative and the goal is to enhance understanding by explicating meanings, patterns, and themes of human experience (Pilkington, 1997a). The assertion that human experience is the paramount reality emerges from the assumption that humans are intentional beings who are free to choose meaning in situations. Epistemologically, this assumption leads to the focus on participants' descriptions of lived experience as the primary data. Qualitative research approaches consistent with this perspective assume that persons are able to accurately

represent their personal experiences, and methodologies are designed to elicit rich, in-depth descriptions of individuals' personal experiences (Pilkington, 1997a). Finally, the notion that humans exist with, influence, and are influenced by others at multidimensional realms of the universe implies an assumption that the researcher is involved with the phenomenon being investigated. Research is considered an intersubjective process between researcher and participant, in which the researcher seeks better understanding of persons' realities as lived (Pilkington, 1997a).

This descriptive-exploratory study explored the lived experiences, including the meanings, values, relationships, and hopes of participants as they experienced them in day-to-day life and as they related them to the quality of their lives. It was anticipated that the knowledge about quality of life gained from this qualitative study would enhance understanding and clarify opportunities for additional research. This chapter provides an overview of the purpose, conceptual framework, research question, and objectives which guided this study. It also presents the study's measures to protect participants, design, sample, and data gathering techniques.

Purposes

The purposes of this qualitative investigation were: (a) to contribute to nursing knowledge about patients' perspectives of quality of life when living with congestive heart failure, (b) to enhance understanding of quality of life issues for additional study, and (c) to specify practice approaches aimed at enhancing quality of life for persons with congestive heart failure.

Conceptual Framework and Protection of Participants

The conceptual framework and measures to protect human subjects are consistent with the ones in the quality of life research program with which this study was aligned (Mitchell,

Carson, Fisher, Kolodny, & Vander Laan, 1994). With permission of the authors, the sections included here have been added to and modified to be specific to this study.

Conceptual Framework

An analysis of the issues surrounding theory-guided qualitative research has been described elsewhere (Mitchell & Cody, 1993). The arguments on both sides of the debate are complex and both schools of thought are supported by multiple scholars. The researcher who conducted this study was consistent in approach with Kockelmans (1985) who said: "If in each human science there were no a priori synthesis, no framework of meaning constituted in advance of the scientific research in this field, there would be no possibility of methodological research in regard to human phenomena" (p.224). The researcher has presented the guiding theoretical framework for this research so that others can evaluate findings for consistency with the guiding framework.

Parse's (1981, 1987, 1992, 1995, 1996a, 1997) theory of nursing provided guidelines for developing this study. The theory, called human becoming, is rooted in human science and it focuses on lived experiences of health. Human beings are viewed as irreducible wholes who co-participate in life experiences. Health from Parse's perspective is the way persons live what is important for them day-to-day. Health is a process that links to meaning, values, and becoming the person one wants to be (Parse, 1990a).

Quality of life for Parse (1990a, 1994) is viewed from the person's perspective and the individual and family are considered the experts on quality of life issues. Quality of life is what life is like for people. It is the "whatness... or the essence of life" (Parse, 1994, p.17). It is "what the person there living the life says it is" (Parse, 1994, p. 17). From the researcher's perspective quality of life is about meaning and values, desires and dreams, relationships and plans, concerns and fears. A person's view of quality of life guides their decisions about health-related choices.

Parse guides nurses to focus practice on the person's /family's meanings of a situation. Enhanced knowledge of quality of life issues will prepare nurses and other professionals to attend to matters important to clients themselves. A broad understanding of human experiences encourages a professional openness to the unique complexities of lived experience against a background of shared meaning.

Three themes emerge from the assumptions of Parse's theory: meaning, rhythmicity, and transcendence (Parse, 1981, 1992, 1995, 1997). The three principles of the human becoming theory flow directly from the themes. The principles and their related concepts provide a theoretical basis for understanding the experience of quality of life. The first principle is: "Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging" (Parse, 1981, p.42). It relates to the way human beings continuously structure the meaning of multidimensional experiences that occur all-at-once (Parse, 1981). Structuring meaning happens through the processes of languaging, valuing, and imaging. Languaging relates to the ways individuals make known the unique meanings they have assigned to their multidimensional experiences through speaking-being silent and moving-being-still (Parse, 1981). Valuing is the process of choosing and living cherished beliefs (Parse, 1981, Pilkington and Jonas-Simpson, 1996). Imaging is cocreating reality, or knowing, at explicit and tacit realms all-at-once (Parse, 1981, 1992).

The second principle of the human becoming theory is: "Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting separating" (Parse, 1981, p. 50). The theme of this principle is rhythmicity. From the human becoming perspective, human experience is inherently paradoxical and rhythmical in nature. Seemingly opposite experiences coexist as distinct dimensions of one rhythm that are lived simultaneously (Parse, 1981, 1992). The paradoxical concepts linked with the second

principle are: revealing-concealing, enabling-limiting, and connecting-separating. Revealing-concealing is simultaneously disclosing some aspects of self while hiding others (Parse, 1981, p. 52). Enabling-limiting represents the simultaneous existence of an infinite number of opportunities and limitations in all choices individuals make. In choosing among options individuals are enabled to move in one direction and limited from moving in other directions (Parse, 1981, p.53). Connecting-separating is the process of connecting with one phenomenon while separating from others. "In each connecting there is inherent separating and in each separating, inherent connecting" (Parse, 1994, p. 18).

The theme of the third principle of the human becoming theory, "cotranscending with the possibles is powering unique ways of originating in the process of transforming" (Parse, 1981, p.55), is transcendence. It is about the ways humans change and unfold in life as they reach beyond what was and is with what is not-yet (Parse, 1981). The three concepts of the third principle are: powering, originating, and transforming. Powering is the continuous pushing-resisting process of "affirming self in light of the possibility of non-being" (Parse, 1981, p.57). Originating is "choosing a particular way of self-emergence through inventing unique ways of living" (Parse, 1981, p.60). Transforming is the changing of change and the shifting of views of one's life situation (Parse, 1981).

As will be discussed in more detail later on, the research objectives for this study were derived from the principles and themes of the theory. Findings were considered in the language of the participants and in relation to the theory's three principles and their nine concepts. The researcher focused on the meanings persons assigned to quality of life, the patterns of relating that influenced quality of life, and the ways persons described their concerns, fears, plans, hopes, and dreams. Findings are presented as major themes or ideas and written in the researcher's

language. Practice will be informed at many different levels as findings are woven into the researcher's theoretical perspective and experience.

Protection of Participants

This study was approved by the Research Ethics Board of Sunnybrook Health Science Centre (see Appendix A). Following notification by the patient care manager, educator, professional practice leader, clinical nurse specialist, or staff nurse that a patient agreed to talk with the researcher about quality of life, the nurse investigator scheduled a meeting at the patient's convenience to briefly outline the purposes of the study, participant expectations and measures to protect individual rights. Potential participants were told that some nurses at Sunnybrook Health Science Centre (SHSC) were conducting research to learn about experiences of quality of life. Clients were also told that participation meant having a discussion with the researcher on tape and that they should feel completely free to participate or not. If clients accepted the invitation, the researcher proceeded with a more thorough explanation of the study.

Specific information related to protection of rights covered the following points: participants are free to withdraw from the research at any time throughout the project without any effect on care; a tape recorder will be used so that the researcher can record discussion and tapes will be erased upon completion of the study; risks and benefits; transcribed data will be coded, locked in the researcher's office and shared only with other researchers participating in the project; participants are free to call the primary investigator at any time throughout the project to discuss questions or concerns; publications/presentations will have all identifying information removed; and the researcher will ensure the protection of the confidentiality of participants.

Participants were at all times respected as independent decision makers about participating and the researcher did not use persuasion or other measures to encourage their involvement.

All participants who indicated an intent to participate met with the researcher for the purpose of reviewing the consent form (see Appendix B). Following a review of the consent form participants were asked to sign the form indicating their informed consent. All participants signed an informed consent. A copy of the consent form and an information sheet (see Appendix C) was given to each participant.

During the research a situation occurred in which one participant described changes that could be acted on immediately. In that instance, the researcher asked the participant if he would like the researcher to speak to the patient care manager for follow-up. The participant said that with a simple change in his care his quality of life would be improved because he would be more comfortable. The request was arranged and the participant was satisfied.

Research Question

What is the experience of quality of life for persons who live with congestive heart failure?

Study Design

The method for this study of the experience of quality of life for persons living with congestive heart failure was descriptive-exploratory. Descriptive-exploratory designs derive specific objectives and questions for data gathering based on the phenomenon of interest and the researcher's theoretical perspective (Parse, Coyne, & Smith, 1985).

Research Objectives and Interview Questions

The research objectives flow from the three themes of the human becoming theory: meaning, rhythmicity, and transcendence. The three objectives of the study with related interview questions were:

1. To specify the meaning of quality of life for persons living with congestive heart failure.
 - a) What is most important in your life?
 - b) What enhances quality in your life?
 - c) What diminishes quality in your life?
 - d) What does quality of life mean for you?
2. To identify patterns of relating connected to quality of life for persons living with congestive heart failure.
 - a) Who brings comfort to you?
 - b) How do your relationships influence quality of life?
 - c) What is your daily routine like now?
3. To describe concerns, plans, hopes, and dreams related to quality of life for persons living with congestive heart failure.
 - a) What do you see for yourself in the future?
 - b) What would you like to do to change the quality of your life?
 - c) What are your hopes and dreams?
 - d) What are your concerns about quality of life?

Sample

Eleven persons agreed to speak about their experience of quality of life. The process of recruiting persons for the study was described earlier in the section outlining the measures that were taken to protect participants. Participants ranged in age from 49 to 91. Six of the 11

participants were over the age of eighty. Two of the participants were under the age of 55. There were six men and five women. All participants had a diagnosis of congestive heart failure. The interviews were tape recorded and transcribed verbatim. They ranged in length from 10 to 50 minutes. At the time of their interview, the participants had been in hospital for an average of two to three days. For convenience, they were all selected from acute patient care units in the hospital where the researcher was employed. Originally ethical approval was granted for the researcher to recruit participants from an acute care cardiology floor; however, there were insufficient numbers of patients with congestive heart failure available to participate in the study. Consequently, approval was given by the Research Ethics Board at Sunnybrook Health Science Centre to recruit participants from any acute care medical unit where patients with congestive heart failure were admitted.

In the tradition of research with the human becoming theory the only criteria for participation in a study is that participants want to participate and that they can express their thoughts about the phenomenon of concern. The assumption is that universal experiences, or essences of meaning, transcend participants' particular situations. A sample size of 11 was chosen because it was felt that the quality of the data obtained from the 11 participants provided enough depth to allow meaningful analysis. Sandelowski (1995) suggests that a sample is large enough if researchers feel they have achieved either informational redundancy or theoretical saturation, and cautions that collecting too much data may impede detailed analysis.

Data Gathering

Data were gathered through an interview process that was guided by the open-ended questions listed under the research objectives above. The researcher met with individuals for as long as they wished to speak about quality of life. Each interview began with the participants describing what life was like for them. Although the researcher sought answers to the questions

listed above, they were not asked in an interview style. Instead, the researcher went with the participants as they described the quality of their lives in an attempt to seek as much depth and clarity as possible. In some cases, participants spoke about their lives at length, and in the process they provided answers to many of the interview questions before they were asked. In those cases, appropriate questions were withheld so that participants would not have to repeat what they had already said. As participants spoke about quality of life, the researcher asked for clarification and depth about the issues and events they described. The researcher used phrases like: “tell me more about that” and “go on” to seek as much depth and clarity from the participants as possible. For example, when a participant said that the quality of her life was miserable, the researcher asked the person to elaborate on what that meant and what things made life miserable. The researcher also frequently asked participants how the ideas, events, and relationships they described related to their quality of life. The participant’s comfort was of primary concern at all times throughout the interview. The researcher did not probe if participants indicated they did not want to speak about a particular area.

It is worth noting here that one participant requested his wife be present at the time of the interview. He indicated that he would like to participate, but he would be more comfortable with his wife in the room. The researcher agreed to have the participant’s wife in the room in order to make the experience as comfortable as possible for the participant. The interview was somewhat different than those between the researcher and the other participants in that the participant’s wife often participated in the discussion. As well, there were times when the participant appeared to refrain from giving more details about certain topics. The interview was included in the data analysis because the participant described issues and examples that supported, and contributed understanding to, the themes uncovered as the major findings of this study.

Reliability, or reproducibility, of the data generated through the interview process described above was not a concern linked to this descriptive-exploratory research method. Sandelowski (1993) suggested that even when confronted with the same qualitative task, no two researchers will produce exactly the same result. There will inevitably be distinctions related to their philosophical, theoretical, and stylistic differences. There will also be differences in the ways the participants describe their experiences. For example, the fifth assumption of the human becoming theory is: "Becoming is an open process, experienced by the human" (Parse, 1992, p.38). This assumption means that as persons continuously interrelate with the multidimensional realms of their universe they move on with greater diversity. Thus, in the continuous process of relating multidimensionally with past, present, and future experiences, projects, people, and activities, persons move on to different understandings, and thus different descriptions, of the same experience. This notion is supported by Sandelowski (1993) who suggested that participants will never describe their experiences in exactly the same way twice. Research participants will change their descriptions from one telling to the next as new experiences, and possibly the very act of describing those experiences, change how they interpret them.

Data Analysis

Data for this descriptive exploratory study were analyzed according to the following processes (see Davis & Cannava, 1995, p. 11-13; Mitchell & Jonas-Simpson, 1995, p. 11; Parse, 1996b, p.128; Parse, Coyne, & Smith, 1985, p.94):

1. Reading text of interview while listening to tape.
2. Identifying and separating core ideas contained in text about the phenomenon of concern.
3. Identifying and separating core ideas common to all participants.
4. Naming concepts representative of the core ideas common to all participants.

5. Creating themes representative of the essential relationships between concepts.
6. Relating themes to the research objectives.
7. Identifying relationships among themes and forming a unified description that captured the quality of life experience for all participants.
8. Interpreting and discussing findings in relation to nursing science and in relation to knowledge from other literature.

CHAPTER IV

Presentation of Findings

Quality of life as lived and described by persons with congestive heart failure was the phenomenon of interest in this research project. A descriptive-exploratory design was followed to generate data that contributed to themes about quality of life for persons with congestive heart failure in an acute care setting. The objectives of this study were to: specify the meaning of quality of life; identify patterns of relating connected to quality of life; and to describe how persons' concerns, plans, hopes, and dreams related to quality of life for persons living with congestive heart failure. This chapter reports the findings that arose from interviews with the 11 participants who agreed to speak about their experience of quality-of-life. Presented first is a description of the data analysis-synthesis process. It is followed by a presentation of the findings by research objective. Finally, a unified description of the experience of quality of life for the participants in this study is given as the answer to the research question: What is the experience of quality of life for persons who live with congestive heart failure?

Data Analysis-Synthesis

Data analysis was conducted according to the scientific process of the descriptive-exploratory method explicated by Parse, Coyne, and Smith (1985). Transcripts were read and re-read while the researcher listened to the tapes of the interviews. As the researcher dwelled with the participants' descriptions, core ideas were identified and noted in the margins of the text. For example, when one participant said: "I think the key of happiness is truth. If you could not live the truth in life, then you let other people affect you with lies and you won't make it..." the words "truth" and "happiness" were recorded in the margin. The phrase, "comfort and attitude" was noted in the margin when the same participant said: "It takes a long time for someone to learn to give you comfort. If I have a relative that I say: "do this for me" and if I see that relative

does that for me in a nasty way, it's not comfort. It's done but it's done in the opposite way..."

He went on to say: "they think they know it all and they forget the little points of the little patients..., and the little points of the little patients are feelings, and if you cannot please human feelings you're not much of a [professional]...regardless of what you study, you still don't have it. You might know all the theory but you still don't achieve much" and the phrase "importance of feelings" was noted in the margin.

Once all transcripts had been analyzed in this way, the core ideas common to all transcripts were identified, grouped together, and named at a level of abstraction that would capture the experience of all participants. The abstracted concepts representing the core ideas were then synthesized into major themes that linked with the research objectives.

The descriptive-exploratory method, as followed in this study, developed only those core ideas, or aspects of lived experience, shared by all participants. In the initial analysis of the participants' transcripts several other core ideas surfaced; however, they were not present in all 11 transcripts and therefore they were not developed any further. For example, 9 out of 11 participants described situations and feelings that led to extraction of core ideas representative of the abstracted concept "uncertainty." Since the experience of uncertainty was not shared by all participants it was not included as a major finding of this study.

Findings

Findings specified three major themes related to quality of life for the participants in this study. The themes represent the shared experiences of quality of life as described by this particular group of participants. They are decontextualized and written in the researcher's language. To ensure auditability, the writer has reported decisions made in the transformation of data from the language of the participants to the language of the researcher, in order that another researcher, following the decision path, could follow the researcher's logic in the construction of

themes (Burns, 1989). Each theme is stated, linked to a research objective, and explained. A table related to each theme is included in an appendix and provides: examples of the descriptions given by participants; the one or more core ideas extracted from the descriptions; and the abstracted names given as a unified description of each group of core ideas. It is important to note that the core ideas are not mutually exclusive themes in and of themselves. Participants spoke of several core ideas all-at-once. Appendixes D, E, and F include the above mentioned tables as well as a series of more comprehensive excerpts from the descriptions given by each participant that support the way the core ideas have been synthesized into the major themes.

Theme One: Loss Surfaces with Diminishing Vitality

Theme one, loss surfaces with diminishing vitality, links with the first research objective: to specify the meaning of quality of life for persons living with congestive heart failure. The essence of this theme relates to the meaning the participants assigned to quality of life. In speaking of what life was like, the participants spoke about: “suffering;” “feeling something was extremely wrong;” “having to live with decreased strength;” “having days when they were unable to move;” “needing oxygen to breathe;” “feeling knocked out;” “feeling miserable;” “feeling dizzy;” “having to find ways to conserve energy;” and “living with pain.” The following quotes were given by the participants in this study. One participant said: “I had this congestive heart failure which sort of knocked me out.” Another said:

Life’s miserable. Miserable because I’m sick. I can’t breathe and I choke to death and when those crises happen I am in great distress because I can’t catch my breath and I have no oxygen at home... [It is] terrible, because I can’t breathe.

Other persons offered:

Well, there isn't a quality of life that way... you're not living a good kind of life, because you have these attacks and shortness of breath, and so on, you know, so that it certainly isn't a good way to live.

And,

Being sick, being sick day after day... I remember when we were down south, I was told if I went, I had to walk. It's not my favourite pastime. But anyhow, I remember going out and walking around the beautiful circle, and half-sick, half-tired, miserable.

The researcher synthesized and interpreted these phrases as the concept diminishing vitality. Diminishing vitality is a faltering, or lessening of life energy, liveliness, or endurance. All participants described quality of life with phrases that expressed a diminishing vitality.

In addition, all participants spoke about losses that accompanied living with diminishing vitality. For some participants, loss was connected with changes in their health and in day to day living. They spoke about "life disappearing," "life changing," and "having nothing left." One person said: "So, I have everything I could think of. Except the health went, I have nothing left." Other participants spoke about: "being unable to do what they used to do," "being in a cage," "feeling restricted," "being dependent on others," and "losing things they loved." For the majority of the participants the experience of loss was expressed as they related their stories about "having no energy," "feeling miserable," and "feeling knocked out" in the context of how illness and physical limitations decreased options in daily life. They described, activities, events, and experiences they used to, but could no longer, enjoy. Some spoke about being unable "to cook," "to socialize," "to travel," or "to shop" because it took too much energy. One participant offered the following:

Now take me to a mall, and I'm happy as a lamb. Oh yeah, I love to go [to] shopping malls. But you still get, I still got very tired. We would choose days I felt good. Like I would say, "Gee, I feel in a very good state;" then we'd go and do what we wanted to do, you know. But then, there were days I just couldn't move. [On those days] I was usually throwing up, and it took every bit of will power even to walk.... Health is so important. Yeah, if you have a good quality of life and you don't have health, what good is it, you know, if you can't do anything because you're ill or... Like I was to have gone away the end of March; well, I mean, there's no way I'm going anywhere.

Another stated,

Right now I can't [go anywhere]... it's like being in a, in a cage. I am being in a cage now. I am being in my cage. It's not a golden cage and I am not a parrot....the cage is something that I am locked in because I cannot go and take the bus. I cannot go and take the bus to go and take the metro, the subway. The taxi I can get. You have to go but it's frightfully expensive. I do not have the means, I am not the woman I used to be that way. It doesn't change me personally but my possibilities are changed drastically. So this is a little bit uncertain, of course when you cannot do things, when it was nice to take a big ship en route to Argentina or go to Manila by plane, I mean you know that was different. But today it's completely different. The health doesn't stop, it doesn't allow me, and the financial part doesn't allow me either. So I am locked up.

Another person talked about how his illness changed how he lived life:

I enjoyed life very much when... we [had] an old farm house and remodelled it. And then, this physical thing started to get to the point that I couldn't cut grass. Unfortunately, we have about 2 acres of grass and a 600 foot driveway which filled up with snow every winter, and you had to keep that clean in order to get in and out. So, that quality... I had

to give all that up. And yet, I enjoyed doing it, but that's... There's nothing really to take its place. We moved into the condo, so you don't.. no snow-shovelling and no grass-cutting and no this.. no more decoration or anything like that. I'm finding myself doing practically.. well, I say practically nil, outside of reading books and magazines... I guess I should say that I do feel, occasionally... that I'm bored.... I used to use an expression, particularly when we lived up in the farm house, that my choice in the morning is: Well, which job should I try and do today? And now I wake up in the morning and say: Well, what am I going to do today?- which is quite a difference, hey.

For one person the experience of loss was linked to being dependent on oxygen and on other people. He said:

When I get up in the morning, it's terrible; I have to come down and get on oxygen, or I'm in trouble. My whole life is changed... my dependency on other people, ... [on oxygen] to breathe; that's why it's changed.

Another person described loss in terms of changing his lifestyle. He said:

Well, I was a smoker; I imagine I will no longer be a smoker. I'm slightly overweight; I imagine I will lose some weight. I'm slightly diabetic; I'm sure I'll be less diabetic. I'm slightly stressed; I'll be less stressed. So, it'll probably, for me, end up being a total lifestyle change.

In summary, theme one was presented as: loss surfaces with diminishing vitality. This theme best captures the experiences of faltering strength, endurance, and liveliness to be able to do the things most valued in life. Not being able to live in desired ways surfaced feelings of loss as participants changed their patterns of living. Appendix D offers examples from all participants' descriptions that led to the concepts diminishing vitality and loss. Appendix D also contains comprehensive excerpts from the transcripts of each participant which demonstrate that the

synthesis of the concepts diminishing vitality and loss into theme one, loss surfaces with diminishing vitality, captures the unitary nature of this theme as described by the participants.

Theme Two: Patterns of Communion-Aloneness are Consoling-Not Consoling.

Theme two, patterns of communion-aloneness are consoling-not consoling, is related to the second research objective: To identify patterns of relating connected to quality of life for persons living with congestive heart failure. From the human becoming perspective, human experiences are inherently paradoxical (Parse, 1992). Thus, seemingly opposite experiences coexist as distinct dimensions of one rhythm that are lived simultaneously. When human beings describe lived experiences, one dimension of a paradoxical rhythm may present itself explicitly, but both dimensions are actually present even if only at a tacit, unutterable level. The core ideas in theme two relate to the ways participants in this study spoke about the importance of the quality of their relationships with others. In describing who brought comfort to them, how their relationships influenced quality of life, and what their daily routines were like, all participants in some way described how they were living the paradoxical patterns communion-aloneness and consoling-not consoling. Descriptions of communion-aloneness and consoling-not consoling, often occurred together in participants' descriptions. For the purpose of clarity, each will be discussed separately here; however, in Appendix E data to support the two paradoxes is given together.

Participants described situations and experiences in which they felt close to important others. They described family and friends as: "very important;" "what makes life worthwhile;" "wonderful;" and "close." For instance, one person said: "I suppose my wife is [most important to me]. Without her it [quality of life] wouldn't be very much... It wouldn't be very worthwhile. She takes great care of me... she is very important." Others offered: "They're turning out to be a nice

family.... I think I've done a good job... what they are makes life better;" and: "My daughters are wonderful. My husband's very good. We have a very good life, we really do. I'm very grateful."

