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## Quality of Life for Women Living with Advanced Breast Cancer

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QUALITY OF LIFE FOR WOMEN  
LIVING WITH ADVANCED BREAST CANCER

By

Maureen Mika Eberly

A THESIS

Submitted to  
Grand Valley State University  
in partial fulfillment of the requirements for the  
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ABSTRACT

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Parse's Human Becoming Theory of nursing and research methodology were used to describe the structure of the meaning of quality of life for women living with advanced breast cancer. Three core concepts surfaced: grieving-adjusting remaining connected to ordinary life events, reinforcing-distancing relationships preserving individuality, and choosing opportunities clarifying purpose. Through conceptual integration these emerged as *valuing the connecting-separating of powering unique ways*. This study enhances the knowledge on quality of life, expands Parse's theory of nursing, and demonstrates the value of Parse's methodology for uncovering the meaning of lived experiences. Implications for further research and practice are discussed.

Dedication

In memory of my mother, Marilyn Eardley Mika.

Your gentle soul is felt.

## Acknowledgements

To my loving husband, John, whose belief in my abilities inspires me.

To my daughter, Eve, whose pride in me is reward enough.

To my step-daughters, Amanda and Hannah, whose endurance is unending.

To my father, Ernest, whose integrity shines through.

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And, especially, to the women who unselfishly shared their joys and fears and hopes and dreams, whose lives enrich us all.

## Table of Contents

List of Figures.....	vii
List of Tables.....	viii
List of Appendices.....	ix

### CHAPTER

1	INTRODUCTION.....	1
	Purpose.....	3
	Research Question.....	3
	Assumptions.....	3
2	LITERATURE AND CONCEPTUAL FRAMEWORK	5
	Organizing Framework.....	5
	Parse's Human Becoming Theory.....	6
	Significance for Nursing.....	9
	Literature Review .....	10
3	METHODS.....	11
	Sample Selection.....	11
	Setting.....	12
	Protection of Human Rights.....	12
	Data Collection.....	13
	Data Analysis.....	14
	Data Integrity.....	16
4	RESULTS/DATA ANALYSIS.....	18
	Extraction-Synthesis of Participant Dialogues...	18
	Propositions Researcher-Participant Dialogues...	23
	Core Concepts .....	23
	Structure of the Lived Experience.....	24
	Heuristic Interpretation.....	24

5	DISCUSSION AND IMPLICATIONS.....	31
	Discussion of the Findings.....	31
	Limitations of the Study.....	36
	Implications for Research.....	36
	Implications for Practice.....	37
	Summary.....	39
	APPENDICES.....	40
	REFERENCES.....	46
	BIBLIOGRAPHY.....	51

List of Figures

Figure 1 Progression of Abstraction to Conceptual Interpretation.....30



## List of Tables

<u>Table 1</u> Extraction-Synthesis from Participant One.....	19
<u>Table 2</u> Extraction-Synthesis from Participant Two.....	20
<u>Table 3</u> Extraction-Synthesis from Participant Three.....	21
<u>Table 4</u> Extraction-Synthesis from Participant Four.....	22

## List of Appendices

### Appendix A:

Script for Potential Participants..... 40

### Appendix B:

Consent Form..... 43

### Appendix C:

Grand Valley State University Human Research Review Committee Approval... 45

## CHAPTER I

### INTRODUCTION

Breast cancer is the most common cancer in women of all ages and the second leading attributable cause of cancer death in women (American Cancer Society [ACS], 1999). In 1999, an estimated 175,000 new cases of breast cancer are projected (ACS, 1999). Improved prevention and detection methods, as well as advances in medical treatment have resulted in a trend toward increasing numbers of cancer survivors (Beyer, 1995). The 5-year survival rate for localized breast cancer has increased from 72% in the 1940's to 97% today (ACS, 1999). Sixty-nine percent of women diagnosed with breast cancer survive ten years, and 57% survive fifteen years (ACS, 1999). Coping with cancer as a chronic disease is becoming a more common phenomenon.

Mullan (1985) has described three seasons of survival that may be associated with cancer as a chronic disease. The last season is called permanent and may be equated with cure. The likelihood of recurrence is highly diminished, since the disease is considered to be permanently arrested. During this season, the survivor is integrating the unforgettable experience of cancer with normal life activities. Although there are multiple challenges along the way, survivors often find that the experience opens new pathways of personal growth. Uncertainty has been studied (Nelson, 1996; Mishel, 1990) as a common theme among this population, and how uncertainty gives new meaning to quality of life for those survivors has been examined.

Unfortunately, metastases from breast cancer generally is a fatal condition. If the cancer has spread regionally, the 5-year survival rate is 77%, while for women with distant metastases the rate is 22% (ACS, 1999). Awareness of how women continue to

find purpose, meaning, and a sense of well being during this time is of interest to health care providers who work with this population. Research has demonstrated the positive effects of support groups on quality of life and length of survival within this patient population (Speigel, 1993), as well as other groups such as cardiovascular patients (Ornish, 1993).

The concept of quality of life (QOL) is elusive, and to date, no consensus exists on a conceptual definition of QOL (King et al., 1997). One of the earliest definitions which added psychosocial variables as a component of the biomedical evaluation is the World Health Organizations' definition of health. This definition includes "complete physical, mental, and social well-being and not merely the absence of disease and infirmity" (World Health Organization, 1947). Included here is the acknowledgement of "quality" as an added dimension to some other definitions which focus only on the disease state (McCabe, 1998). Cella and Tulsky (1990) state that QOL is a "patient's appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal." McDaniel and Bach (1994) define QOL as "the congruence or lack of congruence between actual life conditions and an individual's hopes and expectations."

Quality of life, according to Parse's Human Becoming Theory (Daly, Mitchell, & Jonas-Simpson, 1996), is regarded as health, or simply how the individual is living and becoming the person he or she chooses to be. The quality of one's becoming represents the incarnation of the person's shifting value priorities, and only the person's own description discloses his or her quality of life. Parse's approach through theory and

research methodology seeks to fully describe individual's lived experiences, thus uniquely defining quality of life within the shared context of human patterns.

### Purpose

The purpose of this study was to describe the structure of the meaning of quality of life for women living with advanced breast cancer. Understanding the dynamics of this lived experience serves to enlighten health professionals so that they recognize and encourage those choices that have meaning for the individual. This understanding will also further nursing science through application of Parse's Human Becoming Theory.

This study built upon Coward's (1990) previous study regarding the lived experience of self-transcendence in women with advanced breast cancer, while utilizing Parse's Human Becoming Theory and research methodology (Parse, 1996c).

### Research Question

The research question of this study was: What is the meaning of the experience of quality of life for women living with advanced breast cancer?

### Assumptions

The study of describing lived experiences requires a different approach than the traditional scientific approach. Research concerning human behaviors or attitudes demands an approach that captures the human experience holistically and meaningfully. According to Polit and Hungler (1995, p. 14), an alternate model of inquiry has emerged that has its intellectual roots in the philosophical tradition known as *phenomenology*:

The phenomenological approach rests on different assumptions about the nature of humans and how that nature is to be understood. Phenomenologists emphasize

the inherent complexity of humans, the ability of humans to shape and create their own experiences, and the idea that truth is a composite of realities.

Duplication of behavior is not expected from duplicate data within a phenomenological study (Omery, 1983); however, similar meanings of experience may produce similar behavior, and similar experiences of feelings may be elicited when read or shared with others because of a shared humanness within experiences. Assumptions are also made that the participants' statements accurately reflect what they perceived the experience to be and responded to the research question within reference to their own experiences.

## CHAPTER II

### LITERATURE AND CONCEPTUAL FRAMEWORK

#### Organizing Framework

A phenomenological approach was utilized in this qualitative study with a descriptive exploratory design. As the purpose of the study was to describe the quality of life of women with advanced breast cancer, all attempts were made to encourage open dialogue without leading or limiting the flow of ideas from the individual's description of her lived experience of the phenomenon.

The advantage of the descriptive exploratory design is its value in generating meaning and identifying patterns through narratives (Parse, 1996a). Self-disclosures from individuals living the experience provide perspectives that either support or clarify similar experiences, or contribute to a shift in thinking not previously contemplated. The individual benefits from the opportunity to validate the meaning of those experiences (Pelusi, 1997).

The disadvantage to this approach is the inability to generalize the findings to all individuals in the particular population. Ironically, the uniqueness of each individual's experience serves to limit its applicability. Discovery of the dimensions of the lived experience, however, provide a basis for later quantitative study.