Participants also described their patterns of relating in ways that conveyed they experienced isolation, distance, separation, or loneliness when they could not be with important others in remembered or valued ways. The following quotes are characteristic of those given by the participants. One person reported: "I rather live like... not a recluse, but rather like a, in the shadow. I would not make many efforts to socialize." Another offered:

Unfortunately, I lost my wife, and since then, I live alone.. by myself. We didn't have any children... I am too much by myself, alone, and my mind is too much on certain things which.. for instance, about my illness...

Someone else said:

I've been married twice...the first time when I was young... We had a very, very good life together for 40 years. And then, he died of cancer. And my second husband... it was a good life; he was very, very good to me... and then in January of '96 he died... and I lived alone again for a while. With my first husband... we had 2 circles of friends, and we gave dinner parties; about once a month it'd be our turn, you know. There were 8 of us, and I guess they're all gone now except 2 of them...

The researcher synthesized and interpreted these phrases as the concept communion-aloneness. Communion-aloneness is a paradoxical pattern of relating characterized by two seemingly opposite dimensions in which relationships are close and constant; and distant, shifting, isolating, in the past, or lonely, all-at-once. All participants described past and present experiences of closeness and distance from family, friends, and health care providers which can be captured as communion-aloneness.

Participants also reported that living patterns of communion-aloneness were both consoling and not consoling. At a lower level of abstraction consoling-not consoling, as described by the participants in this study, is comforting-discomforting. Relationships considered consoling, or comforting, were those that were described as “helpful,” “satisfying,” and “bringing happiness.” Relationships were considered not consoling, or discomforting, when described as “worrisome,” “frustrating,” “uncomfortable,” “concerning,” “saddening,” or “difficult.” For example, one person spoke of the pleasure of being with her grandchildren. She smiled and her face lit up as she said:

They love to see us and we love to see them. Oh yeah, it's great. My little grandson said to me last week when I went home, "Have you got clothes on, Nanna?" Cause I guess he's only ever seen me in night-shirts. "Got clothes on?" But that's what it means to him. No, they're great. They come and they more or less do what they want while they're at the house.

And then her voice softened and she had tears in her eyes as she went on to say:

It's just that the little one is.. I guess they're all the same, they demand attention. And now I can't give it to them; that makes it hard... I don't know if I'll ever be able to mind them again.

One woman described how her times of being with and away from others were both consoling and not consoling in the following way:

I am very happy with my daughter and granddaughter. We are friends. [But] I look terrible. I've never looked that bad and I frighten my poor daughter. I can see in her eyes that she is frightened when she looks at me and I don't want her to be frightened... sometimes I put a little make-up to make, to make up, but... I guess she, she is frightened because she is frightened when she looks at me and I know exactly what she thinks. She

thinks that I am letting go and I shouldn't let go, I should really be more disciplined and I should do it for her because she has a very difficult job, a very, very responsible and she does it very well and she is under tremendous stress, so I should not add to my daughter's stress, I should not. So I am going to try to really, not change but do a little more disciplined thing. And eat a little more, because they, they are complaining that I don't eat... More disciplined... That means getting up at a certain hour, having a more regular way of life, listen to my son-in-law who is absolutely destroying me, because he loves me but he criticizes me and we are like, like bulls with horns because he wants to change me but nobody can change me at my time it's very, it would be very difficult. It would be actually... no nobody can change me. I will try to be a little less negative. Because I've been negative lately. I mean I'm guilty. I mean I uh I don't mind saying so. Because not being in good shape you are you, you, you feel bad... I can't say that I don't care, it's not true, I do care... I do care a lot.

Another participant said:

I guess there's worse people off than me... I have a nice apartment, and, comfortable the only thing is my family live out of town, my sister and my daughter and that live in Montreal, I used to live in Montreal but, anyway, but my daughter is always talking about coming up here but she's been sick herself... my daughter's children... they're married. I'm glad for them, you know. They're doing well... My son lives in Whitby. He's doing well, he's got his beautiful home and he's got three children. They want me to, they keep asking me to go out there but, he says: "I'll come and get you" but I, I just didn't want to go. I just want to stay home because I when you don't feel well you don't feel comfortable in someone else's house so I don't go... So Thanksgiving they didn't ask

me... because I turned them down so many times but that doesn't bother me...it didn't bother me because I'm, I'm...[crying].

And another said:

There are 2 or 3 ladies with whom I keep contact...they know about my illness, and when I was invited, a few times I had to say, "I'm sorry, I couldn't go, because I don't feel well." And the result I was, my feeling was that 2 or 3 times they still did invite me, but after that they stopped, especially one or two or three of my friends, but I still have 5 or 6. I still have 3 very good friends who they are, they are caring about me. This is why, you asked that why I felt depressed. This is one reason, I found that, well they tried and now they are neglecting me... I am too much by myself, alone, and my mind is too much on certain things which.. for instance, about my illness.

Consoling or comforting relationships were not necessarily connected with specific acts or tasks that brought increased comfort. Rather, whether or not relationships were consoling or comforting was sometimes linked to the attitude of the comforting or consoling person. For instance, one participant said: "If I have a relative that I say, 'Do this for me,' and if I see that relative does that for me in a nasty way, it's not comfort. It's done, but it's done the opposite way...." The same person's description then went on to illustrate what it was like for him to be surrounded by family, friends, and health professionals who intended to be helpful, but who left him feeling isolated and alone. Consider the following example:

If you're on the top, that's fine; the minute you're in the bottom and you get sick, every person wants to tell you what to do. You have no say into anything.[It's] Very bad, very bad. There's nothing worse than when a man loses power completely. And if I can go home, meet my friends, they all have sayings for me. If I come to the hospital, I meet the

staff, they all have sayings for me. My wife comes and visits me, and my children - they tell me what to do. So whatever I learn throughout life, it don't mean anything any more. And this is the big frustration of my sickness. So I might come to a point, a week before the operation, not to listen to nobody except my professionals, not even the other doctors around here, just my surgeon and my cardiologist, but drastically hard, and I might make it, but I don't know.

And,

See, just getting a little bit water alone, sometimes takes so much hassle, that you get so tired and out of breath before you could get something that they could make it easier for you guys before it started. Many times I ask for real simple glass of water, because my throat, you know, gets too dry; that's my problem. But the answer is no because it's by the rule, and then I have to explain. I explain things, and so on, and tell them that the responsibility is mine, until they let me have a little bit. So, wouldn't it be easier for me to get a little drop of water before I make myself that tired, you know? I have, in reality, 2 more weeks to live, or many years to go, but 2 weeks that's what I'm going to be operated... So with that in mind, in 2 weeks I can go either way, so, why not please someone in 2 weeks that could come or go? I have no, no clue of understanding how small a mind can be, without making certain exceptions, even when they have no idea. But that's human beings. Human beings are made, I guess, to disagree with one another. The very first thing people do, if I say this is cold, "Oh no, it's not," or this is hot, "Oh no, it's not." It's common sense the very first thing that comes to their mind.

The researcher synthesized and interpreted these phrases as the concept consoling-not consoling. Consoling-not consoling is a paradoxical pattern of relating characterized by two seemingly opposite dimensions in which relationships are comforting, satisfying, soothing, or

helpful; and not comforting, not satisfying, not soothing, or not helpful, all-at-once. All participants described quality of life with phrases that expressed the consoling-not consoling nature of the relationships they lived.

In summary, theme two was presented as: patterns of communion-aloneness are consoling-not consoling. This theme best captures the participants' experiences in relationships that were close and constant; as well as distant, shifting, isolating, in the past, or lonely. Being close to and apart from others was sometimes comforting or helpful and sometimes not comforting and not helpful. To further clarify the meaning of this theme, Appendix E offers examples from each of the participants' descriptions that led to the extraction of the concepts communion-aloneness and consoling-not consoling. Appendix E also contains comprehensive excerpts from the transcripts of each participant which demonstrate that the synthesis of the concepts communion-aloneness and consoling-not consoling into theme two, patterns of communion-aloneness are consoling-not consoling, captures the unitary nature of this theme as described by the participants.

Theme Three: Desired Anticipations Mingle with Acceptance of What Will Be

The core ideas in theme three, desired anticipations mingle with acceptance of what will be, link with the third research objective: To describe concerns, plans, hopes, and dreams related to quality of life for persons living with congestive heart failure. The essence of this theme relates to the ways participants found to move forward in their lives amid their day-by-day struggles. All participants expressed hope for how life might be, yet simultaneously they described acceptance as a way of moving on in daily life.

In speaking about their quality of life, participants talked about their “hope for improvement,” “hope for how life will end,” “hope to stay independent,” and “hope for financial security.” The following quotes were given by the participants in this study. One person said:

I might be in better shape, I hope. It's up to me. I have to be a little more disciplined... On the other hand, each time I come into this hospital or any, I specify, right away that I do not want any resuscitation or artificial prolongation of life. This I am completely against. I think it's a misery to do that to the people because most of the time they are not even aware, they are vegetables and it's terrible. For the people who stay and for the people themselves. So the quality, this quality of life I don't want. I want a decent... I don't want a luxury but I want a decent ... I hope that I am polite enough to take my leave without lengthening too much... It's going to happen... just I wish that it would happen in my sleep....

And another stated: “I mean I would like it to be more peaches and cream. Like to be able to do more... So I'm hoping that things will improve somewhat when I get home.”

For all participants, hope was described, in some way, as an expectation of a desirable outcome in the future that arose with the envisioning of new possibilities while living with day-to-day struggles in life. Participants all spoke about envisioned possibilities that, if actualized, would bring them satisfaction of some sort. One woman who described not being able to go out and do things said:

We never stayed in the apartment unless it was a very bad day. All day we went somewhere. And I think that's what I miss the most. But maybe I'll be back out there very soon, you can't tell; get some weight back on and get on my feet. But I do love to go places. Just hope that I can do it again.

Another man envisioned being able to care for himself so his wife would not have to stay home with him. He said:

One reason for my reluctance about coming home, is the fact that she's [his wife] getting on in years... and she's been doing this volunteer palliative care work... she likes doing it, I know she doesn't want to give it up, but she's been indicating that if I'm going to be home in this condition, maybe she'd better give it up. And I'm hoping that I get well enough that she doesn't have to get out of it.

As noted in the findings related to theme one, participants spoke of their changing abilities and limited routines, yet they spoke simultaneously of their hopes for tomorrow. They recognized their constraints yet envisioned what they wanted and believed possible for the future. One participant spoke about realizing there may not be any medications that could help him yet he said: "It is not the first time that the medication has been changed. Certainly, I agree to it, because every human being has a hope. And this is what I right now in this moment I hope." Another participant clearly articulated that he was aware he probably would not survive his upcoming surgery, yet he believed it was possible and that if he did survive life would be better. He said: "I could die on the operation table. But that's one thing that I make up my mind - if I cannot live better than what I'm living right now, I may as well die. But I have faith in my cardiologist, in my operator, so let's see what they can do for me."

The researcher synthesised and interpreted these phrases as the concept desired anticipations. Desired anticipations are the hoped for outcomes, or expectations, of future events, relationships, or changes in participants' lives. All participants described quality of life with phrases and examples that revealed desired anticipations.

In describing their desired anticipations all participants in this current study also spoke about accepting what will be. Acceptance as a way of going on in daily life emerged as

participants talked about: “making the best of it;” “taking it in stride;” “going on faith;” “going along with what happens;” “being cheerful about things;” and “living day-by-day.” Consider the following descriptions of acceptance of what will be. They are typical of the descriptions given by persons in this study. One participant said: “I completely realise my situation. I know that it, I'm not a doctor, but I don't know, I know it [improvement with new medication] can't last too long... Until it lasts it lasts.” Another offered,

When you're going down there's no coming back, like with what I got so you just got to make the best of it... Well you just got to be, be... I don't know what to say... you've just got to be ...as I said, you've just got to make the best of it. You can't do anything else, you got to, you got to just take every day as it comes.

And other participants said,

It'll happen just cause it'll happen. How do I feel about it? It doesn't bother me, cause it's always on the back of one's mind. I just happened to sort of have an eye-opener that sort of jumped into the forefront, where it's basically life and death. If I don't do it, I probably won't live another 10 years, so it's not a great situation to be in. But it's also something that one always thinks about... I guess I feel it's probably more my own fault, so I only have myself to blame, primarily. And on the other hand, I'm lucky enough to have caught it, probably, in time. I don't quite know yet. We'll maybe find out by the end of the week. But it's caught, and I guess life will go on.

And,

Well, what would you expect at that age? You can't go on forever... Well, I don't think people, when they get up in their 80's, expect too much... I had such a good life before, with everything I wanted... It's just that your life changes so drastically when you've been very ill, you know, and so, you just go on day by day and do the best you can.

The researcher synthesised and interpreted these phrases as the concept “acceptance of what will be.” “Acceptance of what will be” is yielding to, or going along with, whatever happens. All participants described quality of life with expressions that revealed “acceptance of what will be” was an attitude they chose to help themselves go on living.

In summary, theme three was presented as: desired anticipations mingle with acceptance of what will be. This theme best captures the way participants described what they hoped life might be like even though they were prepared to go along with whatever happened. To further clarify the meaning of this theme, Appendix F offers examples from each of the participants’ descriptions that led to the extraction of the concepts “desired anticipations” and “acceptance of what will be”. Appendix F also contains comprehensive excerpts from the transcripts of each participant which demonstrate that the synthesis of the concepts “desired anticipations” and “acceptance of what will be” into theme three, desired anticipations mingle with acceptance of what will be, captures the unitary nature of this theme as described by the participants.

Unified Description of Quality of Life

This study described the experience of quality of life for 11 persons who live with congestive heart failure. The research question was: What is the experience of quality of life for persons who live with congestive heart failure? The findings consist of the three themes described above that, when joined together, form the unified description of quality of life as per the descriptive-exploratory method delineated by Parse, Coyne, and Smith (1985) and used by Carson (1996); Davis & Cannava (1995); Fisher & Mitchell (1997); Kolodny (1996); Mitchell & Jonas-Simpson (1995); and Parse (1996b). The unified description of quality of life is representative of the unitary nature of human experience. Although knowledge and

understanding of each theme that contributed to the unified description is necessary to appreciate the complexities of human experience it represents, the unified description contributes a reminder that human experience is a unitary phenomenon. For instance, in the data supporting the three separate themes presented as the findings of this study, the participants spoke of all the themes simultaneously - at times making it difficult to separate out data that exclusively represented one theme or another. Thus, the unified description representing the unitary experience of quality of life for persons who live with congestive heart failure is: Loss surfaces with diminishing vitality amid patterns of communion-aloneness that are consoling-not consoling while desired anticipations mingle with acceptance of what will be.

CHAPTER V

Discussion of Findings

The phenomenon of interest in this study was quality of life as lived and experienced by persons with congestive heart failure. The researcher, guided by Parse's (1981, 1987, 1992, 1995, 1997) theory of human becoming, explored the phenomenon with 11 persons who were living with congestive heart failure. The research question was: What is the experience of quality of life for persons who live with congestive heart failure? It was answered by synthesizing the three major themes that emerged from the participants' descriptions into a unified description of quality of life. The unified description was: Loss surfaces with diminishing vitality amid patterns of communion-aloneness that are consoling-not consoling while desired anticipations mingle with acceptance of what will be. In this chapter, the participants' descriptions of quality of life are further discussed in relation to the first purpose of the study: to contribute to nursing knowledge about patients' perspectives of quality of life when living with congestive heart failure.

The descriptive-exploratory design guided by Parse's theory of human becoming partially fulfilled the purpose of the study stated above in that it explicated the participants' perspectives of quality of life. Rudestam and Newton (1992) suggest that "a good discussion embeds each result within the theoretical context that was presented in the literature review... as well as return[s] to the literature to seek additional ways of understanding ... results" (p.123). Thus, in order to further contribute to knowledge about patients' perspectives of quality of life, the themes uncovered in this study are discussed in relation to the literature on quality of life and congestive heart failure as well as in relation to other qualitative literature that provides additional ways of understanding the concepts within each theme. Further, the themes are

described in light of Parse's human becoming theory in order to expand the knowledge base of nursing from the human science perspective.

Theme One in Relation to the Literature on Quality of Life

and Congestive Heart Failure

Theme one, loss surfaces with diminishing vitality, relates to the way participants in this study described losses associated with experiences such as "having no strength," "living with pain," "feeling dizzy," "falling," "feeling sick," "feeling miserable," "feeling tired," and "suffering." Loss, for many of the participants, was closely associated with less energy and endurance which limited day to day choices in what it was possible for them to do. For others, loss related to the disappearance of their independence, to the view that life was disappearing, to the notion that life had changed suddenly, or to the feeling there was nothing left.

The descriptions of loss and diminishing vitality uncovered in this study are consistent with the descriptions of the findings of other studies on quality of life for persons with congestive heart failure. For example, tiredness (Grady et al., 1992; Mayou et al., 1991); fatigue (Muirhead et al., 1992); decreased energy level (Grady et al., 1995); decreased physical strength (Muirhead et al., 1992); and whole body weakness (Grady et al., 1992) were among the most frequent, and the most distressing, symptoms patients reported about their experiences of living with congestive heart failure. Patients also reported being least satisfied with their current health status, inability to travel, decreased energy for daily activities, and inability to do things around the house (Grady et al., 1995).

This current study contributes a deeper understanding of what it is like for persons with congestive heart failure to live with some of the symptoms listed above. Participants' descriptions of "having no strength," "feeling miserable," "feeling tired," and "feeling knocked out" led to the extracted concept "diminishing vitality." Data that support the concept "diminishing vitality"

contribute depth and understanding about the consequences of lessening life energy, liveliness, and endurance. For example, diminishing vitality influenced choices about what activities were most important, or indeed possible, to do in a day. Feeling tired, or having no strength, meant that persons declined invitations to visit with friends and family, had difficulty doing housework, found it hard to prepare meals, ate little, and could not get out of bed. In addition, participants revealed stories and examples about how life had changed given that they had to manage with less energy and endurance. Their descriptions contributed the knowledge that when living with changes in health that lessen life energy, persons with congestive heart failure often experience feelings of loss.

Theme One In Relation to Other Literature on Loss and Diminishing Vitality

No published studies were found which specifically linked the experience of loss and living with congestive heart failure; however, the experience of living with loss is a common theme associated with having other chronic illnesses. An examination of some of the findings from other studies connecting loss with a variety of chronic illnesses provides additional ways of understanding loss as it was described by the participants in this current study.

For example, Michael (1996) conducted a phenomenological inquiry to explore how adults integrate chronic illness into their lives. Confronting loss was one of four major themes that emerged from the data given by 17 participants. As well, Lindgren, Burke, Hainsworth, and Eakes (1992) linked the concept of chronic sorrow with losses associated with chronic illness. According to Lindgren et al., losses are an integral part of chronic illness and disability. The term chronic sorrow has been used to describe the long-term periodic sadness persons who are chronically ill and their caregivers experience in reaction to continuous losses (Eakes, 1993, 1995; Hainsworth, 1994, 1995; Hainsworth, Eakes, & Burke, 1994; M.L Walters, 1994).

Loss has been associated with grieving by numerous authors (see for example, Cody, 1991, 1995; Cowles & Rodgers, 1991; Downy, 1983; Martocchio, 1985; Miller, 1973; Pilkington, 1993; Schneider, 1984). Grieving is believed to occur with any event experienced as a loss; hence, there is potential for loss and grieving in all life's changes (Cody, 1995). For instance, Cody (1995) investigated the meaning of grieving for families living with AIDS. The participants in his study explicitly stated they were grieving many losses, such as the anticipated loss of self, loss of career, money, friends, energy, freedom, hopes and dreams. Participants in this current study also spoke explicitly about loss of friends, freedom and energy, and, in several instances, about their "anticipated loss of self" as they discussed how they hoped their death would be.

The simultaneous accounts of loss and diminishing vitality given by the participants in this study are also consistent with findings from several other descriptive-exploratory studies on quality of life for persons living with various types of chronic illness. In those studies, loss was described in relation to: important relationships, activities and abilities that had been of central importance (Fisher & Mitchell, 1997; Kolodny, 1996; Mitchell & Jonas-Simpson, 1995; Parse, 1996b); how the participants' lives at the time of their interviews compared to how they used to be (Carson, 1996; Fisher & Mitchell, 1997; Parse, 1996b); and tempered freedom linked with the necessity of having to rely on others (Kolodny, 1996; Mitchell & Jonas-Simpson, 1995).

For instance, in their studies exploring quality of life for individuals living in long term care facilities, Mitchell and Jonas-Simpson (1995) and Kolodny (1996) uncovered themes about loss which represented participants' descriptions of how illness and physical limitations restricted choices in daily life and necessitated having to rely on others. For one person in this present study, the experience of loss was linked to being dependent on oxygen and on other people. He said: "When I get up in the morning, it's terrible; I have to come down and get on oxygen, or I'm

in trouble. My whole life is changed... my dependency on other people, ... [on oxygen] to breathe; that's why it's changed." For other participants in this current study the experience of loss surfaced in their descriptions of what it was like for them to live with limitations on what it was possible for them to do. One person spoke of not being in a position to "play golf," "go to Florida," or "do more work on his computer." Another person described not being able "to go out the door hardly," and someone else talked about not being able to cook Sunday dinner for his family.

Findings from two other descriptive-exploratory studies guided by the human becoming theory are related to this theme about loss and diminishing vitality. In Carson's (1996) study about quality of life for persons tolerating persistent pain, participants talked about how their lives now compared to how they used to be. The participants in Carson's study described loss, life changes, and forced withdrawal from previous activities in ways similar to the descriptions given by the participants in this current study. As well, participants in Fisher & Mitchell's (1997) descriptive-exploratory study of quality of life as experienced by adults hospitalized on an inpatient psychiatric unit all spoke of the way life used to be for them, and about how changes have led to different priorities. A person in this current study described similar details of the experience of loss that accompanies living with limitations that change how life is lived. He spoke about having fewer choices available to him simply because he could no longer do things he used to get great satisfaction out of doing. Being able to do fewer things brought about a shift in how he planned his days. Instead of choosing between many possible options he now had to find an option that was possible.

In another related study, Mitchell (1992) used the Parse research methodology (Parse, 1987, 1990b, 1995, 1997) to uncover the structure of the paradoxical experience of restriction-freedom with 12 persons aged 75-92. Three core concepts emerged from the extraction-synthesis

process of the data analysis. The first core concept, anticipating limitations, is relevant to the discussion of theme one in this present study. In Mitchell's study, anticipating limitations was described by participants as "a process of reflecting on restrictions in the now, as well as how restrictions might be experienced in time to come" (Mitchell, 1992, p.62). For several participants in this current study the experience of loss was associated with anticipated restrictions. One person spoke about what changes he would have to make now that his taken-for-granted health could no longer be taken-for-granted. Another person spoke about what it would be like when he could no longer take care of himself, and another described how she felt about the possibility of having to live in a nursing home. For all these individuals, loss was related to the realization that the future may bring further, and unwelcome, restrictions on their life.

All participants in this current study described experiences of loss and diminishing vitality in ways that were uniquely circumscribed within the contexts of their own lives. Prior to this report, literature noted that persons with congestive heart failure experienced symptoms such as fatigue, tiredness, decreased energy levels, and whole body weakness. What this study adds is the detail of how those experiences change daily patterns of living. These details help enhance understanding about how not being able to live in desired ways links with loss and diminishing vitality for persons who have congestive heart failure.

Theme Two in Relation to the Literature on Quality of Life and Congestive Heart Failure

The core ideas in theme two, patterns of communion-aloneness are consoling-not consoling, relate to the ways participants in this study spoke about the importance of the quality of their relationships with others. They spoke about ways in which their patterns of relating with others enhanced and diminished quality of life all-at-once. Patterns of communion-aloneness in relationships with others were expressed as persistent and close ties with family, friends, or health

care providers, and as relationships that had shifted or diminished over time. The participants described their relationships with others as comforting, or consoling, in some instances yet discomforting, or not consoling, in others.

The importance of sustaining meaningful relationships with family, friends, and health care providers has been reported in other explorations of quality of life. For example, patients with congestive heart failure reported some of their most frequent and upsetting concerns were those related to the future and to their family (Muirhead et al., 1992). Good quality of life was associated with patients' satisfaction with sources of emotional support and with relationships with their partners (Grady et al., 1995). Quality of life was diminished by negative changes in patients' relationships with friends and extended family (Dracup et al., 1992).

The findings of the studies described above are consistent with and extended by knowledge gained from this current study. In ways similar to the descriptions given above, participants in this study spoke of how their connections with others enhanced and diminished quality of life. What the findings from this current study add are details about what concerned the participants about their relationships. For instance, participants in one study reported they sometimes had to pretend things were better than they were in order to protect others (Muirhead et al., 1992). Participants in this current study talked about not wanting to burden their friends, and not wanting to scare their family, but they also described how they avoided being too burdensome to their friends and family. They said they had "to eat more," "wear a little make-up," or "return from vacations with friends" so that others would not worry so much about them. Participants in this study also described feeling abandoned, feeling isolated, and feeling lonely when their contact with important others dwindled.

Although other researchers (Dracup et al., 1992; Grady et al., 1995; Muirhead et al., 1992) reported quality of life was enhanced by satisfying relationships and decreased by negative

ones, prior research did not address the paradoxical complexities of relationships as captured here. Findings here suggest that relationships are sometimes comforting and helpful and sometimes not, depending on particular concerns and expectations of the moment. This current study also provides details of what contributes to relationships being comforting and helpful, or not comforting and not helpful. For instance, one person described her relationship with her son-in-law. She explained that he loved her, yet he was destroying her because he kept criticizing her and trying to tell her what she should do. Another man described what it was like when his family and his health care providers did things for him in ways that conveyed the message that they were not happy to be doing it. These findings provide the knowledge that not all relationships considered “close” or “helpful” by others are necessarily considered to be so by the person living them.

Theme Two In Relation to Other Literature Linked With the Concepts Communion-Aloneness and Consoling-Not Consoling

Participants in this present study found living patterns of communion-aloneness both consoling and not consoling. A review of the literature found no published studies with participants with chronic illness which explicitly discussed either dimension of the consoling-not consoling paradox. However, literature connected with the concepts comfort and comforting is available and relevant to this discussion.

For the participants in this current study, consoling or comforting relationships were not necessarily connected with specific acts or tasks that brought increased comfort. Rather, whether or not relationships were consoling or comforting was linked to the human messages of intent that revealed the attitude of the comforting or consoling person. The majority of the literature relating to the comforting-discomforting paradox is linked to methods of providing comfort. There is a general assumption in the literature that nurses can be comforting if they know, and

can operationalize, a variety of pre-defined strategies. For example, Bottoroff, Gogag, & Engelberg-Lotzkar (1995) suggest that awareness of strategies can lead to reflection on practice and purposeful incorporation of combinations of strategies in patient care activities. Comforting strategies commonly discussed include: talking and listening (Morin & Welsh, 1996); comforting touch (Moore & Gilbert, 1995; Bottoroff et al.); connecting touch (Bottoroff et al.); providing relief from pain (A.J Walters, 1994); providing physical comfort, using emotionally supportive statements (Bottoroff et al.); providing relief from anxiety; communicating; providing comfort to family and friends (A.J. Walters, 1994); using gentle humor (Bottoroff et al.); and using comfort talk (Proctor, Morse, & Khonsari, 1996).

Kolcaba (1995) wrote about the art of comfort care stating that it is a nursing art entailing the process of comforting actions performed by a nurse for a patient and the outcome of enhanced comfort that is brought into being. According to comfort theory (Kolcaba, 1994), patients experience needs for comfort in stressful healthcare situations. Some of these needs are met by patients and their support groups and others are identified by nurses who then implement comfort measures to meet the needs.

Even though they were all interviewed when they were inpatients in an acute care setting, participants in this study did not offer specific examples of nursing comforting measures. However, several of them did offer specific examples of when a nursing act was discomforting. For example, one person described having to argue with staff to get a drink of water, and another described not feeling cared about when she had to wait:

I seem to have had good nurses and good care, up until last night; there was one I didn't like... I think if they act as if they cared for you and they don't mind doing things for you, you know.. but when they let you wait and wait before they come, you know... especially if you have to go to the bathroom, it's not much fun waiting.

Several authors have reported studies in which the patients' perspectives of being comforted have been elicited. Interestingly, and consistent with the two participants' experiences described above, a conceptualization of comfort as an attitude rather than an act has been alluded to in several instances. For example, Hamilton (1989) reported that whether or not patients perceived relationships as comforting related to the approach and attitude of staff. In another study, Kennedy (1991) explored how comfort was experienced by acutely ill patients. From the participants' unique descriptions of comfort, several comfort categories were identified. A "caring attitude" was the most frequently mentioned comfort measure.

Jenny & Logan (1996) did a secondary analysis of interviews with patients in an ICU to examine the metaphors used to describe the experience of being weaned from a ventilator. Of the four themes that emerged, one was related to nurse caring. All but 3 metaphors related to this theme portrayed positive images of nurses' caring to enhance patient comfort. The authors reported that patients mentioned care several times and implied that caring involves both attitude and action. Patients said things like "[It's] just the attitude that they're on your side," and "they talked to you like you were one of them" (Jenny & Logan, 1996, p.350), when describing caring nurses. Descriptions of non-caring nurses related to accounts of impersonal and task-oriented behavior. One person described non-caring nurses as: "the ones who walked in just to do the business... because they may get things done, but they forget the personal side and forget that you're a person to" (Jenny & Logan, 1996, p.350).

Finally, the presence of humanness in relationships with staff was also connected to comforting (Taylor, 1992). Provision of comfort and human warmth helped patients feel cared about by the staff. This arose from displaying kindness, warmth, individualized attention, and other messages that recognized the person as an important individual and not just "another patient" (Pound, Bury, Gompertz, & Ebrahim, 1995). One person in this present study spoke at

length about the importance of health professionals acknowledging human feelings. He said that professionals who ignored patients' feelings "don't achieve much". A person in Mitchell and Jonas-Simpson's (1995) study echoed the words of the participant in this current study. She said: "When nurses acknowledge me and what I need, it makes me feel like I am a human being, not just a number in a book or a body lying in a bed. It makes me feel on an even footing with them, that they are not better than I am, or that I am less of a person..." (p.44).

The paradoxical rhythm of communion-aloneness is one that has surfaced in several other studies guided by the human becoming theory (see for example, Cody, 1995, Daly, 1995; Davis & Cannava, 1995; Pilkington, 1993; Parse, 1996b). In all these studies the participants somehow alluded to the importance of being with and apart from others. In this current study participants spoke of close and important relationships with others. They also described diminished relationships with others which were "isolating", "strained", or "difficult". One participant described what it was like to go on without his spouse, to have relatives who were there when needed, and to have friends who were "neglecting" him. He said he felt close to his relatives but that some were busy and others lived out of town.

In Cody's (1995) investigation of the meaning of grieving for families living with AIDS, the core concept "bearing witness to aloneness with togetherness" emerged. Cody reported that every family discussed multiple significant close relationships in which the importance of being together was evident; yet the participants also spoke about a strong sense of solitude in grieving. One participant said she just stays in a little shell all the time because no one knows what she's going through (Cody, 1995). A participant in this current study spoke at length about how close he was with his family, and how helpful and committed they all were to him. Yet, he also found it difficult to speak about them and he did not want to say too much about how he was feeling in front of his wife who was present at the time of the interview.

Daly (1995) investigated the lived experience of suffering. The core concept, entanglements of engaging-disengaging, arose from all participants' descriptions of being with and apart from others in suffering. Daly reported that the participants talked about experiencing a strong sense of aloneness at times, even in the presence of others. This was congruent with the experiences of several participants in this current study. There was one person in particular whose words illustrated what it was like for him to be surrounded by family, friends, and health professionals who intended to be helpful, but he said, quite clearly, that his family and his health care providers were not helpful when they interacted with him with the intent to tell him what to do, and when routines and rules guided their interactions. Participants in other studies have also spoken about the consequences of living with some of the rules, restrictions, and routines inherent in the health care setting (Kolodny, 1996; Mitchell & Jonas-Simpson, 1995).

In the next example, the authors reported their participants' descriptions of being with and apart from others, as well as an account of the ways in which living this paradoxical pattern of relating with others was discomfoting (Fisher & Mitchell, 1997). The theme: "upset and calm shifts patterns of being with and apart from others" (Fisher & Mitchell, 1997, p.8) was about a sense of discomfort in relationships that are seen to provide support and about wishing to be able to relate to others in a different way. Similarly, in this current study one person said:

My family does everything for me. They come in every day, they do what I ask them, but things are done in such a way that I'm not happy. I try to do it [comfort] for myself, since that the other people don't know how to do it. It takes a long time for someone to learn to give you comfort. If I have a relative that I say, "Do this for me," and if I see that relative does that for me in a nasty way, it's not comfort. It's done, but it's done the opposite way, so I don't know. I don't know at this point. Maybe when you get old, people don't want you around. You don't know.

Theme Three in Relation to the Literature on Quality of Life and Congestive Heart Failure

Theme three, desired anticipations mingle with acceptance of what will be, is about the way persons described anticipating, or hoping for, the opportunity to go on in ways they valued while at the same time accepting that whatever happens will happen. For example, participants spoke about “hoping they would feel better,” “hoping medication would work,” “hoping surgery would help,” “hoping for a peaceful death,” “hoping to get out and do more,” and “hoping to live a little healthier.” They talked about trying to “walk more,” “give up smoking,” “eat differently,” and “think positively.” Amid their descriptions of hope came forth the notion that they would accept whatever did happen. They described “going along with whatever happened,” “making the best of it,” “looking on the bright side,” “having no expectations,” and “having improvements last until they last.” The reports of the participants in this current study are consistent with those of participants in the investigation conducted by Muirhead et al. (1992) who reported maintaining a positive attitude toward the efficacy of medical treatment, anticipating leading a healthy life and anticipating at least a five year survival.

The importance of hope has, however, not been well addressed by other researchers interested in quality of life for persons with congestive heart failure. In fact, in the over 25 tools used to assess quality of life in prior studies (see Acanfora et al., 1995; Baligadoo et al., 1990; Blackwood et al., 1990; Cowley & Skene, 1994; Dracup et al., 1992; Grady et al., 1992; Grady et al., 1995; Kubo et al., 1992; Linde et al., 1995; Mayou et al., 1991; Muirhead et al., 1992; Rector et al., 1993; Rogers et al., 1994; Walden et al., 1994; Walden et al., 1989) none was designed to ask patients about their hope.

Only one study which investigated various concepts thought to be related to quality of life for persons with congestive heart failure addressed the possible importance of hope to patients' perceptions of quality of life. As part of a larger trial to assess the quality of life of patients with

left ventricular dysfunction for up to two years following randomization to treatment with either enalapril or a placebo, Rogers et al. (1994) measured changes in “hopefulness” of participants. They found no significant differences either between the treatment groups or over time. In addition, the results of the study do not reveal any details about the significance of hope to the participants in the above study, or whether having hope made a difference to how they answered other questions about quality of life on the questionnaire. This current study, then, contributes new understanding about the importance of hope in the day-to-day life of persons who have congestive heart failure.

The concept “acceptance of what will be” did not surface as important to quality of life in any other investigations about quality of life for persons with congestive heart failure. In fact, Muirhead et al. (1992) specifically stated that “acceptance” and “escapism” were not commonly reported by their participants. The findings from this current study are in contrast with those reported by Muirhead et al. The importance of “acceptance of what will be” for the participants in this current study provides readers with a different understanding of the way some persons choose to live with congestive heart failure day by day. It is an important concept for health care providers to consider. Historically, research into quality of life issues for persons with congestive heart failure has focused on identifying beneficial treatments and on evaluating the impact of various treatments on symptoms and side effects, physical functional status, social functioning, and psychological status (see for example, Baligadoo et al., 1990; Grady et al., 1992; Kubo et al., 1992), but there is little that has helped health care professionals understand what helps persons with congestive heart failure go on in daily life.

Theme Three In Relation to Other Literature on Hope and “Acceptance of what Will Be”

Descriptions of hope surfaced in the findings from several other descriptive-exploratory studies about quality of life that were guided by the human becoming theory (Carson, 1996;

Fisher & Mitchell, 1997; Mitchell & Jonas-Simpson, 1995; Parse, 1996b). For example, Fisher & Mitchell (1997) found that for persons admitted to an inpatient psychiatry unit “distant hopes fuel[led] the relentless struggle to carry on” (p.9). Integral to their struggle to carry on was the decision to fight against diminishing energy in the hope that someday their situation may improve. In a congruent manner, Carson (1996) reported that all participants in her study about quality of life for persons living with persistent pain described their hope for some pain relief. Participants in this study about quality of life for persons with congestive heart failure shared details about what it was like to live with diminishing vitality. They spoke of their changing abilities, restricted routines, and curtailed ways of living; yet, paradoxically they spoke simultaneously of hopes for tomorrow, and of learning new ways of living. They talked about how life was for them at the time of their interview, and about how hoping that things would be better was what helped them to make choices about, for example, “taking medications,” “having surgery,” “eating better,” and “quitting smoking.”

Four phenomenological studies were found which were designed to elicit the participants’ perspectives of hope (Brunsman, 1988; Parse, 1990b; Stanley, 1978; Wang, 1997). In all of these studies, hope was described, in some way, as an expectation of a desirable outcome in the future that arose with the envisioning of new possibles while living with day-to-day struggles in life. These findings are consistent with this current study in which participants all spoke about envisioned possibles that, if actualized, would bring them satisfaction of some sort. For example, participants envisioned what it would be like to feel better, to be able to go places again, to take care of themselves, or to be able to care for grandchildren.

The findings from this current study are also consistent with other literature in which hope has been described as a multidimensional experience involving interpersonal relations, a future focus, and desire for goal achievement (Dufault & Martocchio, 1985; Ersek, 1992; Hall,

1990, 1994; Pilkington, 1997b; Ross, 1995). For instance, Dufault and Martocchio (1985) developed a definition of hope as a multidimensional and process-oriented “dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant” (p. 380). Participants in this present study recognized their constraints yet envisioned what they wanted and believed possible for the future. One participant spoke about realizing there may not be any medications that could help him yet he said that he hoped there might be. Another person hoped his surgery would be successful even though he was told he probably would not survive.

Pilkington (1997b) noted that hope has been linked with coping by a number of nursing scholars (see Brown, 1989; Farran, Herth, & Popovich, 1995; Gamlin & Kinghorn, 1995; Herth, 1989, 1990; Kim 1989; Rusteon, 1995). Pilkington further suggests the linkage between hope and coping has contributed to the notion that hope may be unrealistic or unjustified in some situations (Ersek, 1992; Hinds, 1988; O’Malley & Menke, 1988), and that hope must be reality based in order to be actualized (Brown, 1989; Dufault & Martocchio, 1985). The findings from this current study contribute the understanding that having hope is a way that persons with congestive heart failure often choose to be with what is happening in their lives. Whether or not a hoped for outcome is thought to be realistic does not prevent the person from “hoping” for it. In their simultaneous descriptions of hope and acceptance of what will be, all participants in this current study described quality of life with phrases and examples that revealed hoped for outcomes, or expectations, of future events, relationships, or changes in their lives. In most cases, participants explicitly acknowledged that what they hoped for may not be possible; yet, they continued to hope for it because it helped them get by day by day. Whether or not their desired anticipation was realistic, or not realistic, did not stop them from having, for example,

“hope for improvement,” when improvement was not likely; or “hope to stay independent” when they thought it was not probable.

In Parse's (1996b) descriptive-exploratory study about quality of life for persons with Alzheimer's disease, hope and acceptance of what will be coexisted in the participants' descriptions of their lives. They noted there were many limitations in the now, but added that opportunities were also present. They thought about and considered what would happen next in their lives. They all knew there would be changes but they were unsure what those changes would be like. One participant said: “I wish this would all change, but it's not going to. Things have changed a lot, and I wish they would find something, a miracle thing, but that doesn't seem likely. Oh, I'm sure someday they'll find out what to do. But after all, who am I when President Reagan, even if somebody such as he - so there's nothing you can do... I wish I could be out more...just be outside” (p.130). As noted earlier, all participants in this current study reported living with limitations associated with diminishing vitality. Similar to the descriptions given by the participants in Parse's study, many of the participants in this study also spoke about what they hoped would happen in ways that revealed they were unsure what would actually come about. Participants talked about: “worrying about what will happen;” “never knowing what would happen;” and “being concerned about what would happen.”

Mitchell and Jonas-Simpson (1995) uncovered the theme: “an appreciative acceptance with what is coexists with moments of anger and frustration amidst hope for change” (p.99) in their study about quality of life for persons in a long-term care setting. It was very similar to the theme: desired anticipations mingle with acceptance of what will be that was uncovered in this current study. For example, Mitchell and Jonas-Simpson reported that most participants in their study related their hopes and dreams for what might be without knowing if they would or would not come true, and, in a way that was similar to the way participants in this current study

described it. In both studies, participants expressed an attitude of acceptance of the way things were. In Mitchell and Jonas-Simpson's study, participants spoke about "making the best of it," "having a good attitude," and "taking each day as it comes," whereas participants in this current study used phrases like "making the best of it," going along with what happens," "taking it in stride," and "being cheerful about things" to describe their attitude of accepting whatever happens.

The phenomenon "acceptance of what will be" surfaced in several other phenomenological studies (Mitchell, 1990, 1992, 1994). It was variously described as "taking life day-by-day" (Mitchell, 1990), yielding to change (Mitchell, 1992), and "rolling with the vicissitudes of life" (Mitchell, 1994). Further insight into the significance of the phenomenon "acceptance of what will be" for the participants in this current study can be gleaned from the findings in Mitchell's (1990) exploration of the lived experience of taking life day-by-day in later life. One core concept that arose in Mitchell's (1990) study was: the unburdened journeying of moving beyond. It was specified in statements such as: "taking life day-by-day is not a worry. I just want to get the most out of life that I can" and "taking life day-by-day you don't worry about everything at the same time" (p.34).

Similarly, descriptions of participants in Mitchell's (1992) study about the paradoxical rhythm of restriction-freedom brought forth the core concept: yielding to change fortifies a resolve for moving beyond. Mitchell said it related to a complex rhythm of yielding to or going along with change. "Moving beyond was represented by participants' descriptions of continuing on, choosing an attitude to go on with, and changing perspectives about self and others. Change is a continuous process of unfolding, and moving on day-by-day is a way of moving beyond. Typically persons think of pushing and struggling to propel on" (p.66). Participants in this study disclosed that at times yielding is also a way to propel on. The persons in Mitchell's study yielded

to the loss of favorite activities and routines. Changing restrictions that were described were accepted, embraced, and endured by the participants who spoke of deciding to accept, adjust, and go along. One person said “you just have to live day-by-day and what you can’t do you just have to learn to live with it” (p.66-67). Participants in this current study also provided examples of times when they yielded to changes in their lives. One woman described how she used to love to travel. She now realized she could no longer travel and she had decided to be content with the fact that she had had the chance to do that in her lifetime. Another person talked about wanting to be able to get out and walk around but “if you can’t do it, you can’t do it.” Others said they no longer tried to cut the grass, to golf, or to invite company for meals. They all accepted things as they came along even though that sometimes meant living with loss and limitations.

The Findings in Relation to the Principles and Concepts of the Human Becoming Theory

Parse’s (1981, 1987, 1992, 1995, 1997) theory of human becoming guided the research described here. The human becoming theory specifies three theoretical principles that provide a framework for interpreting research findings. The objectives of this research were: to specify the meaning of quality of life; to identify patterns of relating connected to quality of life; and to describe concerns, plans, hopes, and dreams related to quality of life for persons living with congestive heart failure. The objectives flow from the three principles of Parse’s theory. In chapter four, each of the three themes that emerged as one of the major findings of this study was linked to one of the three research objectives, and thus is most closely associated with the principle of Parse’s theory from which that objective was derived. However, the themes all relate, in some way, to all three principles of the human becoming theory and are discussed in this chapter as a unified description of quality of life. The unified description of quality of life for the participants in this study was: Loss surfaces with diminishing vitality amid patterns of

communion-aloneness that are consoling-not consoling while desired anticipations mingle with acceptance of what will be. The unified theme is discussed below in light of the human becoming theory's principles and their related concepts in order to contribute new insights to nursing knowledge about human becoming.

Principle One

The first principle of the human becoming theory is: "Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging" (Parse, 1981, p.42). It relates to the way human beings continuously cocreate their realities by assigning meaning to multidimensional experiences that occur all-at-once (Parse, 1981). The theme of this principle is meaning. The participants in this study revealed details about the meanings they assigned to quality of life in their descriptions of what it was like for them to live, day-by-day, with congestive heart failure. The shared meanings of quality of life for all research participants related to their descriptions of loss and diminishing vitality, to the significance of being with and apart from others in relationships that were both consoling and not consoling, and to their hopes and dreams for the future that surfaced amid their acceptance of whatever happened.

The first principle of the human becoming theory has three related concepts: languaging, valuing, and imaging. Participants in this study have contributed to understanding about what valuing, imaging, and languaging is like for persons with congestive heart failure. Languaging relates to the way individuals disclose details of the unique meanings they have assigned to their multidimensional experiences. Languaging occurs in the processes of speaking-being silent and moving-being still. For instance, persons use various words, volumes, tones, and tempos as well as multiple gestures, gazes, touches, and postures when relating with others (Parse, 1981, 1995).

Meanings not immediately apparent in the written transcripts were languaged by participants in the way they spoke, the way they sat, and the way they moved. For example, as

persons spoke about “accepting what will be” they often sighed, shrugged their shoulders and waved their hands in the air. When they described situations and meanings related to living with diminishing vitality, some were sitting slumped in their chairs and others were lying down. As they spoke about not being able to breathe, one person reached for oxygen and another held her neck as if she was choking. Another man grimaced when describing not having enough energy to get out of bed, having legs that were full of fluid, and feeling constantly thirsty. As he spoke he kept pointing to his legs and he had to stop frequently to catch his breath. As other participants spoke about the people, events, and activities that were important to them, their memories of what had been brought smiles to their faces. One man laughed as he remembered precious moments with his children. Another person laughed when she described humorous times spent with friends.

Participants in this study also revealed the depth of their feelings for close others in the tone of their voices as they recalled past events and times of togetherness that meant so much to them. Voices frequently cracked and faded, and descriptions were often halted as tears streamed down their faces. For instance, one person had to pause to cry when he talked about how much his family meant to him. When another person spoke of her family, she turned away and cried silently as she remembered good times that had meant so much, and as she talked about not being invited to her son’s house for Thanksgiving. She also cried as she shared that her daughter, who lived in another city, was being treated for a serious type of cancer.

Several participants also described the way verbal and non-verbal messages given by staff and family members related to their quality of life. For example, an interview with one of the participants was interrupted by another staff member. After waving the person away, the participant described that person’s entry into the room as an intrusion. He then cried as he spoke about losing all power, and about the disregard of staff who assume he knows nothing about his

situation. It is these details that are not evident in the typed transcripts that contribute to understanding the experiences of quality of life.

Valuing, the second concept of the first principle, is the living of cherished beliefs, plans, hopes, and dreams through the process of choosing among imaged options (Parse, 1981). "Value priorities guide life choices and shape patterns of relating day-by-day.... From among available options people make choices about what to do, who to relate with, what attitudes to have, and so on" (Mitchell & Jonas-Simpson, 1995, p. 105). The words of the participants in this study provided many examples of choices being made in day-to-day life based on the priorities and hopes of the persons making the choices. From these examples, it is possible to learn to appreciate the complexities that lead persons to make certain choices, choices which they know are best for them, but which an outsider may not recognize as the best option. For instance, one participant explained that he had chosen to return home from his vacation when he became ill. At the time, professionals had discouraged him from traveling; however, he chose to fly home anyway because he did not wish to burden his friends with having to care for him, and he did not want to spoil their vacation. Another participant chose to drink water against professional advice. For him, relief from severe thirst was more important than the possible consequences of having a few extra sips of water a day.

Imaging, the third concept of the first principle, refers to knowing at both explicit and tacit realms all-at-once (Parse, 1981, 1992). It is the process through which persons construct reality, search for answers, and come to understand the world through the integration of new ideas (Mitchell, 1992; Parse, 1981). Imaging can include creative imagining, which Parse (1990a) described as "the picturing of what a situation might be like if lived in a particular way" (p.138). Participants in this current study imaged themselves being with their limitations in the now and in the future. They described what they thought it would be like for them, for example, to live in a

nursing home, to stop smoking, to live through surgery, to have cardiopulmonary resuscitation (CPR), or to feel better. Images of preferred and dreaded future outcomes, helped participants clarify their options and make choices. One man related how terrible it would be for him to continue if he had to live with continuous pain. He chose to keep trying new medications in the hope that one of them would work. Another person talked about what it would be like for her and for her family if she had CPR and survived. She said “I think it’s a misery to do that to the people because most of the time they are not even aware, they are vegetables and it’s terrible - for the people who stay and for the people themselves. So this... I don’t want... each time I come into this hospital I specify right away that I do not want any resuscitation or artificial prolongation of life”.