The descriptive exploratory design was chosen also for its ease in the subsequent application of Parse's Human Becoming Theory and research methodology. The goal of nursing in Parse's theory is quality of life (Parse, 1992). Parse's perspective embraces a

belief in the person as the one who knows the way to live in any health-related situation (Daly et al., 1996). For Parse, quality can only be defined by persons themselves. According to Daly et al. (1996), expanding knowledge of quality of life with Parse's theory requires the systematic study of what people themselves describe as meaningful through qualitative methodologies. Enhanced understanding for nurses offers opportunities to practice with people in ways that differ from and complement other disciplines.

### Parse's Human Becoming Theory

The Human Becoming Theory evolves from Parse's Philosophical Assumptions, Assumptions about Human Becoming, and Principles of the Human Becoming Theory. Human Becoming is a unitary construct referring to the human being's living health (Parse, 1997). The nine assumptions of the theory were constructed in 1981 from a synthesis of ideas from Roger's Science of Unitary Human Beings. Existential phenomenological thought, primarily of Heidegger, Sartre, and Merleau-Ponty, set forth the philosophical premises that specified a unique human science perspective of nursing (Parse, 1997).

Parse's philosophical assumptions. The first four assumptions specify the human as an open being in mutual process with the universe, while the last five specify health as a process of becoming. Each of the nine assumptions is a synthesis of concepts juxtaposed in such a way as to create the underpinnings of a new product, Parse's Theory of Human Becoming (Parse, 1992).

- The human is coexisting while coconstituting rhythmical patterns with the universe.



- The human is open, freely choosing meaning in situation, bearing responsibility for decisions.
- The human is unitary continuously coconstituting patterns of relating.
- The human is transcending multidimensionally with the possibles.
- Becoming is unitary human living health.
- Becoming is a rhythmically coconstituting human–universe process.
- Becoming is the human’s patterns of relating value priorities.
- Becoming is an intersubjective process of transcending with the possibles.
- Becoming is unitary human evolving.

Principles of the Human Becoming Theory. From these philosophical assumptions, the basic themes of meaning, rhythmicity, and transcendence led to specification of the three principles of the theory (Parse, 1997). Each of the 3 principles involves paradoxical rhythms that describe the human’s way of living. These paradoxical rhythms are ways the human structures meaning, cocreates rhythmical patterns, and cotranscends with the possibles through powering.

- Principle 1. *Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging.* This principle specifies that humans in mutual process with the universe structure personal meaning, thus reality. Each human’s reality is the meaning of the situation. Paradoxical rhythms include explicit-tacit, confirming-not confirming, speaking-being silent, moving-being still --- what the person chooses to make known as well as keep to him/herself through language and imagery provides meaning to his/her reality.
- Principle 2. *Cocreating rhythmical patterns of relating is the living paradoxical unity*

*of revealing–concealing and enabling–limiting while connecting–separating.* This principle refers to the notion that humans disclose hide meanings all at once as opportunities and limitations arise in everyday life while they move with and away from others, ideas, objects, and events. The paradoxical rhythms of revealing–concealing, enabling–limiting, connecting–separating are occurring simultaneously and define reality for the individual.

- Principle 3. *Cotranscending with the possibles is powering unique ways of originating in the process of transforming.* This principle refers to the pushing–resisting process inherent in forging unique ways of becoming. In creation of the new, there is always the certainty and uncertainty of striving to conform in some ways and not conform in other ways all at once. Humans move beyond the moment as the unfamiliar becomes familiar in the presence of a new light and as the familiar is visited anew through shifting perspectives. When the well-recognized or familiar is seen in a new light, the old view is transformed and is never the same again.

According to Parse (1996d), these principles written at a theoretical level of abstraction make up the theory. The verbal noun forms are used to connote and denote the process orientation of this theory. The principles bring to light the notion of paradox as fundamental to human becoming. Parse (1996d) continues to explain how nursing theory regards paradoxical processes as inherent to being human. The paradoxes are not considered problems to be solved or eliminated but, rather, natural rhythms of life. Further, these rhythms arise with changing patterns and are lived multidimensionally all at once. They are ways humans live meaning.

In 1985, the original nine philosophical assumptions were further synthesized into three assumptions on Human Becoming (Parse, 1997).

Assumptions about human becoming. This theory, like Rogers' Science, created new language for the discipline in keeping with the notion that all disciplines must have unique expressions to specify the nature of their phenomenon of concern.

- Human becoming is freely choosing personal meaning in situations in the intersubjective process of relating value priorities.
- Human becoming is cocreating rhythmical patterns of relating in mutual process with the universe.
- Human becoming is cotranscending multidimensionally with the emerging possibles.