Principle Two

The second principle of the human becoming theory is: “Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating” (Parse, 1981, p.50). The theme of this principle is rhythmicity. Humans live rhythmical patterns of relating, which are paradoxical in nature, and cocreated with the human-universe process (Parse, 1992). The participants in this study disclosed details about the paradoxical, rhythmical patterns they lived with others. For example, in describing their quality of life, they all, in some way, described past and present relationships in which they experienced the paradoxical pattern of communion-aloneness in ways that were consoling and not consoling all-at-once.

The second principle of the human becoming theory has three related concepts: revealing-concealing, enabling-limiting, and connecting-separating. The findings of this study expand understanding of these concepts by contributing descriptions related to quality of life for persons with congestive heart failure. Revealing-concealing, the first concept of the second principle, “is

the simultaneous disclosing of some aspects of self and hiding of others” (Parse, 1981, p.52).

When human beings participate in relationships, there are always dimensions of the individual’s reality that remain hidden from oneself and others since the multidimensional realms that coconstitute who one is can never be completely disclosed (Parse, 1981). Inherent in this paradox, then, is the view that persons are always more than what is shown in any situation or relationship.

All participants in this study revealed aspects of what it was like for them to live with congestive heart failure while describing diminishing vitality and loss, and being with and apart from others in ways that were consoling and not consoling. They also disclosed details about what they hoped for and about accepting whatever happened. As participants described their quality of life, the revealing-concealing paradox as lived in relationships with others was highlighted. For example, one participant spoke about being treated like he “knew nothing” and about the attitudes and actions of family and staff that diminished his quality of life. He said he was not able to discuss how he felt with his family or with professional staff because “it might make it worse”. Another person began to relate how much his family meant to him and then he stopped because he said it was too hard to go on talking about it. Another participant told his friends that he had not been feeling well, yet he chose to conceal the seriousness of his illness so his friends would not have to worry about him. Someone else spoke of worrying about frightening her daughter, and so when she was with her she tried to act like she felt better by putting on make-up and making an effort to eat “a little healthier”.

Enabling-limiting, the second concept linked with the second principle, represents the simultaneous existence of infinite opportunities and limitations in all choices made by individuals. Individuals choose ways to be in situations and in choosing, they enable themselves to move in one direction while simultaneously limiting their movement in another direction. Individuals are

enabled and limited by all choices (Parse, 1981, 1992). “Every situation holds options for persons, even if choices are limited to what attitude to have or what fears are most worrisome” (Mitchell & Jonas-Simpson, 1995, p.108).

Participants in this study described choices they had made. For instance, they chose hope and “acceptance of what will be” as ways to go on living. Choosing to hope for desired outcomes enabled them to go on day by day and it influenced other choices. Examples from their descriptions bring to light how those choices were both enabling and limiting all-at-once. For instance, aloneness surfaced in several participants’ descriptions of not feeling well enough to go out and do things with friends or family. One woman talked about why she had chosen not to go to her son’s house and the consequences of that choice. She said: “They want me to, they keep asking me to go out there but, he says: ‘I’ll come and get you’ but, I just didn’t want to go. I just want to stay home because... when you don’t feel well you don’t feel comfortable in someone else’s house; so I don’t go...So Thanksgiving they didn’t ask me so ..because I turned them down so many times, but that doesn’t bother me...it didn’t bother me because I’m... [crying].”

Another participant described similar circumstances. He chose not to go out with friends on several occasions because he was not feeling well. He said: “they know about my illness, and when I was invited, a few times I had to say, ‘I’m sorry, I couldn’t go, because I don’t feel well.’ And the result was, my feeling was that 2 or 3 times they still did invite me, but after that they stopped... well they tried and now they are neglecting me.” The same participant also chose to return home from his vacation rather than have his friends worry about how he was doing. In doing so, he knew he was also limiting the support his friends would be able to give him.

Another gentleman made choices about how to relate with staff which enabled him to achieve certain things but which also left him tired and out of breath. He chose to argue with the nurses until they let him have some water but was then so exhausted he had no more energy for

anything else. The same person also chose to have a rare type of surgery that he was told he probably would not survive. He hoped that the surgery would be successful and that he would feel better afterwards. From his perspective, feeling better meant being able to “live better” than he was living at the time. In choosing the option that gave him hope for improvement, he limited the choices he had about how to spend what may have turned out to be the last two weeks of his life. As persons choose from among many possible options they both connect and separate with other people, ideas, and life projects.

Connecting-separating, the third concept linked with the second principle, “is a rhythmical process of moving together and moving apart. In moving together with one phenomenon, the individual moves away from other phenomena” (Parse, 1992, p.38). As individuals connect and simultaneously separate with people, places, and events that are important to them they move on with greater diversity (Parse, 1981).

Participants in this study spent a lot of time describing their patterns of connecting and separating with others and with activities and events and places that were important to them. They spoke about how being with family, friends, and nurses changed quality of life. They also related how diminished strength, endurance, and liveliness changed their ability to do some of the things most valued in life. Participants described connections with others that “improved life”, “made life worthwhile”, “helped”, “brought comfort”, and made them “proud”; yet, the concept “aloneness” surfaced in the findings regarding experiences like “feeling neglected”, “having less contact with friends”, “living in a shadow”, and being in a “loving but critical relationship”.

Principle Three

Parse’s (1981) third principle is, “Cotranscending with the possibles is powering unique ways of originating in the process of transforming” (p.55). It suggests that human beings are future-oriented and reach beyond their current reality to what is not-yet (Parse, 1981). The theme

of this third principle is transcendence. "It is about the ways people change and unfold in life" (Mitchell & Jonas-Simpson, 1995, p.111). Participants in this current study all spoke about what they hoped for in the future. They imagined possibilities and made plans to go on in ways that had the potential to help them actualize what they hoped for.

The third principle of the human becoming theory has three related concepts: powering, originating, and transforming. The findings of this study expand understanding of these concepts by contributing illustrations of their meaning for persons who live with congestive heart failure. Powering, the first concept of the third principle, is the energizing force which propels humans beyond the moment with cherished plans, hopes, and dreams (Parse, 1981). To be is to power. Powering is "the continuous affirming of self in light of the possibility of non-being" (Parse, 1981, p.57). It "happens in light of threats that may not only lead to non-being, or death, but threats that challenge one's sense of self as a human being" (Mitchell & Jonas-Simpson, 1995, p.111). Powering "relates to the human being's will to go on in life, to courage, risk and to conflict.... it shows itself when persons dream about the future or when they fear for tomorrow; it is the pushing-resisting rhythm of reaching beyond the now moment - it shows up in statements like: life is hard but the hard knocks make me stronger" (Mitchell, 1994 p.76).

Powering, for the participants in this study, was evident in descriptions of hope amid descriptions of diminishing vitality. The participants talked about things like "hoping for improvement" even though they felt "miserable", "knocked out", "in pain", "lightheaded", and "unable to breathe." Participants had the courage, for instance, to: try new medications, hope, risk surgery, dream about things being better, imagine what they might be able to do in a few months, stop smoking, and change their lifestyle.

For one participant, powering showed itself in his resolve to go on despite feeling powerless when family, friends and staff treated him like he knew nothing. He said: "There's

nothing worse than when a man loses power completely... That's not right, but that's the way life is. I have very much faith in my cardiologist, and I have much faith in my operator right now, but these are the things that... I just go on faith at this point.” The same participant also described the pushing-resisting rhythm he lived with staff: “Just getting a little bit [of] water... sometimes takes so much hassle, that you get so tired and out of breath... they could make it easier.... Many times I ask for real simple glass of water, because my throat...gets too dry. But the answer is no because it's by the rule, and then I have to explain. [I] tell them that the responsibility is mine, until they let me have a little bit. So, wouldn't it be easier for me to get a little drop of water before I make myself that tired?”

Originating, the second concept of the third principle, “is choosing a particular way of self-emergence through inventing unique ways of living” (Parse, 1981, p.60). Unique ways of living surface through interconnections with people and projects (Parse, 1992). Parse (1981) identified the paradoxical rhythms conformity-nonconformity and certainty-uncertainty as inherent to the originating process. Conformity-nonconformity relates to the notion that people strive to be like others yet simultaneously choose ways to be unique (Mitchell, 1994). Certainty-uncertainty suggests that in every choice there is certainty about what one wants to do yet uncertainty about how the decision will unfold (Parse, 1981).

The personal priorities of the participants in this study evolved through living the certainty-uncertainty paradox as they chose their unique ways of living with congestive heart failure. Participants all made choices about what to hope for, how to live with losses that accompanied diminishing vitality, how to be in relationships, and how to make the best of life on a day-to-day basis. They were clear about how they would like life to be and they made choices with that in mind; however, when persons hoped for preferred outcomes there was always a degree of uncertainty about what would actually happen.

The findings of this study also illuminated ways some participants lived the conformity-nonconformity paradox. Some individuals were called upon by others to conform with, for example, treatment options, social invitations, and advice from family, friends, or professionals. In some circumstances participants chose to go along with what was being asked. One person spoke about: eating more and wearing make-up to please family members. In other circumstances, participants chose not to follow advice, or to accept social invitations. For instance, aloneness, for two of the participants, was linked to choosing not to go out with friends or to visit family. After making that particular choice on several occasions their contact with those people lessened. For another person, the not consoling, or discomfoting nature of his relationships with nursing staff linked to his decision to have more water than they were advising him to have.

Transforming, the third concept of the third principle, is “the shifting of views of the familiar as different light is shed on what is known” (Parse, 1992, p. 39). It is linked to the continuous changes in life that accompany changing views of one’s life situation (Mitchell & Jonas-Simpson, 1995). All participants described change related to diminishing vitality, loss, and shifting relationships. They described their struggle to live with the consequences of congestive heart failure, and in the process, they made evident their shifting value priorities. They spoke of seeing others in new ways, recognizing their limitations, finding new ways to accomplish their goals, discovering new ways to spend their time, and coming to new understandings of what life was like for them. For instance, one participant talked about having a vague awareness that he should probably stop smoking, reduce his stress, and eat healthier; he noted that his current situation made the importance of these seem much more urgent: “I guess the whole thing has been a total eye-opener for me... I just happened to sort of have an eye-opener that sort of jumped into the forefront, where it's basically life and death. If I don't do it, I probably won't live

another 10 years, so it's not a great situation to be in. But it's also something that one always thinks about... and maybe it just took a hit over the head to change whatever I've got to.

Another participant illustrated how his life was different. He said: "Two, three years ago a lot of my friends were saying, 'You are so busy,' when they called me and invited me, because I'd say, 'Well, for the next two, three weeks, I'm busy; I'm invited..' and this and that. And everybody was saying that I manage my life very well. I didn't think about it, I didn't think about it. I thought this is how it will go all the time, but all of a sudden, ... you know.. I don't know what else to say."

The human becoming theory provides a rich and complex framework for exploring the experience of quality of life. Exploration of the findings of this study in light of the principles and concepts of the human becoming theory added depth to the meaning of the findings, illuminated ways persons transformed personal meanings and values as they lived with congestive heart failure, and shed light on the complexity and diversity of human becoming.

CHAPTER VI

Conclusions, Recommendations, and Reflections

This research study explored the experience of quality of life for persons who live with congestive heart failure. The purposes of this study were: 1) to contribute to nursing knowledge about patients' perspectives of quality of life when living with congestive heart failure, 2) to enhance understanding of quality of life issues for further study, and 3) to specify practice approaches aimed at enhancing quality of life for persons with congestive heart failure. The participants were 11 persons between the ages of 49 and 91 who described their experience of quality of life. The descriptive-exploratory design of this study, guided by Parse's theory of human becoming (Parse, 1981, 1992, 1995, 1997) elicited the participants' perspectives of quality of life. The findings consisted of three themes of shared meaning which were joined together to form the unified description of the experience of quality of life for persons who live with congestive heart failure: Loss surfaces with diminishing vitality amid patterns of communion-aloneness that are consoling-not consoling while desired anticipations mingle with acceptance of what will be. The findings were discussed in relation to the participants' descriptions, Parse's theoretical principles and concepts, and related research literature. Findings expand nursing's scientific base and enhance understanding about the meanings, relationships, values, hopes and dreams connected to the experience of quality of life for persons with congestive heart failure. In this chapter, conclusions and recommendations are presented, and reflections on this study are offered.

Conclusions

The findings from this study contribute insight and understanding about what quality of life is like for persons who have congestive heart failure. Participant descriptions that contributed to theme one, loss surfaces with diminishing vitality, provide details about how living with

lessened life energy and endurance changes patients' patterns of living and about how changes in patterns of living are experienced by individuals as loss. The descriptions also provide opportunities for others to develop a deeper appreciation of how persons with congestive heart failure may experience losses related to past, present, and anticipated activities, abilities, and relationships.

Theme two, patterns of communion-aloneness are consoling-not consoling, illuminates the paradoxical nature of patients' relationships with family, friends, and health care professionals. As noted earlier, previous research emphasized the importance of family, friends and staff to how patients evaluated their quality of life; however, the findings from this current study highlight details of what concerned participants about their relationships as well as what contributes to relationships being comforting and helpful, or not comforting and not helpful. The findings also provide examples of how it was possible for the participants to feel alone even when surrounded by family, friends, and staff.

Finally, theme three, desired anticipations mingle with acceptance of what will be, demonstrated that it is possible for hope for preferred outcomes to coexist with acceptance of one's situation. Hope gave the participants in this study a reason to go on in daily life, while accepting, or yielding to, whatever happens was the participants' way of being with the worries and disappointments that might come if what they hoped for did not happen. Theme three also provided the insight that hoping for desired anticipations occurs even when what is hoped for seems unrealistic to others. Persons can hope for desired outcomes while simultaneously acknowledging that they are probably not possible. Having hope is a way of moving forward, and it is what helps people make choices about what to do in a day, what medications to take, and what treatments to have.

Recommendations

The goal of research with qualitative methods in general, and with those guided by Parse's human becoming theory in particular, is to enhance understanding about lived experiences of health, and to generate ideas for further research, thereby advancing the science of nursing. Another important purpose of this study was to contribute to patients' quality of life by suggesting nursing practice approaches aimed at enhancing quality of life for persons with congestive heart failure. In the following section, implications for professional practice and recommendations for future research are discussed.

Implications for Professional Practice

With qualitative research, there is no attempt to generalize findings to populations. It would be impossible to predict how persons will experience a health phenomenon. Rather, the aim of this research was to enhance understanding of the experience of quality of life for persons who have congestive heart failure. The way nurses understand individuals' experiences has the potential to influence how they are with patients in practice.

Nurses who have the opportunity to ponder the findings of this study may discover previously unfamiliar ways of understanding what it is like for persons to live with faltering strength, endurance, and liveliness to be able to do the things most valued in life. Nursing practice could then focus on exploring what it is like for patients to live with less energy than is necessary to be able to do the things they like to do. Patients could be given the opportunity to discuss their priorities and to plan ways to participate in the activities most important to them. Nursing care could then be directed by patients' priorities and preferences and could concentrate on assisting patients with activities the patients feel are important. In addition, knowing that grieving losses is a common experience for persons with congestive heart failure, means that nurses could take opportunities to explore loss and to be with people as they work through issues

and clarify their priorities. Nurses could ask patients what would help them to live with their losses and they could address issues in ways patients identify as beneficial.

Nurses who have the chance to consider the findings of this study may also gain a new appreciation for the complexity and meaning of persons' relationships with their families and friends, as well as with staff members. Patients may then be given the opportunity to discuss their relationships, and to speak about what is, or is not, comforting to them. Nursing practice approaches would include family and friends in whatever ways the patient and family felt appropriate and would respect patient or family choices to involve-not involve families in care. Nurses would also be aware of the messages of intent given and taken in interactions with patients that convey an attitude of concern and respect for patients as leaders and experts of their own care. They would also be aware of restrictive rules and regulations that may not be perceived as useful by the persons receiving care and they would be more open to challenging rules and restrictions that prevent patients from leading their care.

Finally, nurses who have the chance to reflect upon the findings of this study may reach new understandings of what it means for persons to have hope for what life might be like; yet to go along with whatever happens. Nursing practice would respect patients' decisions to yield to changes in their lives. It would also acknowledge that patients are the experts about what their situation means to them by providing them with the opportunity to discuss what they hope happens without having their hopes labeled realistic or unrealistic. Patients could also be given a chance to speak about what would help them achieve what they hope for, as well as to clarify their priorities by talking about what would happen if what they hoped for happened, and what would happen if what they hoped for did not happen.

Recommendations For Future Research

This research study created a unified description of quality of life from the descriptions of eleven participants with congestive heart failure. Parse's theory guides researchers to explore universal experiences of human becoming. A universal lived experience is any experience that it seems reasonable to say is experienced by everyone at one time or another. An examination of the descriptions and themes presented in this research uncovered particular universal lived experiences linked to quality of life for persons with congestive heart failure that require additional exploration. The most salient experiences lead to the following questions for future research:

1. What is the lived experience of hope?
2. What is the lived experience of going along with whatever happens?
3. What is the lived experience of feeling comforted by another?
4. What is the lived experience of feeling alone while with others?
5. What is the lived experience of feeling uncomfortable with others?
6. What is the lived experience of loss?
7. What is the lived experience of feeling restricted?
8. What is the lived experience of feeling tired?
9. What is the lived experience of taking life day by day?

Finally, the themes uncovered in this study raise further questions about what helps persons with congestive heart failure manage when they are at home given that their descriptions of quality of life often include phrases like: "feeling knocked out," "feeling tired," and "feeling miserable," as well as accounts of how diminishing vitality limits what they are able to do. Questions such as these suggest that the research conducted here should be repeated with other

groups of persons with congestive heart failure in other areas in order to further enhance understanding of what life is like for persons living with congestive heart failure.

Reflections

The idea for this study germinated in a practice setting where a philosophy of patient focused care defines the quality of the nurse-person relationship in a manner consistent with the human becoming theory. From the human becoming perspective, patient focused care calls forth a commitment from nurses to seek to understand patients' perspectives of their health situation, to trust that patients will speak about how to care for them in ways that make a difference to their quality of life, and to structure their care in ways that address patients' perspectives of what is important. In working with nurses to implement patient focused care, the researcher witnessed the power and splendor of nursing practice which focused on understanding and respecting the patient's perspective; as well as the suffering and disregard experienced by patients whose perspective was either not heard or not respected. In the introduction to this study Mrs. G's story was told as an example of how sharing a person's perspective can change understanding and transform the quality of the nurse-person relationship in ways that make an incredible difference to quality of care and quality of life.

This study has elicited the perspectives of the participants who agreed to tell their story. One of the limitations of this study was the researcher's lack of experience conducting interviews which seek as much depth and clarity as possible about issues brought up by participants. In the descriptive-exploratory method used in this study the interviewer is instrumental to the quality of the data obtained. There were one or two transcripts of interviews in which very little detail was given. Perhaps this was cocreated by the comfort level of the participants to reveal their feelings and experiences, and by the researcher's inexperience with the interview technique. Nevertheless, the researcher has learned many things from the descriptions that were given. Some of the

learnings were happy, some were sad, and all were deeply moving. The themes that were common to all participants were put forth as the major findings of this study. Others who take the opportunity to consider the meanings captured by these themes will find insights, stories, and experiences that deepen one's understanding of the experience of quality of life for the participants in this study.

REFERENCES

- Aaronson, N.K. (1988). Quality of life: What is it? How should it be measured? Oncology, 2, 69-74.
- Acanfora, D., Lanzillo, T., Papa, A., Longobardi, G., Furgi, G., Rengo, C., Melillo, E., & Rengo, F. (1995). Congestive heart failure in elderly patients: Controlled study of delapril versus captopril. American Journal of Cardiology, 75, 37F-43F.
- Arteaga, W.J., & Windle, J.R. (1995). The quality of life of patients with life-threatening arrhythmias. Archives of Internal Medicine, 155, 2086-2091.
- Baligadoo, S.J., Subratty, H., Manraz, M., Tarral, A., Maiti, D., & Murday, M. (1990). Effects of enoximone on quality of life. International Journal of Cardiology, 28, S29-S32.
- Blackwood, R., Mayou, R.A., Garnham, J.C., Armstrong, C., & Bryant, B. (1990). Exercise capacity and quality of life in the treatment of heart failure. Clinical Pharmacology and Therapeutics, 48, 325-332.
- Borghetti-Maio, S.A., Romano, B.W., Bocchi, E.A., Moreira, L.F.P., Barreto, A.C.P., Stolf, N.A.G., Bellotti, G.V., Pilleggi, F., & Jatene, A.D. (1994). Quality of life after cardiomyoplasty. Journal of Heart and Lung Transplantation, 13, 271-275.
- Bottoroff, J.L., Gogag, M., & Engelberg-Lotzkar, M. (1995). Comforting: Exploring the work of cancer nurses. Journal of Advanced Nursing, 22, 1077-1084.
- Brown, P. (1989). The concept of hope: Implications for care of the critically ill. Critical Care Nurse, 9, 97-105.
- Brown, J.S., & Rawlinson, M.E. (1979). Psychosocial status of patients randomly assigned to medical or surgical therapy for chronic stable angina. The American Journal of Cardiology, 44, 546-554.

- Brunsmann, C.S. (1988). A phenomenological study of the lived experience of hope in families with a chronically ill child. Unpublished master's thesis, Michigan State University.
- Burns, N. (1989). Standards for qualitative research. Nursing Science Quarterly, 2, 44-52.
- Carson, M.G. (1996). The patients' view of tolerating persistent pain: A quality of life study. Unpublished manuscript, Sunnybrook Health Science Centre, North York, Ontario, Canada.
- Chocron, S., Rude, N., Dussaucy, A., Leplege, A., Clement, F., Alwan, K., Viel, J., & Etievent, J. (1996). Quality of life after open-heart surgery in patients over 75 years old. Age and Aging, 25(1), 8-11.
- Cleary, P.D., Epstein, A.M., Oster, G., Morrissey, G.S., Stason, W.B., Debussey, S., Plachetka, J., & Zimmerman, M. (1991). Health-related quality of life among patients undergoing percutaneous transluminal angioplasty. Medical Care, 29, 939-950.
- Cody, W.K. (1991). Grieving a personal loss. Nursing Science Quarterly, 4, 61-68.
- Cody, W.K. (1995). The lived experience of grieving, for families living with AIDS. In R.R. Parse (Ed.), Illuminations: The human becoming theory in practice and research (pp. 197-242). New York: National League for Nursing Press.
- Cowles, K.V., & Rodgers, B.L. (1991). The concept of grief: A foundation for nursing research and practice. Research in Nursing and Health, 14, 119-127.
- Cowley, A.J., & Skene, A.M. (1994). Treatment of severe heart failure: quantity or quality of life? A trial of enoximone. British Heart Journal, 72, 226-230.
- Daly, J. (1995). The lived experience of suffering. In R.R. Parse (Ed.), Illuminations: The human becoming theory in practice and research (pp. 243-268). New York: National League for Nursing Press.

- Davis, D.K., & Cannava, E. (1995). The meaning of retiring for communally-living retired performing artists. Nursing Science Quarterly, 8, 8-16.
- DeCampi, W.M., Luikart, H., Hunt, S., & Stinson, E.B. (1995). Characteristics of patients surviving more than ten years after cardiac transplantation. Journal of Thoracic & Cardiovascular Surgery, 109, 1103-1114.
- Dodek, A., Hooper, R.O., & Kiess, M. (1988). Percutaneous balloon valvuloplasty for aortic stenosis: Improved quality of life for elderly patients. The Canadian Journal of Cardiology, 4, 223-227.
- Downy, A.M. (1983). Living, loving, and losing: Implications for health and well-being. Health Values: Achieving high level wellness, 7(1), 7-14.
- Dracup, K., Walden, J.A., Stevenson, L.W., & Brecht, M.L. (1992). Quality of life in patients with advanced heart failure. Journal of Heart and Lung Transplantation, 11, 273-279.
- Dufault, K., & Martocchio, B.C. (1985). Hope: It's spheres and dimensions. Nursing Clinics of North America, 20, 379-391.
- Duquette, R.L., Dupuis, G., & Perrault, J. (1993). A new approach for quality of life assessment in cardiac patients: Rationale and validation of the Quality of Life Systemic Inventory. Canadian Journal of Cardiology, 10(1), 106-112.
- Eakes, G.G. (1993). Chronic sorrow: A response to living with cancer. Oncology Nursing Forum, 20, 1327-1334.
- Ekeberg, O., Klemsdal, T.O., & Kjeldsen, S.E. (1994). Quality of life on enalapril after acute myocardial infarction. European Heart Journal, 15, 1135-1139.
- Ersek, M. (1992). The process of maintaining hope in adults undergoing bone marrow transplantation for leukemia. Oncology Nursing Forum, 19, 883-889.