#### Significance for Nursing

In 1987, Parse articulated a specific research methodology derived from the assumptions and principles of the Human Becoming Theory (Parse, 1997). Qualitative research utilizing this methodology builds the base of the discipline through expanding understandings of nursing's phenomenon of concern. "If the theoretical perspective is embedded in nursing science and the findings are linked to a nursing framework or theory, then the knowledge is indeed nursing knowledge" (Parse, 1996a, p. 10).

Describing the phenomenon of study, the meaning of the quality of life of women living with advanced breast cancer, assists in the understanding of the phenomenon.

Ultimately, this understanding promotes awareness in the complexities of responsive care.

## Literature Review

Preconceptions of the phenomenon under study may bias the researcher towards seeking confirming data. The result may be the exclusion of nuances not formerly considered. This negates the purpose of describing the lived experience according to those living it. Although some knowledge of some of the concepts is unavoidable in choosing the phenomenon of interest, a literature review is delayed until the data is collected and analyzed. This increases the likelihood of analysis of data in its pure form. Some concepts that might be explored in relation to caring for women living with advanced breast cancer would be breast cancer and quality of life, meaning, mastery, hope, and coping.

## CHAPTER III

### METHODS

#### Sample Selection

The convenience method of network sampling was employed in the sample selection process of this study. Criteria for inclusion included any female with advanced breast cancer (Stage IV, metastatic disease) who understood and spoke English and was willing to answer the research questions. Severity of illness did not exclude participation, as none had impaired mental capacity such that the research question could not be addressed in a narrative context.

Breast cancer support group leaders, oncology nurses, Women's Health providers, and nurse researchers were contacted regarding the purpose and procedure of the study. They approached individuals that they thought might be interested in the study, and obtained permission to be contacted by the researcher.

Subsequently, phone contact was made by the researcher, and the study was explained according to the Script for Potential Participants (see Appendix A). Questions were answered. Offers to review a written description of the study and Consent Form (see Appendix B) ahead of the meeting time were declined by those willing to participate.

Four participants were included in the study. According to Parse (1990), two to ten participants are considered adequate in this method in that the quality of redundancy is sought. An indicator of redundancy or saturation of data occurs when the researcher senses a pattern in the engagements repeated by a number of participants. The

information is then considered sufficient to apply to the remaining processes of the method (Parse, 1990).

The sample consisted of women with metastatic breast cancer ranging in ages from 41 to 50 years old. All were Caucasian. Three were married, one was single. All had children, with their ages ranging from 3 to 25 years old. All were high school graduates, 3 had some college education. Three were economically stable. None were employed outside of the home at the time of the study. Elapsed time from the initial diagnosis of breast cancer ranged from 1 ½ to 11 years, with known metastatic disease from 9 months to 3 years.

### Setting

Each participant chose the setting for the interviewing process or dialogical engagement. Settings included a reserved library at an oncology out-patient clinic, a participant's home, and a participant's backyard. Three dialogues were concluded within one sitting, while one occurred over two meetings. Conversations lasted from 1 to 3 hours.

### Protection of Human Rights

Approval for this study was obtained from the Grand Valley State University Human Research Committee (see Appendix C). Informed consent was obtained before proceeding with the interview.

The potential risks to the participants in this study were minimal, but methods to reduce these risks were followed. While individuals often appreciate the opportunity to talk about what they are experiencing, the potential exists for confronting unsettling

feelings not previously divulged. For this reason, the option to explore counseling through community resources was offered to participants.

In order to prevent misunderstanding of the participant upon analysis of the data, the nurse researcher returned to the interested participants after the preliminary analysis to confirm and validate expressed themes. The nurse researcher outlined steps taken to insure confidentiality (no identifying factors to the data, authorized personnel only reviewing data analysis) to reduce the participant's anxiety surrounding privacy of her disclosures. The interview process was stopped at the point the participant expressed the desire to stop or showed signs of fatigue.

### Data Collection

Collection of the data occurred under conditions that optimized the free expression of the individual. The participant chose the setting and time of day that was most comfortable for her. The settings allowed for private and unhurried conversation without interruption or influence by others. The dialogical engagement was unstructured with open-ended questions to initiate conversation and allowed for exhaustion of the topic to the individual's satisfaction. Only one researcher, the author, was responsible for all the engagements using the same framework for each.

The dialogues were audiotaped. The content from the dialogues were then transcribed verbatim. To begin discussion with each participant, the following open-ended questions were asked:

1. To describe the significance of quality of life.
  - a. What is life like for you?
  - b. What contributes to your quality of life?

- c. What may diminish your quality of life?
  - d. What are your priorities right now?
2. To describe patterns of relating connected to quality of life.
  - a. Who is most important to you?
  - b. What changes in your routine or relationships might change your quality of life?  
life?
3. To describe concerns, plans, hopes, and dreams related to quality of life.
  - a. How would you like to change your quality of life?
  - b. What can you do to make this happen?
  - c. What are your concerns?
  - d. What are your hopes and dreams? (Parse, 1996c)

Dialogues, however, were not confined to these questions only.

### Data Analysis

Data analysis stemmed from Parse's research methodology. The purpose of the method is to uncover the structure of universal lived experiences with persons or groups who can articulate the meaning of an experience to enhance understanding of human becoming (Parse, 1996d). Universal lived experiences are those that all humans experience and, given a willingness and an opportunity, could describe. Examples are hope, joy-sorrow, restriction-freedom, considering tomorrow, persevering through a difficult time, grieving, and persisting while wanting to change (Parse, 1996d).

Parse's research methodology . This phenomenological hermeneutic method requires a commitment to seeking understanding of the lived experiences. The



assumptions of the method incarnate a strong value for honoring the research participant as one who can describe the experience (Parse, 1997).

The phenomena for study in this method are universal human health experiences surfacing in the human-universe process reflecting being-becoming, value priorities, and quality of life. The structure of the phenomenon to emerge through this method is the paradoxical living of the remembered, the now-moment, and the not-yet, all-at-once.

The process of the research method involves four steps. The first is participant selection, or persons who are willing to describe the phenomena under study through words, drawings, metaphors, stories, music, and other media.

The next step is dialogical engagement. This is a researcher-participant true presence, not an interview, where the person elaborates on the phenomenon under study and the researcher engages with full attention.

The third step involves extraction-synthesis. This is dwelling in deep contemplation with the participants' descriptions and moving these concrete statements across levels of abstraction to the level of science. This occurs by following a specific outline: extracting and synthesizing essences from transcribed and recorded descriptions (participant's language), synthesizing and extracting essences (researcher's language), formulating a proposition from each participant's essences, extracting and synthesizing core concepts from the formulated propositions of all participants, and then synthesizing a structure of the lived experience from the core concepts.

The final step involves Heuristic interpretation. This is weaving of the structure into the Human Becoming Theory and beyond to expand nursing knowledge through structural integration and conceptual interpretation. Structural integration is moving the

structure of the lived experience up another level of abstraction. Conceptual interpretation further specifies the structure of the lived experience by using concepts of the theory to create a unique theoretical structure which represents the meaning of the lived experience at the level of the theory (Parse, 1990). It is possible that some or all of the participants' extracted essences would be explainable at the level of conceptual interpretation involving Parse's 3 principles of the Human Becoming Theory.

#### Data Integrity

With a qualitative study, the central question to be answered regarding the reliability and validity of the data collected is: Do the data collected by the researcher reflect the truth? The trustworthiness of the data is limited by the individual's honesty in response to the research question and by the researcher's interpretation of the response. In order to establish trustworthiness in this study, the four criteria recommended by Lincoln and Guba (1985) were demonstrated: *credibility*, *transferability*, *dependability*, and *confirmability*.

Credibility. In order to encourage confidence in the truth of the data, certain techniques were employed. The first technique involved the use of triangulation in an effort to draw conclusions about what constitutes the truth through multiple referents. Data triangulation required interviewing several women regarding their experiences living with breast cancer. Method triangulation was not used as the women chose not to respond to the ten interviewing questions in a written narrative form besides the audiotaped dialogical engagement.

A second technique to support credibility of the data involved debriefing with peers and the participants. Debriefing with peers provided an external check on the

inquiry process. With the participants, debriefing during the process of gathering data was employed for clarification. After the initial analysis, feedback was obtained by sending the extraction-synthesis summary to the participant for review and input.

Transferability. In order to encourage the generalizability of this study's small sample size to other settings or groups, as much descriptive data as reasonable with this particular study was provided. In that way, other researchers can evaluate the applicability of the data to other contexts.

Dependability. In order to support the stability of the data over time and over conditions, an inquiry audit was used. An external reviewer, a thesis committee member, was asked to scrutinize the data and relevant supporting documents to confirm this condition had been met.