- Evans, R.W. (1984). The national heart transplantation study: Survival, quality of life, cost. Seattle: Seattle Battelle Human Affairs Research Center.
- Farran, C.J., Herth, C.J., & Popovich, J.M. (1995). Hope and hopelessness: Critical clinical constructs. Thousand Oaks: Sage.
- Fisher, A. & Mitchell, G.J. (1997). Transforming the knowledge base of advanced nursing practice. Unpublished manuscript, Sunnybrook Health Science Centre, North York, Ontario, Canada.
- Fletcher, A., McLoone, P., & Bulpitt, C. (1988). Quality of life on angina therapy: A randomized controlled trial of transdermal glyceryl trinitrate against placebo. The Lancet, *2*, 4-8.
- Gamlin, R., & Kinghorn, S. (1995). Using hope to cope with loss and grief. Nursing Standard, *9*(48), 33-35.
- Glasziou, P.P., Bromwich, S., & Simes, R.J. (1994). Quality of life six months after myocardial infarction treated with thrombolytic therapy. The Medical Journal of Australia, *161*, 532-536.
- Gorkin, L., Norvell, N.K., Rosen, R.C., Charles, E., Shumaker, S.A., McIntyre, K.M., Capone, R.J., Kostis, J., Niaura, R., Woods, P., Hosking, J., Garces, C., Handberg, E., Ahern, D.K., & Follick, J. (1993). Assessment of quality of life as observed from the baseline data of the studies of left ventricular dysfunction (SOLVD) trial quality-of-life substudy. American Journal of Cardiology, *71*, 1069-1073.
- Gortner, S. (1993). Nursing's syntax revisited: A critique of philosophies said to influence nursing theories. International Journal of Nursing Studies, *6*, 477-488.
- Grady, K.L., Jalowiec, A., Grusk, B.B., White-Williams, C., & Robinson, J.A. (1992). Symptom distress in cardiac transplant candidates. Heart & Lung, *21*, 434-439.

Grady, K.L., Jalowiec, A., White-Williams, C., Pifarre, R., Kirklin, J.K., Bourge, R.C., & Costanzo, M.R. (1995). Predictors of quality of life in patients with advanced heart failure awaiting transplantation. Journal of Heart and Lung Transplantation, 14, 2-10.

Hainsworth, M.A. (1994). Living with multiple sclerosis: the experience of chronic sorrow. Journal of Neuroscience Nursing, 26, 237-240.

Hainsworth, M.A. (1995). Helping spouses with chronic sorrow related to multiple sclerosis. Journal of Gerontological Nursing, 21(7), 29-33.

Hainsworth, M.A., Eakes, G.G., & Burke, M.L. (1994). Coping with chronic sorrow. Issues in Mental Health Nursing, 15, 59-66.

Hall, B.A. (1990). The struggle of the diagnosed terminally ill person to maintain hope. Nursing Science Quarterly, 3, 177-184.

Hall, B.A. (1994). Ways of maintaining hope in HIV disease. Research in Nursing and Health, 17, 283-293.

Hamilton, J. (1989). Comfort and the hospitalized chronically ill. Journal of Gerontological Nursing, 15(4), 28-33.

Harlan, W.R., Sandler, S.A., Lee, K.L., Lam, L.C., & Mark, D.B. (1995). Importance of baseline functional and socioeconomic factors for participation in cardiac rehabilitation. American Journal of Cardiology, 76, 36-39.

Herth, K. (1989). The relationship between level of hope and level of coping response and other variables in patients with cancer. Oncology Nursing Forum, 16(1), 67-72.

Herth, K. (1990). Fostering hope in terminally-ill people. Journal of Advanced Nursing, 15, 1250-1259.

- Hillers, T.K., Guyatt, G.H., Oldridge, N., Crowe, J., Willan, A., Griffith, L., & Feeny, D. (1994). Quality of life after myocardial infarction. Journal of Clinical Epidemiology, *47*, 1287-1296.
- Hinds, P.S. (1988). Adolescent hopefulness in illness and health. Advances in Nursing Science, *10*(3), 79-88.
- Hixon, M. (1992). Perceived quality of life before & after percutaneous balloon valvuloplasty. Heart & Lung, *21*, 290.
- Hlatky, M.A., Charles, E.D., Nobrega, F., Gelman, K., Johnstone, I., Melvin, J., Ryan, T., Wiens, R., Pitt, B., Reeder, G., Smith, H., Whitlow, P., Zorn, G., Frid, D.J., & Mark, D.B. (1995). Initial functional and economic status of patients with multivessel coronary artery disease randomized in the bypass angioplasty revascularization investigation (BARI). American Journal of Cardiology, *75*, 34C-41C.
- Hollenberg, N.K., Testa, M., & Williams, G.H. (1991). Quality of life as a therapeutic end-point. Drug Safety, *6*, 83-93.
- Holmes, C.A. (1989). Health care and the quality of life: A review. Journal of Advanced Nursing, *14*, 833-839.
- Jenny, J., & Logan, J. (1996). Caring and comfort metaphors used by patients in critical care. IMAGE: Journal of Nursing Scholarship, *28*, 349-352.
- Kay, G.N., Bubien, R.S., Epstein, A.E., & Plumb, V.J. (1988). Effect of catheter ablation of the atrioventricular junction on quality of life and exercise tolerance in paroxysmal atrial fibrillation. American Journal of Cardiology, *62*, 741-744.
- Kennedy, G.T. (1991). A nursing investigation of comfort and comforting care of the acutely ill patient. Unpublished doctoral dissertation, The University of Texas at Austin.

- Kim, T. (1989). Hope as a mode of coping in amyotrophic lateral sclerosis. Journal of Neuroscience Nursing, 21, 342-347.
- Kinney, M.R. (1995). Quality of life research: Rigor or rigor mortis. Cardiovascular Nursing, 31, 25-28.
- Kinney, M.R., Burfitt, S.N., Stullenbarger, E., Rees, B., & DeBolt, M.R. (1996). Quality of life in cardiac patient research: A meta-analysis. Nursing Research, 45, 173-180.
- Kockelmans, J.J. (1985). Heidegger and science. Washington, DC: Center for Advanced Research in Phenomenology & University Press of America.
- Kolcaba, K.Y. (1994). A theory of holistic comfort for nursing. Journal of Advanced Nursing, 19, 1178-1184.
- Kolcaba, K.Y. (1995). The art of comfort care. IMAGE: The Journal of Nursing Scholarship, 27, 287-289.
- Kolodny, V. (1996). Quality of life: Advancing practice through research. Unpublished manuscript, Sunnybrook Health Science Centre, North York, Ontario, Canada.
- Kornfeld, D.S., Heller, S.S., Frank, K.A., Wilson, S.N., & Malm, J.R. (1982). Psychological and behavioral responses after coronary artery bypass surgery. Circulation, 66(suppl. III), III24-III28.
- Kubo, S.H., Gollub, S., Bourge, R., Rahko, P., Cobb, F., Jessup, M., Brozena, S., Brodsky, M., Kirlin, P., Shanes, J., Konstam, M., Gradman, A., Morledge, J., Cinquegrani, M., Singh, S., LeJemtel, T., Nicklas, J., Troha, J., & Cohn, J.N. (1992). Beneficial effects of pimobendan on exercise tolerance and quality of life in patients with heart failure. Circulation, 85, 942-949.
- Kummel, H.C., VanLeeuwen, P., Heckman, C., Engelke, P., Kesting, G., Kremer, H., & Becher, A. (1993). Quality of life and circadian variation of heart rate and heart rate variability in

short-term survivors and nonsurvivors after acute myocardial infarction. Clinical Cardiology, 16, 776-782.

Lau, C., Tai, Y., & Lee, P.W.H. (1995). The effects of radiofrequency ablation versus medical therapy on the quality-of-life and exercise capacity in patients with accessory pathway-mediated supraventricular tachycardia: A treatment comparison study. Pacing and Clinical Electrophysiology, 18(3 pt.1), 424-432.

Lim, L.L-Y., Valenti, L.A., Knapp, J.C., Dobson, A.J., Plotnikoff, R., Higginbotham, N., & Heller, R.F. (1993). A self-administered quality-of-life questionnaire after acute myocardial infarction. Journal of Clinical Epidemiology, 46, 1249-1256.

Linde, C., Gadler, F., Edner, M., Nordlander, R., Rosenqvist, M., & Ryden, L. (1995). Results of atrioventricular synchronous pacing with optimized delay in patients with severe congestive heart failure. American Journal of Cardiology, 75, 919-923.

Linde-Edelstam, C., Nordlander, R., Uden, A., Orth-Gomer, K., & Ryden, L. (1992). Quality of life in patients treated with atrioventricular synchronous pacing compared to rate modulated ventricular pacing: A long-term, double-blind, crossover study. Pacing and Clinical Electrophysiology, 15(10 pt 1), 1467-1476.

Lindgren, C.L., Burke, M.L., Hainsworth, M.A., & Eakes, G.G. (1992). Chronic sorrow: A lifespan concept. Scholarly Inquiry for Nursing Practice, 6, 27-40.

Mark, D.B., Naylor, D., Hlatky, M.A., Califf, R.M., Topol, E.J., Granger, C.B., Knight, J.D., Nelson, C.L., Lee, K.L., Clapp-Channing, N.E., Sutherland, W., Pilote, L., & Armstrong, P.W. (1994). Use of medical resources and quality of life after myocardial infarction in Canada and the United States. New England Journal of Medicine, 331, 1130-1135.

Martocchio, B.C. (1985). Grief and bereavement: Healing through hurt. Nursing Clinics of North America, 20, 327-341.

- Mathur, V.S., Guinn, G.A., Anastassiades, L.C., Chahine, R.A., Korompai, F.L.,
Montero, A.C., & Luchi, R.J. (1975). Surgical treatment for stable angina pectoris. The New England Journal of Medicine, 292, 709-713.
- May, C.D., Smith, P.R., Murdock, C.J., & Davis, M.J. (1995). The impact of the implantable cardioverter defibrillator on quality-of-life. Pacing and Clinical Electrophysiology, 18, 1411-1418.
- Mayou, R., Blackwood, R., Bryant, B., & Garnham, J. (1991). Cardiac failure: Symptoms and functional status. Journal of Psychosomatic Research, 35, 399-407.
- Mayou, R., & Bryant, B. (1987). Quality of life after coronary artery surgery. Quarterly Journal of Medicine, 62, 239-248.
- Mayou, R., Sleight, P., MacMahon, D., & Florencio, M.J. (1981). Early rehabilitation after myocardial infarction. The Lancet, 2, 1399-1402.
- Michael, S.R. (1996). Integrating chronic illness into one's life: A phenomenological inquiry. Journal of Holistic Nursing, 14, 251-267.
- Mickley, H., Peterson, J., & Nielsen, B.L. (1989). Subjective consequences of permanent pacemaker therapy in patients under the age of retirement. Pacing and Clinical Electrophysiology, 12, 401-405.
- Miller, J.S. (1978). The healing power of grief. New York: Seabury Press.
- Miranda, D.R. (1994). Quality of life after cardiopulmonary resuscitation. Chest, 106, 524-530.
- Mitchell, G.J. (1990). The lived experience of taking life day-by-day in later life: Research guided by Parse's emergent method. Nursing Science Quarterly, 3, 29-36.

Mitchell, G.J. (1992). Exploring the paradoxical experience of restriction-freedom in later life: Parse's theory-guided research. Unpublished doctoral dissertation, University of South Carolina.

Mitchell, G.J. (1994). The meaning of being a senior: Phenomenological research and interpretation with Parse's theory of nursing. Nursing Science Quarterly, 7, 70-79.

Mitchell, G.J. (1996). Quality of life for persons with diabetes. Unpublished manuscript, Sunnybrook Health Science Centre, North York, Ontario, Canada.

Mitchell, G.J., Carson, G., Fisher, A., Kolodny, V., & Vander Laan, R. (1994). Quality of life: Exploring the client's perspective. Unpublished manuscript, Sunnybrook Health Science Centre, Toronto, Ontario, Canada.

Mitchell, G.J., & Cody, W.K. (1993). The role of theory in qualitative research. Nursing Science Quarterly, 6, 170-178.

Mitchell, G.J., & Jonas-Simpson, CM (1995). Quality of life: Exploring the client's perspective. Unpublished manuscript, The Queen Elizabeth Hospital, Toronto, Canada.

Moore, J.R., & Gilbert, D.A. (1995). Elderly residents. Perceptions of nurses' comforting touch. Journal of Gerontological Nursing, 21(1), 6-13.

Morin, S.M., & Welsh, L.A. (1996). Adolescents' perceptions and experiences of death and grieving. Adolescence, 31, 585-595.

Muirhead, J., Meyerowitz, B.E.M., Leedham, B., Eastburn, T.E., Merrill, W.H., & Frist, W.H. (1992). Quality of life and coping in patients awaiting heart transplantation. Journal of Heart and Lung Transplantation, 11, 265-272.

Nissinen, A., Wiklund, I., Lahti, T., Akkila, J., Wilson, A., Wahl, M., & Puska, P. (1991). Anti-anginal therapy and quality of life. Journal of Clinical Epidemiology, 44, 989-997.

- O'Malley, P.A., & Menke, E. (1988). Relationship of hope and stress after myocardial infarction. Heart and Lung, 2, 75-88.
- Page, S.A., Verhoff, M.J., & Emes, C.G. (1995). Quality of life, bypass surgery and the elderly. Canadian Journal of Cardiology, 11, 777-782.
- Parse, R.R. (1981). Man-living-health: A theory of nursing. New York: Wiley.
- Parse, R.R. (1987). Nursing science: Major paradigms, theories, and critiques. Philadelphia: Saunders.
- Parse, R.R. (1990a). Health: A personal commitment. Nursing Science Quarterly, 3, 136-140.
- Parse, R.R. (1990b). Parse's research methodology with an illustration of the lived experience of hope. Nursing Science Quarterly, 3, 9-17.
- Parse, R.R. (1992). Human becoming: Parse's theory of nursing. Nursing Science Quarterly, 5, 35-42.
- Parse, R.R. (1994). Quality of life: Sciencing and living the art of human becoming. Nursing Science Quarterly, 7, 16-21.
- Parse, R.R. (Ed.) (1995). Illuminations: The human becoming theory in practice and research. New York: National League for Nursing.
- Parse, R.R. (1996a). The human becoming theory: Challenges in practice and research. Nursing Science Quarterly, 9, 55-60.
- Parse, R.R. (1996b). Quality of life for persons living with Alzheimer's disease: The human becoming perspective. Nursing Science Quarterly, 9, 126-133.
- Parse, R.R. (1997). The human becoming theory: The was, is, and will be. Nursing Science Quarterly, 10, 32-38.

- Parse, R.R., Coyne, A.B., & Smith, M.J. (1985). Nursing research: Qualitative methods. Bowie, MD: Brady.
- Peduzzi, P., Hultgren, H., Thomsen, J., & Detre, K., (1987). Ten-year effect of medical and surgical therapy on quality of life: Veterans administration cooperative study of coronary artery surgery. American Journal of Cardiology, *59*, 1017-1023.
- Permanyer-Miralda, G., Alonso, J., Anto, J.M., Aljarde-Guimera, M., & Scler-Soler, J. (1991). Comparison of perceived health status and conventional functional evaluation in stable patients with coronary artery disease. Journal of Clinical Epidemiology, *44*, 779-786.
- Pilkington, F.B. (1993). The lived experience of grieving the loss of an important other. Nursing Science Quarterly, *6*, 130-139.
- Pilkington, F.B. (1997a). Persisting while wanting to change: Research guided by Parse's theory. Unpublished doctoral dissertation, Loyola University Chicago.
- Pilkington, F.B. (1997b). The lived experience of hope: A review of the literature. Unpublished manuscript, Sunnybrook Health Science Centre, North York, Ontario, Canada.
- Pilkington, F.B., & Jonas-Simpson, C. (1996). The human becoming theory. A manual for the teaching-learning process. International Consortium of Parse Scholars.
- Pilote, L., Bourassa, M.G., Bacon, C., Bost, J., Detre, K., Mark, D.B., Pitt, B., Reeder, G., Rogers, W.J., & Ryan, T. (1995). Better functional status in American than Canadian patients with heart disease: an effect of medical care? Journal of the American College of Cardiology, *26*, 1115-1120.
- Pound, P., Bury, M., Gompertz, P., & Ebrahim, S. (1995). Stroke patients' views on their admission to hospital. British Medical Journal, *311*(6696), 18-22.
- Proctor, A., Morse, J.M., & Khonsari, E.S. (1996). Sounds of comfort in the trauma center: How nurses talk to patients in pain. Social Science & Medicine, *42*, 1669-1680.

Rector, T.S., Johnson, G., Dunkman, B., Daniels, G., Farrell, L., Henrick, A., Smith, B., & Cohn, J.N. (1993). Evaluation by patients with heart failure of the effects of enalapril compared with hydralazine plus isosorbide dinitrate on quality of life. Circulation, 87(suppl. VI), VI71-VI77.

Rogers, W.J., Johnstone, D.E., Yusuf, S., Weiner, D.H., Ahn, S., Schron, E., Shumaker, S.A., & Sheffield, T. (1994). Quality of life among 5,025 patients with left ventricular dysfunction randomized between placebo and enalapril: The studies of left ventricular dysfunction. Journal of the American College of Cardiology, 23, 393-400.

Ross, L. (1995). The spiritual dimension: It's importance to patients' health, well-being, and quality of life and its implications for nursing practice. International Journal of Nursing Studies, 32, 457-468.

Rudestam, K.E., & Newton, R.R. (1992). Surviving your dissertation: A comprehensive guide to content and process. Newbury Park, CA: Sage Publications.

Rukholm, E., & McGirr, M. (1994). A quality-of-life index for clients with ischemic heart disease: Establishing reliability and validity. Rehabilitation Nursing, 19(1), 12-16.

Rusteon, T. (1995). Hope and quality of life, two central issues for cancer patients: A theoretical analysis. Cancer Nursing, 18, 355-361.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. Advances in Nursing Science, 16(2), 1-8.

Sandelowski, M. (1995). Sample size in qualitative research. Research in Nursing & Health, 18, 179-183.

Searle, C., & Jeffrey, J. (1994). Uncertainty and quality of life of adults hospitalized with life-threatening ventricular arrhythmias. Canadian Journal of Cardiovascular Nursing, 5(3), 15-22.

Schneider, J. (1984). Stress, loss, and grief. Baltimore: University Park Press.

Spertus, J.A., Winder, J.A., Dewhurst, T.A., Deyo, R.A., & Fihn, S.D. (1994).

Monitoring the quality of life in patients with coronary artery disease. American Journal of Cardiology, *74*, 1240-1244.

Stanley, A.T. (1978). The lived experience of hope: The isolation of discreet descriptive elements common to the experience of hope in healthy young adults. Dissertation Abstracts International, *39*(3), 1212(B). (University Microfilms No. AAG7816899)

Strauss, W.E., Fortin, T., Hartigan, P., Folland, E.D., & Parisi, A.F. (1995). A comparison of quality of life scores in patients with angina pectoris after angioplasty compared with after medical therapy: Outcomes of a randomized clinical trial. Circulation, *92*, 1710-1719.

Taylor, B.J. (1992). Relieving pain through ordinariness in nursing: A phenomenologic account of a comforting nurse-patient encounter. Advances in Nursing Science, *15*, 33-43.

Visser, M.C., Fletcher, A.E., Parr, G., Simpson, A., & Bulpitt, C.J. (1994). A comparison of three quality of life instruments in subjects with angina pectoris: The Sickness Impact Profile, the Nottingham Health Profile, and the Quality of Well Being Scale. Journal of Clinical Epidemiology, *47*, 157-163.

Walden, J.A., Stevenson, L.W., Dracup, K., Hook, J.F., Moser, D.K., Hamilton, M., & Fonarow, G.C. (1994). Extended comparison of quality of life between stable heart failure patients and heart transplant recipients. Journal of Heart and Lung Transplantation, *13*, 1109-1118.

Walden, J.A., Stevenson, L.W., Dracup, K., Wilmarth, J., Kobashigawa, J., & Moriguchi, J. (1989). Heart transplantation may not improve quality of life for patients with stable heart failure. Heart Lung, *18*, 497-506.

Waller, D.G. (1991). Effect of drug treatment on quality of life in mild to moderate heart failure. Drug Safety, 6, 241-246.

Wallwork, J., Potter, B., & Caves, P.K. (1978). Return to work after coronary artery surgery for angina. British Medical Journal, 2, 1680-1681.

Walters, A.J. (1994). An interpretive study of the clinical practice of critical care nurses. Contemporary Nurse, 3(1) 21-25.

Walters, M.L. (1994). Chronic sorrow in multiple sclerosis: A case study. Home Healthcare Nurse, 12, 57.

Wang, C.E.H. (1997). Mending a torn fishnet: Parse's theory-guided research on the lived experience of hope. Unpublished doctoral dissertation, Loyola University Chicago.

Weinstein, M.C., & Stason, W.B. (1982). Cost-effectiveness of coronary artery bypass surgery. Circulation, 66(suppl. III), III56-III66.

Wenger, N.K. (1992). Quality of life in chronic cardiovascular illness. Annals of the Academy of Medicine Singapore, 21, 137-140.

Westaby, S., Sapsford, R.N., & Bentall, H.H. (1979). Return to work after surgery for coronary artery disease. British Medical Journal, 2, 1028-1031.

APPENDIX A

Letter of Approval from the Research Ethics Board of Sunnybrook Health Science Centre

MEMORANDUM

Research Ethics Board
 Room S-133, S-Wing
 Reichmann Res Bldg.
 Tel: (416) 480-4276
 Fax: (416) 480-5814

TO: Debra Bourmes
 c/o Gail Mitchell RN, PhD
 Nursing Central Services
 D-404A/B

FROM: Philip Hébert MD.

DATE: August 22, 1996

SUBJECT: Quality of Life for Persons Living With Congestive Heart Failure

Project Identification No: 191-1996
 Approval Date: August 22, 1996

The Research Ethics Board of Sunnybrook Health Science Centre has reviewed the research protocol referenced above on the above captioned date and approved the involvement of human subjects as specified in the protocol. A copy of the approved Information Sheet and Consent Form are attached.

The quorum for approval did not include any member associated with this project.

Should your study continue for more than one year, you must request a renewal on or before one year from the date of this letter. Please advise the Board of the progress of your research annually and/or any adverse reactions or deviations which may occur in the future. The above Project Identification Number has been assigned to your project. Please use this number in any future correspondence.

Yours sincerely,

A handwritten signature in black ink, appearing to be "PH", written over a horizontal line.

Philip Hébert MD., PhD., CCFP(C).
 Chair, Research Ethics Board

2075 Bayview Avenue PH:js
 North York, Ontario
 Canada M4N 3M5

University
 of Toronto

APPENDIX B

Informed Consent & Information Sheet

Quality of Life: The Client's Perspective

Some nurses at Sunnybrook are conducting research that looks at the way different groups of people describe quality of life. Patients who participate in the research and/or their substitute decision-maker will be given a verbal explanation of the study and a copy of this consent form.

The purpose of the research is to help nurses and other health care professionals learn about and understand the patient's perspective and to improve the quality of care by meeting and exceeding patient expectations. The knowledge generated by the research may help health professionals to be more aware of patients' experiences and needs.

The research is being conducted under the direction of Gail Mitchell, RN; PhD, Chief Nursing Officer.

Questions about the project will be answered to your satisfaction.

Participation requires talking with _____ (name of nurse researcher) on tape about the experience of quality of life for approximately one hour. The researcher may return to ask a clarifying question(s) at a later date.

You may withdraw from the study at any time without any effect on care.

A tape recorder will be used during the interview and the tape will be destroyed once the project is completed.

No names will appear on the written transcriptions, reports, or published papers.

There are no specific risks related to participating in the study. The degree of risk is about the same as having a discussion with a nurse about what you are thinking and/or feeling. Direct benefit may be experienced from having the opportunity to express personal thoughts in the presence of an attentive listener. Indirect benefit is anticipated for other patients who receive care that is more sensitive to their needs and wants.

You are free not to answer any question(s) in order to protect privacy. Should fatigue or discomfort develop in the interview, you may stop and either ask for a new appointment or cease participating.

Informed Consent and Explanation Sheet, Page 2

Gail Mitchell can be reached at extension 2778 at any time if questions or concerns come up.

Having read the above information about the proposed research, I agree to participate and offer my signature as consent.

Signature

Date

Having read/or listened to the above information about the proposed research, I agree to participate and offer my verbal consent.

Person Receiving Verbal Consent

Date

APPENDIX C

Information Sheet

Title of Research Program:

Quality of Life: The Client's Perspective

Principle Investigator:

Gail J. Mitchell, RN; PhD, Chief Nursing Officer

Co-Investigators:

Debra Bourmes, RN; BScN; MSc(c); Gail Carson, RN; MScN; Anne Fisher, RN; MScN; Vita Kolodny, RN; MSc(A), & Rika Vander Laan, RN; MScN

Explanation of the Research Program

Some nurses at Sunnybrook are conducting research that looks at the way different groups of people describe quality of life and related experiences like pain, dignity, feeling misunderstood, and incontinence. Patients who participate in the research and/or their substitute decision-maker will be given a copy of this information sheet and a copy of the consent form.

The purpose of the research is to help nurses and other health care professionals learn about and understand the patient's perspective and to improve the quality of care by meeting and exceeding patient expectations. Persons who agree to be in the research will be asked to meet with a nurse researcher for approximately an hour in order to talk about their experience. A tape recorder is required so that the nurse can study what is said. The researcher may return to ask a clarifying question about what was said during the first interview.

There are no known risks for participants and they may benefit from expressing their thoughts and feelings to a concerned and interested listener. Participants are free to speak only about what they wish to and they can stop involvement at any time without any effect on their care. At no time will participants be pressured to participate or to talk about things they do not want to discuss.

The discussions and tapes will be given a number and locked in the researcher's office. No names will appear on any data or paper. Only researchers involved in the analysis will have access to information. Tapes will be destroyed when the research project is complete.

A nurse researcher will be available to speak with any participant or family member who has questions or concerns about the research project.

APPENDIX D

Data to Support Theme One

Table D1: Core Ideas and Concepts in Theme One

Participant	Examples of Descriptions Given by Participants	Core idea(s)	Abstracted Concept
1	I had this congestive heart failure which sort of knocked me out.	Feeling knocked out	
2	Life's miserable. Miserable because I'm sick. I can't breathe and I choke to death and when those crises happen I am in great distress because I can't catch my breath and I have no oxygen at home... [It is] terrible, because I can't breathe.	Life miserable Distress	
	Sometimes I have no strength at home and I can't even do my breakfast and I eat little...	No strength	
3	Did you ever learn that, the ancient mariner? Well you think of that, it's true, it said: "My strength is failing fast said the seaman, the captain to his men..."	Strength failing	
4	I'm 84 years old - I don't want to have any operation again. So, I left the hospital on my own. And ...a few days later, I started to have the angina come back again... And I was here about 4 or 5 days, went home.. they sent me home, and I think a day or 2 days later I came back, because again, I had angina. And at that time the result was that I have.. they tried to monitor with the medication, and they said I have unstable angina. After 4 or 5 days again, I went home, and I had angina at home also, but using one or two sprays, it disappeared... but [then] again, I had to come to the hospital here. And again, they put me on heparin, and they tried to change the medication again - increase, and stop some kind of medication and replace it with this other. But a few days later, again, it happened; and I had to come back... I was happy that sometimes I didn't have angina pain; even a week might pass by without pain...	Living with pain	Diminishing Vitality
5	I have these dizzy spells and light-headedness, you know, and that. And I already fell once. Well, I've had two falls, really. But this last fall I just had last Friday, that's when I had 3 stitches in my head, and I lost quite a bit of blood. And I think that has a lot to do maybe with it, I don't know. Now, since I've fallen... I've found it very painful on my back. I had two.. Pinched nerves, one on each side. That's what's so painful. This is the second time this year I've fallen.	Feeling dizzy Lightheaded Living with pain Falling	

	I was doing up the dishes at a normal day; I could do dishes. Well, it got near the end that I was too tired to do them, and that, so I didn't do much	Tired	
6	Everything was fine 'til this breathing started, and I just couldn't go on... When I get up in the morning, it's terrible; I have to come down and get on oxygen, or I'm in trouble.	Can't go on Need oxygen to breathe	
7	Well, there isn't a quality of life that way... you're not living a good kind of life, because you have these attacks and shortness of breath, and so on, you know, so that it certainly isn't a good way to live.	No quality Not good way to live Short of breath	Diminishing Vitality
8	Now [I have a] lousy, daily routine. If I'm home, I get up, I walk around, I go back to sleep. If I'm in the hospital, that's the life you see [bedridden]. If I start... if I walk too much, I have swelling feet. And not even a medical force could release those things from my feet; I'm going like this for a year; something is extremely wrong...	Lousy daily routine Something extremely wrong Can't walk too much	
9	Being sick, being sick day after day... I remember when we were down south, I was told if I went, I had to walk. It's not my favourite pastime. But anyhow, I remember going out and walking around the beautiful circle, and half-sick, half-tired, miserable.	Feeling sick Feeling Miserable Half tired	
10	Well, I guess the one other thing, at my stage, is the inability to get around. Now, with this knee, it's been... I just couldn't get around. I couldn't climb the stairs without difficulty, and couldn't carry things like heavy loads and so on.	Can't get around Difficult to climb stairs	
11	I've had 2 heart attacks, apparently, which I was unaware of...[and] I've suffered from heart failure...	Suffering	
<hr/>			
1	Quality of life means doing what I would like to be able to do.... At the moment I'm not in that position. Haven't been for some little while.	Not able to do what used to	
2	It's like being in a, in a cage. I am being in a cage now. I am being in my cage. It's not a golden cage and I am not a parrot....the cage is something that I am locked in because I cannot go and take the bus. I cannot go and take the bus to go and take the metro, the subway.... It doesn't change me personally but my possibilities are changed drastically. Today it's completely different... but that's what makes the kind of life I used to like.	Living in a cage Possibilities changed Completely different	Loss
3	I like to go out in the stores, used to go...I used to go lots of places when I was, before I got like this... before I had this by-pass... I never go out the door hardly. I used to go to Europe and everything else you know...but now you	Not able to go places	

	can't go anywhere		
4	A lot of my friends were saying, "You are so busy," when they called me and invited me, because I'd say, "Well, for the next 2, 3 weeks, I'm busy; I'm invited.." and this and that. And everybody was saying that I manage my life very well. I didn't think about it, I didn't think about it. I thought this is how it will go all the time, but all of a sudden, ... you know.. I don't know what else to say.	Life changed suddenly	
	I realized that my heart is no good. So health-wise, I'm restricted.	Restricted by health	
5	I don't get out to go shopping. And I love to go shopping, but I can't go now; I can't go around the stores and walk around like I used to. It's not so nice when you have to get someone to do your shopping for you.	Not able to go places Not nice	
6	My whole life is changed... my dependency on other people. ... to breathe; that's why it's changed.	Life changed Dependent on others	Loss
	Sunday is dinner at... my place; I'm the cook...which I love, all that stuffs sort of gone down by the boards... That stuff's sort of down by the boards when I can't breathe, can't get enough air.	Things loved are gone	
7	It didn't seem any effort to get out the good silver and the good china, and all the rest of it, but it would now... You don't like it [not being able to do that], but I mean, if you're ill, you can't do those things...	Cannot do things because ill	
8	So, I have everything I could think of. Except the health went, I have nothing left.	Health went Nothing left	
	Life for me right now is no good. Life was great before, until 4 years ago... the times changed. I had a heart attack; I don't know what went wrong. I had a second heart attack; I don't know what went wrong.	Life changed	
9	If you have a good quality of life and you don't have health, what good is it, you know, if you can't do anything because you're ill or... Like I was to have gone away the end of March; well, I mean, there's no way I'm going anywhere.	Can't do anything Not going anywhere	
10	That aspect of your life seems to disappear... I guess I always had an inclination to try and be athletic, and keep in fairly good physical condition as much as possible. Then, all of a sudden, now I haven't got it anymore.	Life disappearing	
11	It was basically an eye-opening situation that I've suffered from heart failure which was, in fact, diagnosed previously as a chest infection. There's a slight difference between a chest infection and heart failure, so it was a shock to one's system... you figure that, well,	Suffering from heart failure a shock Not functioning	Loss

you've got a normal cold, and you've got a chest infection, and all of a sudden, a major artery of your body that's fairly important is not functioning quite the way it should be... just the fact of feeling that one could have been dead...

Could have died

Well, I was a smoker; I imagine I will no longer be a smoker. I'm slightly overweight; I imagine I will lose some weight. I'm slightly diabetic; I'm sure I'll be less diabetic. I'm slightly stressed; I'll be less stressed. So, it'll probably, for me, end up being a total lifestyle change.

Doing less
Total lifestyle change

Complete Set of Excerpts from Participants' Transcripts Which Support Theme One

Participant 1

Well, quality of life means doing what I would like to be able to do. Being able to do what I'd like to do. At the moment I'm not in that position. Haven't been for some little while. I like to travel. I like to play golf. I like to go up to our place in Collingwood, down to our place in Florida, and just generally move around you know.

Well I read a bit. I read the newspapers and I have a computer which I do some work with. And uh, I have a lovely balcony and if it's a nice day, I might sit out on the balcony. And uh, watch television of course. Eat three meals. Snooze a bit. And uh, generally lead, lead a very sedentary life, I'd say.

Until, I guess until March, it wasn't really too bad. I was able to play a little golf, and mind you it was last fall when I had the angina, I was delayed from going to Florida until January, and then when I came home in March I had this congestive heart failure which sort of knocked me out.

One of the problems we have is that we have a two story apartment. So I'm not sure about my ability to go up and down stairs or whether I should.

You can't give up everything of-course. No work and no play makes Jack a dull boy. Or all the rest, I should say! So... eat and sleep.... I'll have to resign my three golf clubs. Right? Uh, it wouldn't be the end of the world. I mean I really haven't enjoyed it that much feeling the way I do.

We play bridge. [My wife] plays lots; I play a bit. I used to play more. It's a little more difficult to concentrate [than] it used to be. I don't know. I don't know what causes that. Old age maybe?

You know, life is not all peaches and cream. Let's face it. This stage. I'm just wondering if it ever will be close to that...I'd love that [for life to be more peaches and cream]. Peaches and cream, we'd be going, flying down to Florida in the middle of October. Coming back for Christmas. Going back in January. Coming back in late April. We'd be going up to Collingwood next week for a week maybe. We have a place there also. And uh, playing a little golf. It doesn't have to be a lot, you know. Once a week maybe. Doing more work on my computer. Getting on the Internet. A little more socialising than we've been able to do.

Participant 2

Life's miserable. Miserable because I'm sick. I can't breathe and I choke to death and when those crises happen I am in great distress because I can't catch my breath and I have no oxygen at home... [It is] terrible, because I can't breathe. If I can't breathe I can't do anything, I can't do anything...not that I am a cripple but it's, it's crippled physically, not mentally...and there is nothing one can do.

There are possibilities in life when you have the means and when you don't have the means you cannot have a nurse and you cannot have somebody constantly. I do not have that. I have the

homecare lady who comes to, to give me my shower and I have a little bench in the tub and then we start the shower and she just bristles my back and then I let the shower come and she helps me get out so that, that is taken care of. But...it's not enough. Because sometimes I have no strength at home and I can't even do my breakfast and I eat little. I am not a great uh obsessed person with food, not at all. I can't live without eating but I am not living for eating, I'm eating for survival and not for choice. I used to like good food but uh it doesn't make any difference any more....

Having no strength...well this is terrible. How many things do you enjoy? ...You do not enjoy many things...

Right now I can't [go anywhere] because my cardiologist here he's against it. That wouldn't stop me if I felt well... [not being able to travel], it's like being in a, in a cage. I am being in a cage now. I am being in my cage. It's not a golden cage and I am not a parrot....the cage is something that I am locked in because I cannot go and take the bus. I cannot go and take the bus to go and take the metro, the subway. The taxi I can get. You have to go but it's frightfully expensive. I do not have the means, I am not the woman I used to be that way. It doesn't change me personally but my possibilities are changed drastically. So this is a little bit uncertain, of course when you cannot do things, when it was nice to take a big ship en route to Argentina or go to Manila by plane, I mean you know that was different. But today it's completely different. The health doesn't stop, it doesn't allow me, and the financial part doesn't allow me either. So I am locked up. I am not going to die from that because I've had my share of travel so I am not thinking about this but you ask me what makes the kind of life that I used to like.

I do not cook. Not because I am lazy, I am lazy (laughing)... I must admit, and I am not interested in cooking that much so the children want me to eat with them so I eat with them mostly...

I have dinner with the children. Either we go to a small restaurant or we have dinner in their house. They are very lovely people. They receive much better than I do. I don't receive at all... because I have no strength. Suppose I had four ladies to play bridge. I have to prepare tea, I have to prepare cookies, I have to, to do the dishes. This is, this is work for me that I cannot afford to do so don't do it. Maybe it's laziness of me and maybe it's just laziness and sparing of strength. It's a little mixed. I'm sure it's a mix because I'm not that mean. I'm not that good but I'm not that mean.

I like beautiful clothes, and when I was able I was making most of my own things and it was a enjoyable, fantastic thing because I could use my ideas and put them into shape and do them this was after I was able to go to the big couture houses in France. I never knew how to sew, not even a button because it was not in my education. We did, we are not taught how to do it as you are. But I learned in New York and I made everything except shoes.

Participant 3

I never go out the door hardly. I used to go to Europe and everything else you know...but now you can't go anywhere.

...like where I live the store is just further down the street, I just, it's an effort for me to go there...and, so now my son goes does my grocery shopping but...I like to go out in the stores, used to go...I used to go lots of places when I was, before I got like this, but, before I had this by-pass...

The first few years I was able to go out. But since I had this I go to the shopping mall and something like that but on the bus...because the bus stops right at my door. But [as] far as that I never, I go to the grocery store...

I've got lots of clothes and all I've ever wanted... summer slacks and skirts and things like that... never get dressed up any more... used to go to church and everything else...

I was supposed to go to a big wedding on Saturday... but when I got the invitation it says yes or no so I put no, unable for health reasons and I got an invitation to go a ,a Jack and Jill shower have you ever heard of them? But, you know where it was? It was in Burlington but it was nearer Hamilton at 7:30 on a Friday night. How am I supposed to get there? So I phoned the girl and said I couldn't come.

You know when you get older you, you get all kinds of little things wrong with you and it's it when you're getting old.....so look at my, look at me ,I never, you never saw me with my hair straight like that. I always used to go to the hairdressers.

I can recite Shakespeare and all and ... did you ever learn that, the ancient mariner? Well you think of that, it's true, it said: "My strength is failing fast said the seaman, the captain to his men.

I shall never sail the seas like a _____ again. So while, while yet a drop of blood is in my veins...I don't know what the next verse is but it means that put him on the boat and set fire to it and let it go out to the ocean that's all I can think of...just set fire to the boat and put his precious boat out to sea....I forget the rest of the words but I always remember that part... he said "my strength is failing fast" so at least while he was, got a drop of blood in his veins well, put him in the boat and let him go...

Participant 4

But there's no use in talking about it [being able to move into Baycrest Terrace], because.. maybe 2, 3 years, maybe. Well, if I would have thought about it 2 or 3 years ago, that at least to register, but 2, 3 years ago, even a lot of my friends were saying, "You are so busy," when they called me and invited me, because I'd say, "Well, for the next 2, 3 weeks, I'm busy; I'm invited.." and this and that. And everybody was saying that I manage my life very well. I didn't think about it, I didn't think about it. I thought it this is how it will go all the time, but all of a sudden, ... you know.. I don't know what else to say.

I'm 84 years old - I don't want to have any operation again. So, I left the hospital on my own. And ... a few days later, I started to have the angina come back again... And I was here about 4 or 5 days, went home.. they sent me home, and I think a day or 2 days later I came back, because again, I had angina. And at that time the result was that I have.. they tried to monitor with the medication, and they said I have unstable angina. After 4 or 5 days again, I went home, and I had angina at home also, but using one or two sprays, it disappeared... but [then], again, I had to come to the hospital here. And again, they put me on heparin, and they tried to change the

medication again - increase, and stop some kind of medication and replace it with this other. But a few days later, again, it happened; and I had to come back...

I was happy that sometimes I didn't have angina pain; even a week might pass by without pain. And I had limited activity; I played with my friends once or twice a week bridge, and it was all right.

I realised that my heart is not good. So health-wise, I'm restricted.

Participant 5

I have these dizzy spells and light-headedness, you know, and that. And I already fell once. Well, I've had two falls, really. But this last fall I just had last Friday, that's when I had 3 stitches in my head, and I lost quite a bit of blood. And I think that has a lot to do maybe with it, I don't know. Now, since I've fallen... I've found it very painful on my back. I had two.. Pinched nerves, one on each side. That's what's so painful. This is the second time this year I've fallen.

I haven't done without very much, but I've done without a few things I would have liked to have. Like I used to buy a lot of clothes; well now I don't buy that many clothes. And you miss that, you know. And I don't get out to go shopping. And I love to go shopping, but I can't go now; I can't go around the stores and walk around like I used to. It's not so nice when you have to get someone to do your shopping for you.

What do I do on a normal day at home? Well, not very much. I was doing up the dishes at a normal day; I could do dishes. Well, it got near the end that I was too tired to do them, and that, so I didn't do much. But I did bathe myself, and I did keep my part of the room tidy.

...they were going to have a little party for her, so I planned on wearing my new dress. But I didn't get wearing it [because I ended up in the hospital]; it was rather a disappointment.

Sometimes you do get disappointed in a little way, you know.

I used to go out with my girlfriends every day, after I retired. We used to go downtown shopping and around. I used to even go to court to find out things about the court; you know, see people's crimes and things but I haven't been able to go [out] much in the last 4 or 5 years.

Participant 6

[It's annoying] not being able to eat properly, act properly...

You have to stop and breathe, collect your breath. I use these [puffers] a lot, and I don't know what I'd do if it wasn't for those. Once I have oxygen I'm fine, but until I get oxygen I'm just... no use to anybody... you need it; you just need to breathe. And unless you've got it, you're in trouble. When you can't breathe, you ain't got much quality of life...

Sunday is dinner at the (name)'s, meaning my place; I'm the cook. And my wife.. we're divorced and she's remarried and living in the States, so I'm the chief cook and bottle washer, which I love, all that stuffs sort of gone down by the boards... That stuff's sort of down by the boards when I can't breathe, can't get enough air.

What life's like for you right now? Before or.. after I had the oxygen? It was good quality, very good, except I have trouble breathing, so I have to stop every now and then, and collect my breath. But other than that, it's...

I was a funeral director. I had my own business, so I sold it to my son, now that I'm retired. Everything was fine 'til this breathing started, and I just couldn't go on... I don't know what more to say.

When I get up in the morning, it's terrible; I have to come down and get on oxygen, or I'm in trouble. My whole life is changed... my dependency on other people, ... [on oxygen] to breathe; that's why it's changed.

Participant 7

Well, there isn't a quality of life that way... you're not living a good kind of life, because you have these attacks and shortness of breath, and so on, you know, so that it certainly isn't a good way to live.

Well, I'm living at the moment at Central Park Lodge, so I'm looked after pretty well. I have a companion, for which I pay, and she looks after bathing me, and bringing me my breakfast, and doing all the things that I need, you know; putting me to lie down and get rest, and so on. But when I was living in my house, before I went over there, it was quite a bit more difficult for me.

It didn't seem any effort to get out the good silver and the good china, and all the rest of it, but it would now... You don't like it [not being able to do that], but I mean, if you're ill, you can't do those things...

Most days my companion comes in the morning; she serves my breakfast and gets me bathed and dressed, and usually sitting in a comfortable chair to read the paper, and this sort of thing. Then I maybe rest before I go down for lunch, and maybe have a walk or a rest in the afternoon, and then go down for supper. And that's about the day.

Participant 8

So, I have everything I could think of. Except the health went, I have nothing left. Now [I have a] lousy, daily routine. If I'm home, I get up, I walk around, I go back to sleep. If I'm in the hospital, that's the life you see. If I start.. if I walk too much, I have swelling feet. And not even a medical force could release those things from my feet; I'm going like this for a year; something is extremely wrong, well, on this field.

Life for me right now is no good. When I come to this country in 1965, I was 19 years old; young man. I developed a philosophy that I learned back home: Work, save, and look after yourself, be honest, and take it from there. It was great, life was great before, until 4 years ago, things.. the times changed. I had a heart attack; I don't know what went wrong. I had a second heart attack; I don't know what went wrong. See so many, so many professionals, and one leads me one way, one leads me the other way, so I didn't take the guidance to get the right guidance.

Participant 9

I like to be on the go, and I guess.. I don't know if I could learn to slow down. I guess I could.

We came home from Florida because I was ill.

Health is so important. Yeah, if you have a good quality of life and you don't have health, what good is it, you know, if you can't do anything because you're ill or... Like I was to have gone away the end of March; well, I mean, there's no way I'm going anywhere. But it'll come, I'll go again. As I say, we love to travel. We have plans to go out west in June, it's my husband's army reunion. We go every year, so... I should be all right by then, yeah, yeah.

Being sick, being sick day after day... I remember when we were down south, I was told if I went, I had to walk. It's not my favourite pastime. But anyhow, I remember going out and walking around the beautiful circle, and half-sick, half-tired, miserable. And I kept saying, "I hate walking, I hate walking." But I did it because, you know, they said you had to walk. But I don't know if it did me any good; I don't think it did me any harm. But I did it. But I didn't enjoy it, no. Now take me to a mall, and I'm happy as a lamb. Oh yeah, I love to go shopping malls. But you still get, I still got very tired. We would choose days I felt good. Like I would say, "Gee, I feel in a very good state;" then we'd go and do what we wanted to do, you know. But then, there were days I just couldn't move. [On those days] I was usually throwing up, and it took every bit of will power even to walk. But I'd lie around and, as I say, I always went for my walk, because that was the promise.

I cooked dinner, I did the meals. But I'd get them all cooked, and stand there and look at them and say, "I'm not hungry, I'm not hungry." And my husband would say, "What's the matter with you?" And I'd stand there crying, "I'm sick, I'm sick." But oh yeah, I cooked all the meals. It's a lovely place we have, a beautiful spot, but I thought it would make me feel really well, hey. But I didn't, so we came home.

You can only do so much, and you get tired and you sit down, and then you go again. Like if I'm doing beans, I'll sit in the den with the saucepan in my lap to do them, to conserve energy at that point. Yeah. Oh, you can think of lots of ways to. I'm still cooking the meals; that's the hard part.

Participant 10

Well, I guess the one other thing, at my stage, is the inability to get around. Now, with this knee, it's been.. well, I guess I can't complain at my age; I shouldn't be out playing golf and... But I was able to play golf up until about 10 years ago, and then I had to stop because I couldn't walk the course and do the whole course. And it got to the point that it isn't much fun when the chaps you used to play with and had a good game with and, all of a sudden, you find they're still in the 90's and you're in the 110s, so... But that aspect of your life seems to disappear. And I guess I always had an inclination to try and be athletic, and keep in fairly good physical condition as much as possible. Then, all of a sudden, now I haven't got it anymore.

It's mainly because I just couldn't get around. I couldn't climb the stairs without difficulty, and couldn't carry things like heavy loads and so on. But the other thing which.. I enjoyed life very much when.. it would have been, I guess, 1970.. we bought an old farm house and remodelled it. The contractors did the work, but we did a lot of it ourselves. And it was the satisfaction of

putting an old farm house back together in good shape with all modern conveniences. And there was a certain degree of satisfaction of life in that. And then, this physical thing started to get to the point that I couldn't cut grass. Unfortunately, we have about 2 acres of grass and a 600' driveway which filled up with snow every winter, and you had to keep that clean in order to get in and out. So, that quality.. I had to give all that up. And yet, I enjoyed doing it, but that's... There's nothing really to take its place. We moved into the condo, so you don't.. no snow-shovelling and no grass-cutting and no this.. no more decoration or anything like that. I'm finding myself doing practically.. well, I say practically nil, outside of reading books and magazines. And I've got to the stage where I don't like watching television very much, so... I like reading, and I bought a new toy just before Xmas - a lap computer, which.. I'm having lots of fun with that. But that's just sort of temporary at the moment. I haven't found out how to use it properly yet. But I think it's coming, I think. And so that.. and I don't think I've.. I guess I should say that I do feel, occasionally.. that I'm bored.

My wife and I, we like music, and we've subscribed to the Toronto Symphony for years, but then we found that going all the way down to Toronto from Sharon was too much of a chore. We tried the evening performances, and that meant you didn't get home 'til midnight or later. So then we switched to the afternoon performances and found that was worse because you.. the concerts were over in the middle of the rush hour, so we gave that up.

Participant 11

I guess the whole thing has been a total eye-opener for me, as I've had 2 heart attacks, apparently, which I was unaware of... It was basically an eye-opening situation that I've suffered from heart failure which was, in fact, diagnosed previously as a chest infection. There's a slight

difference between a chest infection and heart failure, so it was a shock to one's system... you figure that, well, you've got a normal cold, and you've got a chest infection, and all of a sudden, a major artery of your body that's fairly important is not functioning quite the way it should be... just the fact of feeling that one could have been dead...

Well, I was a smoker; I imagine I will no longer be a smoker. I'm slightly overweight; I imagine I will lose some weight. I'm slightly diabetic; I'm sure I'll be less diabetic. I'm slightly stressed; I'll be less stressed. So, it'll probably, for me, end up being a total lifestyle change.

APPENDIX E

Data to Support Theme Two

Table E1: Core Ideas and Concepts in Theme Two

Participant	Examples of Descriptions Given by Participants	Core Idea(s)	Abstracted Concept
1	I suppose my wife is [most important to me]. Without her it [quality of life] wouldn't be very much... It wouldn't be very worthwhile. She takes great care of me... she is very important	Wife very important Wife makes life worthwhile	
	We're so close you know... They're all wonderful... We have four [children]... they improve it [quality of life], remarkably so. Well here, we've seen them everyday practically. They come to town. It's been over a month. That's pretty loyal...	Family close Family improve life Wonderful, loyal family	
	I'd love... [to do] a little more socialising than we've been able to do.	Wanting to do more socializing	
	We're [family] very close. If you've been here, you've seen quite a few of them. Can't really talk about it without breaking down... I don't know.	Can't talk about family without breaking down	communion- aleness; consoling-not consoling
2	I rather live like... not a recluse, but rather like a, in the shadow. I would not make many efforts to socialize.	Living in a shadow	
	My daughter and my granddaughter [are most important]. I am extremely proud of both of them. They are, they are gifted and very special...work very hard, my granddaughter... got a job that is very prestigious and is fabulous I am very happy...very, very...With my granddaughter...we are friends...	Friends with family Proud of family Very happy	
	I frighten my poor daughter. I can see in her eyes that she is frightened when she looks at me and I don't want her to be frightened... sometimes I put a little make-up...I guess she...she is frightened when she looks at me and I know exactly what she thinks. She thinks that I am letting go and I shouldn't let go	Frightens daughter Doesn't want to frighten daughter	
	My son-in-law...is absolutely destroying me, because he loves me but he criticizes me and we are like, like bulls with horns because he wants to change me but nobody can change me at my time it's very, it would be very difficult. It would be actually... no nobody can change me.	Family pushing for change is personally destroying Loving but critical	

		relationship	
3	Right now I don't know anybody very much...I used to go down to Montreal and see my friends, what few I have left of them... they're all popping off one by one...	Don't know anybody anymore Friends popping off	
	I've got nice neighbors when they're home. One woman, she works all day but she's very very nice she comes to see me on Sundays and she phones me every night so very nice person and when I was quite sick a few years ago... she was just like an angel of mercy to me, oh she's really, really good. Good people.	Nice neighbors Angel of mercy	
	My daughter is always talking about coming up here but she's been sick herself with cancer... she's got ovarian cancer, she was 61, she'd never been sick in her life, and just this spring and just, bothered me.... she was quite sick... it's, you never how did this happen? ..happen to you... You maybe think that will happen when they get older....I mean, never sick all her life...	Bothered by fact daughter quite sick	communion- aleness: consoling-not consoling
	I've got seven great grandchildren.. my daughter's children...they're married. They all married their kind of their childhood sweethearts... Do you know what I mean? ...my granddaughter got married about six or seven years ago...she had a little girl and then she just got another one recently. So that makes seven. Jackpot. So they're all quite comfortable... I'm glad for them, you know. They're doing well.	Glad family doing well	
	They [son's family] keep asking me to go out there... but I, I just didn't want to go. I just want to stay home because I when you don't feel well you don't feel comfortable in someone else's house so I don't go...So Thanksgiving they didn't ask me so ..because I turned them down so many times but that doesn't bother me...it didn't bother me because I'm, I'm...[crying]	Not comfortable visiting Family stopped asking to visit	
4	Unfortunately, I lost my wife, and since then, I live alone.. by myself. We didn't have any children... I am too much by myself, alone, and my mind is too much on certain things which.. for instance, about my illness...	Lost wife Lonely	
	I have a very good relationship with my sister-in-law who lives in Montreal. Since 3 days I am in the hospital being, she's called me at least 3 times, already; as I say, every day. And when I am at home, we talking on the telephone every week; I call her once every week, and she calls me also.	Very good relationship with family	
	The only relative what I have here in Toronto is a nephew...and his wife; they have 5 children. Even though they are busy, they was always there when I needed them,	Family there when needed	

especially my niece... They are like my...I consider them my children, and they consider me as their...

They know about my illness, and when I was invited, a few times I had to say, "I'm sorry, I couldn't go, because I don't feel well." And the result I was, my feeling was that 2 or 3 times they still did invite me, but after that they stopped, especially one or two or three of my friends, but I still have 5 or 6. I still have 3 very good friends who they are, they are caring about me. This is why, you asked that why I felt depressed. This is one reason, I found that, well they tried and now they are neglecting me.

Sorry to have less contact with friends
Depressed
Feeling neglected

- 5 I was a friend of a girl here for almost 70 years; she passed away 2 years ago; we never had a cross word in our lives, and that was something. And I was very friendly with all her family. They were all very good to me. But they're mostly gone now... It's funny how families go. Well, there's only two of us left in our family.

Friends and family mostly gone

I have the best nieces and nephews. The ones that look after us are the two you met today... So, my whole life.. like not counting when I fell; has been very pleasant so far. I've had a good life. I've gone out and enjoyed myself, and I had nice friends and nice acquaintances and everything...

Family the best
Family help
communion-
aleness:
consoling-not
consoling

- 6 [My quality of life is decreased because] they're [my friends] all concerned about me and my breathing... I can't talk normally to people I've known all my life. They're conscious of it to. Well, just that they're concerned, that's all...

Can't talk normally with friends
Friends concerned

Almost all my friends bring comfort to me. I'm close to them all. And [I see] each of them regularly, or used to.

Friends bring comfort

- 7 I'm always glad when my niece comes, cause she's been a big help to me... And my sister comes; that always helps... I think just having your family with you is a good thing, you know.... You're very thankful for the help of relatives and friends.

Glad for family
Thankful for help of family and friends

I've been married twice...the first time when I was young... We had a very, very good life together for 40 years. And then, he died of cancer. And my second husband... it was a good life; he was very, very good to me... and then in January of '96 he died... and I lived alone again for a while. With my first husband... we had 2 circles of friends, and we gave dinner parties; about once a month it'd be our turn, you know. There were 8 of us, and I guess they're all gone now except 2 of them...

Husbands died
Friends gone

I think if they [nurses] act as if they cared for you and they don't mind doing things for you, you know.. but when they let you wait and wait before they come, you

Nurses show they don't care when

	know...especially if you have to go to the bathroom, it's not much fun waiting.	they make patients wait	
8	I try to do it [comfort] for myself, since that the other people don't know how to do it. It takes a long time for someone to learn to give you comfort. If I have a relative that I say, "Do this for me," and if I see that relative does that for me in a nasty way, it's not comfort. It's done, but it's done the opposite way, so I don't know. I don't know at this point. Maybe when you get old, people don't want you around. You don't know...	Comfort-discomfort with others People don't want you	
	The days...that I was the most happy... was the days that I had a good time with my family, with my friends, and the days that we went on holidays and things together. These were the good life...	Re-remembering good times with family and friends	communion-aloneness: consoling-not consoling
	My family does everything for me. They come in every day, they do what I ask them, but things are done in such a way that I'm not happy...	Family does everything in a way that does not bring happiness	
	The minute you get sick every person wants to tell you what to do. You have no say into anything. There's nothing worse than when a man loses power completely. And if I can go home, meet my friends, they all have sayings for me. If I come to the hospital, I meet the staff, they all have sayings for me. My wife comes and visits me, and my children - they tell me what to do. So whatever I learn throughout life, it don't mean anything any more. And this is the big frustration of my sickness.	Feel powerless Have no say Frustrating to be told what to do	
9	My daughters are wonderful. My husband's very good. We have a very good life, we really do. I'm very grateful.	Wonderful relationships with family Family great Love to see family	
	They [grandsons] love to see us and we love to see them. Oh yeah, it's great. My little grandson said to me last week when I went home, "Have you got clothes on, Nanna?" Cause I guess he's only ever seen me in night-shirts. "Got clothes on?" But that's what it means to him. No, they're great...		
	It's just that the little one is.. I guess they're all the same, they demand attention. And now I can't give it to them; that makes it hard... I don't know if I'll ever be able to mind them again.	Hard when can't give attention to family	
10	The main difficulty now is that the number of your friends and people that you associated with get smaller and smaller every day. Even yesterday, a fellow I knew pretty well, he passed on in the K-wing here, you know. You just.. "Well, there's another one gone.." is sort of the attitude. That gets depressing a lot. You know, how long	Friends dying Another one gone Depressing	communion-aloneness: consoling-not consoling

does that keep going? Just as long as you do...

They're turning out to be a nice family. Well, I guess, basically, this might sound a little on the queer side, but I have sort of an inner satisfaction that you've done a good job. I think I've done a good job, I hope I've done a good job. And I feel, in one sense, that I've got a.. it's a very.. just the fact that they're.. what they are makes life better

Family make
life better

11 I don't really have a large family. I only have a wife; we don't have any kids. And I have a mother and a half-sister. And I guess, primarily, my wife, is very important to me, and I think she would prefer me to stick around for awhile, as opposed to burying me... I guess the pressure of what's happened to me has probably affected her more than me.

Wife
important
Worry about
pressure on
wife

Like.. most.. a lot of people are probably moderately jealous of my lifestyle, and the fact I work too hard for too long, but basically, my lifestyle is fairly.. people tend to be jealous of it..

Jealous
relationships

I have a lovely family. I'm very happy.

Lovely family
Happy

Complete Set of Excerpts from Participants' Transcripts Which Support Theme Two

Participant 1

Well I suppose my wife is [most important to me]. I'm really relatively unimportant when I think about it. My condition, Without her it [quality of life] wouldn't be very much. Really. It wouldn't be very worthwhile. She takes great care of me as you've seen I guess. So she is very important.

We're [family] very close. If you've been here, you've seen quite a few of them. Can't really talk about it without breaking down... I don't know.

Really. Well we're so close you know. They're all wonderful. We have four [children] as J. said: Jimmy, Judy, Jill and Janet. Jimmy has a lovely wife and two girls. Judy has a lovely husband and two boys. Jill, our number two daughter, has a lovely husband and two of her own children - one of her own and one half one - she's married the second time. One child with her present husband and he has

three of his, so they're a family of five children really. And they get along very well. Little Janet, who is our youngest. Not so little any more... they improve it [quality of life], remarkably so. Well here, we've seen them everyday practically. They come to town. It's been over a month. That's pretty loyal. One of our girls is coming today again to take J. to lunch or bring her lunch. Her husband is over in London at the moment, so that, she's spent a lot of time here in the last 10 days or so.

I'd love... [to do] a little more socialising than we've been able to do.

Participant 2

You do not enjoy many things...because I rather live like... not a recluse, but rather like a, in the shadow. I would not make many efforts to socialize.

[More] disciplined... That means getting up at a certain hour, having a more regular way of life, listen to my son-in-law who is absolutely destroying me, because he loves me but he criticizes me and we are like, like bulls with horns because he wants to change me but nobody can change me at my time it's very, it would be very difficult. It would be actually... no nobody can change me. I will try to be a little less negative. Because I've been negative lately. I mean I'm guilty. I mean I uh I don't mind saying so. Because not being in good shape you are you, you, you feel bad... I can't say that I don't care, it's not true, I do care....I do care a lot...

I look terrible. I've never looked that bad and I frighten my poor daughter. I can see in her eyes that she is frightened when she looks at me and I don't want her to be frightened... sometimes I put a little make-up to make, to make up, but... I guess she, she is frightened because she is frightened when she looks at me and I know exactly what she thinks. She thinks that I am letting

go and I shouldn't let go, I should really be more disciplined and I should do it for her because she has a very difficult job, a very, very responsible and she does it very well and she is under tremendous stress, so I should not add to my daughter's stress, I should not. So I am going to try to really, not change but do a little more disciplined thing. And eat a little more, because they, they are complaining that I don't eat...

My daughter and my granddaughter [are most important] I am extremely proud of both of them. They are, they are gifted and very special...work very hard, my granddaughter work like a dog after the... Today she got a job when I, I never got a job like that. She's got a job that is very prestigious and is fabulous I am very happy...very, very...With my granddaughter...we are friends, I have traveled with her when I could. I took her when she was 14 to a tour of Europe like my grandmother used to take me to a tour of Europe when I when I was 17. And we're great friends we are uh it's not a grandmother-granddaughter relation, not at all. It's a women's relation, friendly. Very friendly...

Participant 3

I guess there's worse people off than me....I have a nice apartment, and, comfortable the only thing is my family live out of town, my sister and my daughter and that live in Montreal, I used to live in Montreal but, anyway, but my daughter is always talking about coming up here but she's been sick herself with cancer... she's got ovarian cancer, she was 61, she'd never been sick in her life, and just this spring and just, bothered me.... she was quite sick... it's, you never how did this happen? ..happen to you... You maybe think that will happen when they get older....I mean, never sick all her life and then she takes that...but anyway, she's on the...she's getting better. She takes, she takes treatments but the treatments don't agree with her but for three days she, you

know but she's not great... She's talking about coming up but she's says her husband doesn't want to drive up to stay for a week. He'd rather just stay for two days . But I said what's the sense of you coming by train and he's coming by car? She said "well that..." Another thing she said is she can't lift the bag from the station, you know, all the steps and that . She's got...you know I've got seven great grandchildren.. my daughter's children...they're married. They all married their kind of their childhood sweethearts... Do you know what I mean? and the first daughter got married first and she had oh, anyway, she's got two children nine and the other one's six ..and then the other one got married this, the eldest son she 's only got one son and he's got three and they, my granddaughter got married about six or seven years ago, I'm not sure and she had a little girl and then she just got another one recently. So that makes seven. Jackpot. So they're all quite comfortable... I'm glad for them, you know. They're doing well.

My son lives in Whitby. He's doing well, he's got his beautiful home and he's got three, three children, a boy 20 and one 19 and a girl 17. So he's got a good job. He works for Canadian Tire....he's got a good job...They want me to, they keep asking me to go out there but, he says: "I'll come and get you" but I, I just didn't want to go. I just want to stay home because I when you don't feel well you don't feel comfortable in someone else's house so I don't go...So Thanksgiving they didn't ask me so ..because I turned them down so many times but that doesn't bother me...it didn't bother me because I'm, I'm...[was crying]

I've got nice neighbors when they're home. One woman, that's nice, she works, she works across the street and she comes from the same place as I do and, in England and all. In fact, this, this one that lives next door went to see China last Thursday night late she brought me to the hospital and she phoned at seven o'clock in the morning to see how I was and, but she's gone for

two weeks. But my other neighbor she works all day but she's very very nice she comes to see me on Sundays and she phones me every night so very nice person and when I was quite sick a few years ago it was on the other side, she was just like an angel of mercy to me, oh she's really really good. Good people.

Well, if you are healthy you could go places and enjoy yourself...go out with friends, and, but.....right now I don't know anybody very much....because I've been feeling...about fifteen years I guess. I used to go down to Montreal and see my friends, what few I have left of them... they're all popping off one by one.

My husband died a long time ago, 55, 55 years, not 55 he was 57 but.....I had a good husband but ... too bad... so I can't complain. I never run short of anything. You know what I mean. Never ...

I get up in the morning, have my breakfast and I have one of these radios by my bed with the earphones and sometimes I can't sleep in the middle of the night I just listen to the radio... yeah... but...it's just like having someone with you...

Participant 4

But I realised that being alone... I had only a few friends what I had there, but I didn't want to impose myself on my friends, and because I realise that I, I can't expect from my friends that I should disturb their holiday, and have them worrying about me and that what I'm doing. And when I realised that, I decided that I had to come back to Toronto.

I was happy that sometimes I didn't have angina pain; even a week might pass by without pain. And I had limited activity; I played with my friends once or twice a week bridge, and it was all right; I could get together with my friends. I don't know if I mentioned I live by myself, 1989 October of which, unfortunately, I lost my wife, and since then, I live alone.. by myself. We didn't have any children. And the only relative what I have here in Toronto is a nephew who is a chartered accountant, and his wife; they have 5 children. Even though they are busy, they was always there when I needed them, especially my niece, because my nephew has an office and he doesn't have much time and...

They are like my.. I consider them like my children, and they consider me as their... And I have a very good relationship with my sister-in-law who lives in Montreal. Since 3 days I am in the hospital being, she's called me at least 3 times, already; as I say, every day. And when I am at home, we talking on the telephone every week; I call her once every week, and she calls me also.

I had a very good marriage. ...very smart person, very intelligent, and very friendly. She was very friendly to everyone, and very, very helpful to everyone. I miss her very much...that's all.

Depressed because... well, I feel that I have very good friends - 5 or 6 couples. I didn't commit myself with a single person, woman person, because I did have friends when my wife was alive, and they invited me, and so I had company. And also, I didn't want to commit myself to anybody. I realised that I am not, even before I had unstable angina, I realised that my heart is not good. So health-wise, I'm restricted. And there are 2 or 3 ladies with whom I keep contact, but that didn't mean or doesn't mean that I'm going out with them to a movie or... Once or twice with

one or 2 or 3 of them, I went out for dinner or something, but otherwise, I have telephone contact with them every 3 or 4 weeks. They know about my illness, and when I was invited, a few times I had to say, "I'm sorry, I couldn't go, because I don't feel well." And the result I was, my feeling was that 2 or 3 times they still did invite me, but after that they stopped, especially one or two or three of my friends, but I still have 5 or 6. I still have 3 very good friends who they are, they are caring about me. This is why, you asked that why I felt depressed. This is one reason, I found that, well they tried and now they are neglecting me and the other reason was that I was depressed was because I know I'm 84 years old and, and I know that there is no such help that can.. surgery or something like that - I'm living on borrowed life. And, and sometimes it depresses me.

I am too much by myself, alone, and my mind is too much on certain things which.. for instance, about my illness...

And in the building there is two.. I wouldn't say my friends, although we lived there 20 years already in that apartment, but they are very nice. They are always either they are phoning or... Especially one who lives on the same floor; a couple, almost every day just drops in for a minute - how are you- to see that I am, to see that I'm...

Participant 5

I was a friend of a girl here for almost 70 years; she passed away 2 years ago; we never had a cross word in our lives, and that was something. And I was very friendly with all her family. They were all very good to me. But they're mostly gone now. She only has one brother left, that's all. It's funny how families go. Well, there's only two of us left in our family.

I have the best nieces and nephews. The ones that look after us [lives with her sister] are the two you met today. She comes from Florida and he from Mississauga.

So, my whole life.. like not counting when I fell; I went on about that.. has been very pleasant so far. I've had a good life, I've gone out and enjoyed myself, and I had nice friends and nice acquaintances and everything...

Participant 6

[My quality of life is decreased because] they're [my friends] all concerned about me and my breathing.

So, if I get this stuff [the oxygen] going all right, I can't talk normally to people I've known all my life. But they're conscious of it too. Well, just that they're concerned, that's all...

Almost all my friends bring comfort to me. I'm close to them all. And [I see] each of them regularly, or used to.

[What's most important in your life?] My family, I guess... and my home and my friends.

Participant 7

Well, I've been married twice. And the first time when I was young, of course, in my twenties, I had a wonderful wedding and everything. We had a very, very good life together for 40 years. And then, he died of cancer. And my second husband's a distant relation to my first husband. And

we knew all of the same people; it didn't seem strange or anything, so... And he had lost his wife a little earlier, so we married. And it was a good life; he was very, very good to me. And we travelled a lot, did most of the things we wanted to do, and then in January of '96 he died... and I lived alone again for a while. But I wasn't too well, so it wasn't as easy. I still have my house; I haven't sold it. I still have my car... With my first husband, we travelled, we played bridge, we had 2 circles of friends, and we gave dinner parties; about once a month it'd be our turn, you know. There were 8 of us, and I guess they're all gone now except 2 of them. But we had some awfully good times together.

I'm always glad when my niece comes, cause she's been a big help to me. She has my power of attorney, and she helps me with business and so on.... And my sister comes; that always helps... I think just having your family with you is a good thing, you know.... You're very thankful for the help of relatives and friends.

They've looked after me fairly well in hospital, I think. I seem to have had good nurses and good care, up until last night; there was one I didn't like... I think if they act as if they cared for you and they don't mind doing things for you, you know.. but when they let you wait and wait before they come, you know... especially if you have to go to the bathroom, it's not much fun waiting.

Participant 8

If you're on the top, that's fine; the minute you're in the bottom and you get sick, every person wants to tell you what to do. You have no say into anything.[It's] Very bad, very bad. There's nothing worse than when a man loses power completely. And if I can go home, meet my friends, they all have sayings for me. If I come to the hospital, I meet the staff, they all have

sayings for me. My wife comes and visits me, and my children - they tell me what to do. So whatever I learn throughout life, it don't mean anything any more. And this is the big frustration of my sickness. So I might come to a point, a week before the operation, not to listen to nobody except my professionals, not even the other doctors around here, just my surgeon and my cardiologist, but drastically hard, and I might make it, but I don't know.

I try to do it [comfort] for myself, since that the other people don't know how to do it. It takes a long time for someone to learn to give you comfort. If I have a relative that I say, "Do this for me," and if I see that relative does that for me in a nasty way, it's not comfort. It's done, but it's done the opposite way, so I don't know. I don't know at this point. Maybe when you get old, people don't want you around. You don't know...

And yet, my family does everything for me. They come in every day, they do what I ask them, but things are done in such a way that I'm not happy.

The days that I made a lot of money was not the days that I was the most happy. Never came to it. It was the days that I had a good time with my family, with my friends, and the days that we went on holidays and things together. These were the good life that today I look back and see it; I don't look back and see the days that I make big money on stocks, or big money on wages, or big decisions in the office and fire this person because they didn't please me. These are not the things that please me at all.

If something happens to your life, always make sure that you find professional that speak the truth. Here in this hospital, I've not been here that long. They don't have any professionals...

They have people that say something to pass the buck, to get things away from, you know...

That's not right, but that's the way life is. I have very much faith in my cardiologist, and I have much faith in my operator right now, but these are the things that... I just go on faith at this point. They could let me down or they can help me a great deal. And the other staff around, many of them... I don't want to mention names, but many of them are not the right persons. I like to be operated in this hospital because the closest one where I live it's the university; they have all the facilities for me, but sometimes when you work in a university, peoples go brainwashed and they think they know it all, and they forget the little points of the little patients... the little points of the little patients are feelings, and if you cannot please human feelings, you're not much of a doctor; regardless what you study, you still don't have it. You might know all the theory, but you don't achieve much.

See, just getting a little bit water alone, sometimes takes so much hassle, that you get so tired and out of breath before you could get something that they could make it easier for you guys before it started. Many times I ask for real simple glass of water, because my throat, you know, gets too dry; that's my problem. But the answer is no because it's by the rule, and then I have to explain. I explain things, and so on, and tell them that the responsibility is mine, until they let me have a little bit. So, wouldn't it be easier for me to get a little drop of water before I make myself that tired, you know? I have, in reality, 2 more weeks to live, or many years to go, but 2 weeks that's what I'm going to be operated... So with that in mind, in 2 weeks I can go either way, so, why not please someone in 2 weeks that could come or go? I have no, no clue of understanding how small a mind can be, without making certain exceptions, even when they have no idea. But that's human beings. Human beings are made, I guess, to disagree with one another. The very first thing people do, if I say this is cold, "Oh no, it's not," or this is hot, "Oh no, it's not." It's common

sense the very first thing that comes to their mind. And that's why we have wars all over the world; they say that little thing. Peoples don't agree with one another.

Participant 9

They [grandsons] love to see us and we love to see them. Oh yeah, it's great. My little grandson said to me last week when I went home, "Have you got clothes on, Nanna?" Cause I guess he's only ever seen me in night-shirts. "Got clothes on?" But that's what it means to him. No, they're great. They come and they more or less do what they want while they're at the house. It's just that the little one is.. I guess they're all the same, they demand attention. And now I can't give it to them; that makes it hard... I don't know if I'll ever be able to mind them again.

My daughters are wonderful. My husband's very good. We have a very good life, we really do. I'm very grateful.

Not a lot to do in a day around here, you know. I have some knitting and I have some reading. And of course, my husband, he's on his way in now. And then, my daughter pops up and down. She works here, so she pops up and down. And the day passes.

Participant 10

The main difficulty now is that the number of your friends and people that you associated with get smaller and smaller every day. Even yesterday, a fellow I knew pretty well, he passed on in the K-wing here, you know. You just.. "Well, there's another one gone.." is sort of the attitude. That gets depressing a lot. You know, how long does that keep going? Just as long as you do.

I've never felt life should be.. quality of life should be an isolated thing; it should be in conjunction with family, friends, and so on, because that's the major part of life, I think, is knowing people, and helping people, and being helped by people.

As you were saying about quality of family life, both our boys have turned out, I think.

Hopefully, I'm not boasting too much. But they have turned out exceptionally well. The lad who was here is now, lives in Keswick and practises in Newmarket. He's just given up being the chairman of the District Health Council for York region, and he's very much involved with the social service agencies up there. So we've trained him very well. Our older son... went through and became a nuclear physicist, and he's now in charge of what they call the radiation section at the National Research Council in Ottawa, so... And he's doing very well. I guess I feel rather proud that he's got to that position. And his wife happens also to be a nuclear physicist. And so, they both have responsible jobs, and are doing well, and they're bringing up a nice bunch of children. So now, I think I guess at my age, your family becomes important.

They're turning out to be a nice family. Well, I guess, basically, this might sound a little on the queer side, but I have sort of an inner satisfaction that you've done a good job. I think I've done a good job, I hope I've done a good job. But no, I feel sorry for some of these chaps whose children haven't grown up and are having problems, family problems. And I feel, in one sense, that I've got a.. it's a very.. just the fact that they're.. what they are makes life better; I don't have to worry about them too much. And we've now got a great grandson that's.. you begin to feel like a senior citizen.

Participant 11

I don't really have a large family. I only have a wife; we don't have any kids. And I have a mother and a half-sister. And I guess, primarily, my wife, is very important to me, and I think she would prefer me to stick around for awhile, as opposed to burying me. We're not looking for our next pay cheque or our next dollar, so I can fully retire now, which will happen. But I guess the pressure of what's happened to me has probably affected her more than me.

[Quality of life means] monetary independence, good friends, family, and I guess health has now sort of jumped to the forefront of life.

I guess just basically, my quality of life is 3 out of 4 is not bad, but the fourth is probably the most important. I have.. probably, a reason, but like.. most.. a lot of people are probably moderately jealous of my lifestyle, and the fact I work too hard for too long, but basically, my lifestyle is fairly.. people tend to be jealous of it. I do just about anything I want: I travel, I have more money than I probably need, and I come and go as I please, I'm my own boss, I have a lovely family, I'm very happy. That's about all.

APPENDIX F

Data to Support Theme Three

Table F1: Core Ideas and Concepts in Theme Three

Participant	Examples of Descriptions Given by Participants	Core Idea(s)	Abstracted Concept
1	I mean I would like it to be more peaches and cream. Like to be able to do more...So I'm hoping that things will improve somewhat when I get home.	Hope for improvement	
2	I might be in better shape, I hope. It's up to me. I have to be a little more disciplined...On the other hand, each time I come into this hospital or any, I specify, right away that I do not want any resuscitation or artificial prolongation of life. This I am completely against. I think it's a misery to do that to the people because most of the time they are not even aware, they are vegetables and it's terrible. For the people who stay and for the people themselves. So the quality, this quality of life I don't want. I want a decent...I don't want a luxury but I want a decent ... I hope that I am polite enough to take my leave without lengthening too much.	Hope to be in better shape Hope for how life will end	Desired anticipations
3	Well, he said "my strength is failing fast" so at least while he was, got a drop of blood in his veins well, put him in the boat and let him go. That's the best way... you think of all these hundreds of people in nursing homes. I hope I never have to go to one.	Hope to stay out of nursing home	
4	It is not the first time that the medication has been changed. Certainly, I agree to it, because every human being has a hope. And this is what I right now in this moment I hope.	Hope medication will work	
5	Either the money will run out or I'll run out. I hope I'll run out first... I think everybody feels more content if their pensions are large enough to bring them up, you know.	Hope finances hold out	
6	If I get over this, I'd be fine - which they say I can. Personally, I think if I co-operate with them I can. It's sure annoying as hell...	Hope to get over this	Desired anticipations
7	I'd like to go back to the kind of life I had, where I was driving the car, running my own house, and so on... Well, if I were better it would be, of course... [my] quality of life would improve.	Hope to go back to life as was	
8	I could die on the operation table. But that's one thing that I make up my mind - if I cannot live better than what I'm living right now, I may as well die. But I have faith in my cardiologist, in my operator, so let's see what	Hope to live better after operation Faith	

	they can do for me.		
9	We never stayed in the apartment unless it was a very bad day. All day we went somewhere. And I think that's what I miss the most. But maybe I'll be back out there very soon, you can't tell; get some weight back on and get on my feet. But I do love to go places. Just hope that I can do it again.	Hope to get back on feet	
10	One reason for my reluctance about coming home, is the fact that she's [his wife] getting on in years... and she's been doing this volunteer palliative care work... she likes doing it, I know she doesn't want to give it up, but she's been indicating that if I'm going to be home in this condition, maybe she'd better give it up. And I'm hoping that I get well enough that she doesn't have to get out of it.	Hoping to get well	
11	Hopefully, it'll get better, live a little healthier, and things will improve. And maybe it just took a hit over the head to change whatever I've got to.	Hope to get better	
<hr/>			
1	Well, I'm very fatalistic about the future... I mean it's, everybody only has so long. And I would think that I'm closer to the end than the beginning. Wouldn't you? I don't really worry about it too much except for my wife and family. And, you know, if it happens, it happens. I won't know about it, unless I have one of those awful congestive heart failure things again. But then I'll suspect it.	If it happens it happens	
2	So... what can I do? I can take it in my stride that's all. There is nothing I can do except not panic.	Can't do anything but take it in stride	
3	When you're going down there's no coming back, like with what I got so you just got to make the best of it... Well you just got to be, be... I don't know what to say... you've just got to be ...as I said, you've just got to make the best of it. You can't do anything else, you got to, you got to just take every day as it comes.	Making the best of it Take every day as it comes	Acceptance of what will be
4	I completely realise my situation. I know that it, I'm not a doctor, but I don't know, I know it [improvement with new medication] can't last too long... Until it lasts it lasts.	Improvement lasts until it lasts	
5	[Quality of life is] the way you look at it, in a way. You know what I mean? Its the way you... You try to make it as pleasant for yourself as possible... another thing - you have to be cheerful about things.	Have to be cheerful about things	
6	Quality of life is normal everyday life... which is good for me; I'm retired, and successful. So, you can't ask for any more than that.	Can't ask for any more	

7	Well, what would you expect at that age? You can't go on forever... Well, I don't think people, when they get up in their 80's, expect too much... I had such a good life before, with everything I wanted... It's just that your life changes so drastically when you've been very ill, you know, and so, you just go on day by day and do the best you can.	Going on day by day Do the best of you can Can't go on forever	
8	That's not right, but that's the way life is. I have very much faith in my cardiologist, and I have much faith in my operator right now, but these are the things that... I just go in faith at this point. They could let me down or they can help me a great deal.	It is the way life is Going on faith	
	You put all the eggs in one basket, and if they all break, you waste.	If your eggs break that's it	
9	Getting out of here and leading.. back to a life [is important]. Being able to go out to walk like a human being, you know. But I guess, if you can't do it, you can't do it...	If you can't do it you can't	Acceptance of what will be
10	I used to use an expression, particularly when we lived up in the farm house, that my choice in the morning is: Well, which job should I try and do today? And now I wake up in the morning and say: Well, what am I going to do today? - which is quite a difference, hey.	Plan each day when you wake up	
11	It'll happen just cause it'll happen. How do I feel about it? It doesn't bother me, cause it's always on the back of one's mind. I just happened to sort of have an eye-opener that sort of jumped into the forefront, where it's basically life and death. If I don't do it, I probably won't live another 10 years, so it's not a great situation to be in. But it's also something that one always thinks about.	It will happen because it will happen	

Complete Set of Excerpts from Participants' Transcripts Which Support Theme Three

Participant 1

This congestive heart failure which sort of knocked me out. And I've had it twice since and I'm not sure what, when I'll have it again. You know, or if. So it's a bit of a worry. You know, you can't help but think about it.

Well, I'm very fatalistic about the future... I mean it's, everybody only has so long. And I would think that I'm closer to the end than the beginning. Wouldn't you? I don't really worry about it too much except for my wife and family. And, you know, if it happens, it happens. I won't know about it, unless I have one of those awful congestive heart failure things again. But then I'll suspect it.

Well, I mean I would like it to be more peaches and cream. Like to be able to do more. Maybe I should try harder, I don't know. You know, with the - apparently my heart is, you know it's a tired one and so therefore I don't know what stressing it means, you know.

So I'm hoping that things will improve somewhat when I get home.

Participant 2

I think I told you that I've had a wonderful life. And a very active life. Very active. And I am now in the autumn in my days I'm on to the winter. I'm on to the winter. The winter is the end, the end of the cycle. I am not bothered by fright no, only that I, that I can't breathe. But by what happen, hell or purgatory and all that nothing at all.

The quality of life is that, if your brain works. I am lucky that from here to here (was pointing to body from neck up) I am OK. From here down it's all going to pieces. I am 87. It's not young. So...what can I do? I can take it in my stride that's all. There is nothing I can do except not panic. But it's very difficult to tell myself: "Don't Panic". I panic when I have the...short of breath and I, I can't breathe at all. It's terrible.

But I think people who have cancer and people who have multiple sclerosis, or Christopher Reeves of superman, all the things that happen to young people and I think that I should not be ungrateful that it didn't happen to me. It's not good what I have. I know that it's not going to get better. I might be able to stand it a little more. But when I cannot stand it there is nothing I can do. A miracle [would help me stand it]... but there are no miracles. You don't, you don't get out of a heart condition like mine.

If I was in good health it [quality of life] would improve considerably. But I know that this is not going to happen. Like a miracle. No. I might be in better shape, I hope. It's up to me. I have to be a little more disciplined.

Well it's like I am getting there, I am dying, that's all, and there is nothing I can do, I mean there is not an injection I can give myself. On the other hand, each time I come into this hospital or any, I specify, right away that I do not want any resuscitation or artificial prolongation of life. This I am completely against. I think it's a misery to do that to the people because most of the time they are not even aware, they are vegetables and it's terrible. For the people who stay and for the people themselves. So the quality, this quality of life I don't want. I want a decent...I don't want a luxury but I want a decent ...

I didn't know that I would end up in the hospital this week...

It's going to happen...just I wish that it would happen in my sleep but nobody knows...

I hope that I am polite enough to take my leave without lengthening too much.

Participant 3

Just to get well... perhaps that....you know when you get older you, you get all kinds of little things wrong with you and uh it's it when you're getting old.... you never know...

I never went anywhere like the movies or anything like that...you get used to it...

I get the albums out and look at them . I said ; "well, I've been there"... You have to look on the bright side...

I've got a picture taken of me when I was 72 and I keep looking at it and I say "my God I look good there." (laughing) I had a nice tan and I used to get my hair colored and everything else. It was beautiful... anyway, such is life, I guess there's worse people off than me....

... I get up in the morning at about 0900, have my breakfast, watch the , some show on the TV and about one o'clock I have my lunch....sometimes I do a washing about...once a week.. but, in the afternoon I lie down on the bed, what else can I do? You got to be in a good frame of mind that's all. Not get dep, I don't get depressed. I say that, I say "shake out of it". I don't get depressed, why get depressed, what's the difference? At my age you've got to make the best of it that's all. I mean look at these people in these nursing homes...

When you're going down there's no coming back, like with what I got so you just got to make the best of it... Well you just got to be, be... I don't know what to say... you've just got to be ...as I said, you've just got to make the best of it. You can't do anything else, you got to, you got to just take every day as it comes.

Well, he said "my strength is failing fast" so at least while he was, got a drop of blood in his veins well, put him in the boat and let him go. That's the best way... you think of all these hundreds of people in nursing homes. I hope I never have to go to one.

Participant 4

But when I didn't have the unstable angina since a year, I didn't have any such a feeling; I wasn't depressed. Everybody was saying that, how good I coped with the situation. And, so I had to realise that I had to go on with my life, and I did until a year ago, which my quality of life wasn't not very good. All the time when the angina started, the scare of - will it come back or will it not? And so many times. This is 6 times that I'm during a one year period that I'm in pain in Sunnybrook Hospital.

It is not the first time that the medication has been changed. Certainly, I agree to it, because every human being has a hope. And this is what I right now in this moment I hope. I completely realise my situation. I know that it, I'm not a doctor, but I don't know, I know it can't last too long... Until it lasts it lasts.

I can't say that I don't think about death. I don't, I can't say that, because a lot of times it is in my mind. I'm not afraid of dying or... I don't know if I could say that I'm not afraid. Although that I am, I know the situation, but still, I don't think that I could say that. Well, I can say that I'm afraid that I will have, that I will be incapacitated. From this, I am afraid. Right now I can look after myself still...

Participant 5

But you never know from one day to the next what's going to happen... you just wait and see. I can't explain what it's like, really...

[Quality of life is] the way you look at it, in a way. You know what I mean? Its the way you... You try to make it as pleasant for yourself as possible... another thing - you have to be cheerful about things. You have to do so many things you'd rather not do, at times, you know.

Either the money will run out or I'll run out. I hope I'll run out first... I think everybody feels more content if their pensions are large enough to bring them up, you know.

Participant 6

Well, I'm concerned about [my breathing] too, just laid up in here, being in the hospital. Get excellent treatment here, but I'd still rather be home. I just bought a new home less than a year ago. We just got it fixed up and this starts. If I get over this, I'd be fine - which they say I can. Personally, I think if I cooperate with them I can. It's sure annoying as hell...

Quality of life is normal everyday life... which is good for me; I'm retired, and successful. So, you can't ask for any more than that.

Participant 7

I'd like to go back to the kind of life I had, where I was driving the car, running my own house, and so on, but that isn't possible now. I had the major heart attack in July of '95. That's what triggered the whole thing, apparently.... And both the doctors were very frank; they said, "You know, you weren't supposed to get better; people don't recover from a heart attack like that." But he said, "You must be a fighter because you did." But since then, I've been in and out of hospitals 2 or 3 times... there isn't a quality of life that way... you're not living a good kind of life, because you have these attacks and shortness of breath, and so on, you know, so that it certainly isn't a good way to live.

Well, if I were better it would be, of course... [my] quality of life would improve .

Well, what would you expect at that age? You can't go on forever... Well, I don't think people, when they get up in their 80's, expect too much... I had such a good life before, with everything I wanted. I've been married twice.

It's just that your life changes so drastically when you've been very ill, you know, and so, you just go on day by day and do the best you can.

I guess just going on day by day [is most important]... what does anybody do, but go on day by day? There's nothing else you can do when you're older, and not too well. You just take the day as it comes. I don't look to the future... I take it a day at a time.

Participant 8

Life [is most important]. Nothing else but life. And when you lose your health, life don't mean anything. And that's what I lost - my health. So, if I can gain my health back... that's the most important thing in my life. I have everything else... I work; we have a house, you know; our finances are not too bad. So, I have everything I could think of. Except the health went, I have nothing left.

For the last 4 years, life has been hell. I have water in the lungs for a long time, but they could not even take it away from me. I think it should be the easiest thing, but I still have it. So, with that in mind, I could die on the operation table. But that's one thing that I make up my mind - if I cannot live better than what I'm living right now, I may as well die. I don't know. At this point, I have no idea [what will help me get through this]. I still don't have the turning table to give me the energy to go the other way at all. I'm a very strong man; maybe in the last couple days I will pull it off, but at this point, I don't know... Close to the date of the operation I might be very strong, and then if enough faith, this operation goes good, but life is always hard.

I have faith in my cardiologist, in my operator, so let's see what they can do for me. These are the only two that I focus on this hospital at this point. When I first turned here, I changed everything here, this family doctor, I want everything in the house... you put all the eggs in one basket, and if they all break, you waste.

That's not right, but that's the way life is. I have very much faith in my cardiologist, and I have much faith in my operator right now, but these are the things that... I just go in faith at this point. They could let me down or they can help me a great deal.

Participant 9

I've been sick a lot since last July, and I have faced two operations, and I wonder if I'll ever be the same. I don't think so, but...

[It] would be nice to be able to walk like a human being and just do things like I used to do. We travelled a lot, we went away a lot. I was on the go all the time. And I played with my grandchildren, and I don't know, we were active people, maybe not in the sense of exercise and whatnot, but we were active people. Like even out where we live, we never stayed in the apartment unless it was a very bad day. All day we went somewhere. And I think that's what I miss the most. But maybe I'll be back out there very soon, you can't tell; get some weight back on and get on my feet. But I do love to go places. Just hope that I can do it again.

But I'd like to feel better. I haven't felt good in a long time. That seems to be, you know, the only thing. You know, you get up every day and you think: Maybe today it'll be nice. Blah, it's not nice, you know. I kept saying, I'm sick, I'm sick, and I kept throwing up; that's not a quality of life.

Getting out of here and leading.. back to a life [is important]. Being able to go out to walk like a human being, you know. But I guess, if you can't do it, you can't do it...

I'm quite content at home, and I knit and I do different things. I'm very content, but just that I wish, each day I'd get a little bit better. They tell me it's a long road back, so we'll see. I asked the other day if I was ever going to be better, and he said yes, but a long time, so.. but that's... I like getting out and about.

Your health is so important, so important. You just never know.

[Quality of life means] living, and enjoying it, you know. We have a good quality of life, we're very fortunate. But I guess quality will now mean, will I be all right?

Participant 10

[I don't see] a heck of a lot [in the future], other than, hopefully, I can still get around.

I still think that at my age, the quality of life is still being able to do things, understand things. I guess I have a little bit of a religious bend to my life. I guess I have a fair amount of faith in that end of life; I basically don't control my life, except maybe my fiscal end of it, but...

One reason for my reluctance about coming home, is the fact that she's getting on in years... and she's been doing this volunteer palliative care work at the York County Hospital, she likes doing it, I know she doesn't want to give it up, but she's been indicating that if I'm going to be home in this condition, maybe she'd better give it up. And I'm hoping that I get well enough that she doesn't have to get out of it.

I used to use an expression, particularly when we lived up in the farm house, that my choice in the morning is: Well, which job should I try and do today? And now I wake up in the morning and say: Well, what am I going to do today? - which is quite a difference, hey.

Participant 11

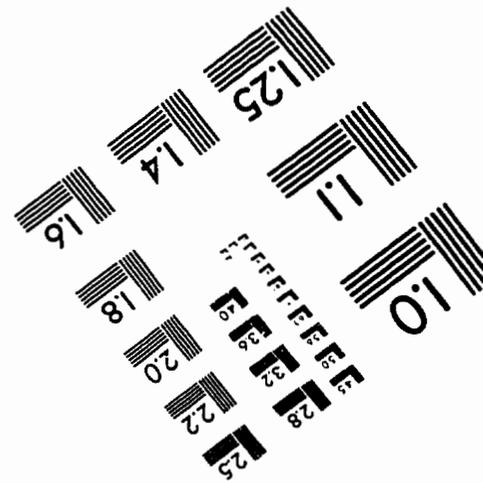
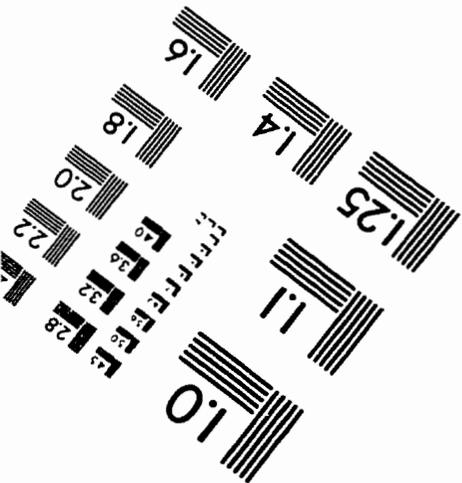
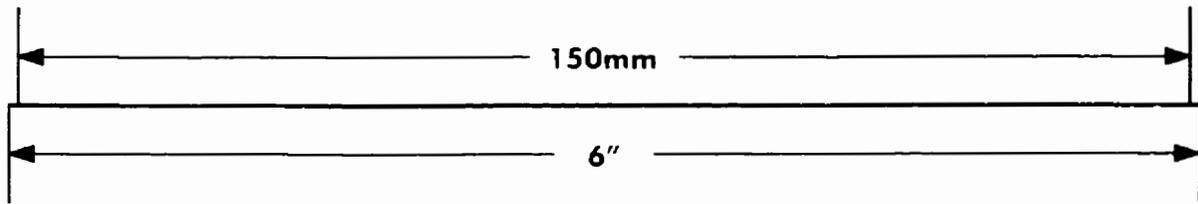
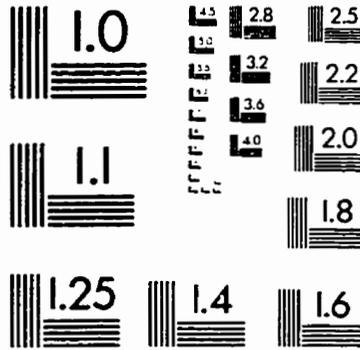
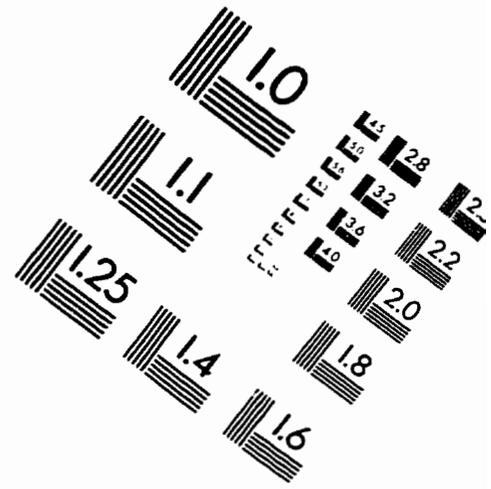
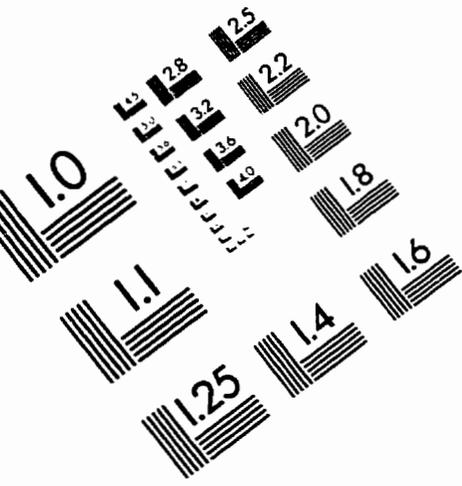
It'll happen just cause it'll happen. How do I feel about it? It doesn't bother me, cause it's always on the back of one's mind. I just happened to sort of have an eye-opener that sort of jumped into the forefront, where it's basically life and death. If I don't do it, I probably won't live another 10 years, so it's not a great situation to be in. But it's also something that one always thinks about.

I guess I feel it's probably more my own fault, so I only have myself to blame, primarily. And on the other hand, I'm lucky enough to have caught it, probably, in time. I don't quite know yet.

We'll maybe find out by the end of the week. But it's caught, and I guess life will go on.

Hopefully, it'll get better, live a little healthier, and things will improve. And maybe it just took a hit over the head to change whatever I've got to.

IMAGE EVALUATION TEST TARGET (QA-3)



APPLIED IMAGE . Inc
 1653 East Main Street
 Rochester, NY 14609 USA
 Phone: 716/482-0300
 Fax: 716/288-5989

© 1993, Applied Image, Inc., All Rights Reserved