Confirmability. In order to establish objectivity or neutrality of the data collected, agreement between two or more independent people about the data's relevance or meaning was sought. As with dependability, an inquiry audit was utilized, providing an audit trail. This required a systematic collection of materials and documentation that allowed for an independent auditor to come to conclusions about the data. The inquiry auditor then proceeded to audit the trustworthiness of the data and the meanings attached to them.

## CHAPTER IV

### RESULTS/DATA ANALYSIS

#### Extraction-Synthesis of Participant Dialogues

Following Parse's research methodology, the extraction-synthesis from the dialogue of each participant interaction is outlined in Tables 1 – 4. The language of the participant was grouped in one of three ways depending upon the type of question being addressed: 1) meaning, 2) rhythmicity, or 3) cotranscendence. Essences from the language of the participant were synthesized into language of the researcher, resulting in the formulation of a proposition from each participant's description.

Table 1

Extraction-Synthesis for Participant One

<u>Language of Participant</u>	<u>Language of Researcher</u>
1) Looks at life in different way, grieving loss of abilities while adjusting and grateful for remaining abilities. Doesn't want to miss today by worrying about future and prioritizes energy to maximize each day. Benefits to treatment plan outweigh drawbacks if able to prolong life.	1) Prioritizing choices daily while grieving losses of life past.
2) Prefers direct approach and connecting with people by structuring environment for engagement. Appreciates support from others, specific in requests and guards time. Feels it's important to give support back to others with cancer. Feels it's important to stay healthy for others' sake in order to participate in life's events.	2) Proactive balancing of giving and receiving support in meaningful relationships.
3) Tailors peaceful days through use of humor, guided imagery, and meditation. Seeks out mood lifters, and opportunities to improve someone else's day. Longs for chronicity of disease, to experience normal life events in future. Believes in eternal life, not afraid of death, but fears dying process with total dependence on others and reluctant to give up on earthly life. Struggles with envisioning best life for spouse and child without her in it.	3) Contemplation of life beyond tempered by desire to remain in life present.

Proposition

The experience of living with advanced breast cancer is prioritizing choices daily while grieving losses of life past through the proactive balancing of giving and receiving in meaningful relationships with contemplation of life beyond tempered by desire to remain in life present.

Table 2  
Extraction-Synthesis for Participant Two

<u>Language of Participant</u>	<u>Language of Researcher</u>
<p>1) Life is busier now with various appointments, but it's a good life with more appreciation for simple things, such as sunshine, flowers, happy times, special moments with husband and children. Doesn't waste time being unhappy or bored; doesn't put off talking about things. Wants to continue doing what already doing by being part of everyday life, including getting satisfaction from mundane chores. Confronting mortality, wants to be educated on all can do to prolong productive life. Will choose chemo again and again as long as she's able to be useful in some way to loved ones.</p>	<p>1) Making complicated choices to extend the ability to experience simplicity in life present.</p>
<p>2) Developing closer relationships with family and friends. Annoyance with new attention received resulting from illness replaced now with appreciation. Accepting of others' style of support. Support in groups not always consistent with own level of need. Bonding with particular professional, prefers honesty vs. shielding in communication. Understanding of those who have chosen not to continue friendship. Struggles with remaining indispensable to husband/children vs. fostering independence.</p>	<p>2) Strengthening open meaningful relationships while forgiving the loss of relationships from life past.</p>
<p>3) Maintaining positive outlook through worst moments by envisioning future happiness. Living life now as example to children. Does not want to become burden to family. Feels lucky to have chance to prepare for death, leaving traces of self through notebooks, planting of perennials, decorating the mailbox, and assigning keepsakes. Projecting life of husband without her including remarriage. Attempting to instill in children value of happiness through good relationships, not material things. Desires ability of children to face future challenges by thinking of how well their mother handled challenges. Wants to stay alive longer with advances in research in order to be part of children's life events. Wants to be remembered with a smile on her face.</p>	<p>3) Grateful preparation for death by living a good example in life present while yearning for an integral part in life future.</p>

Proposition

The experience of living with advanced breast cancer is making complicated choices to extend the ability to experience simplicity in life present and strengthening open meaningful relationships while forgiving the loss of relationships from life past with grateful preparation for death by living a good example in life present while yearning for an integral part in life future.

Table 3

Extraction-Synthesis for Participant Three

<u>Language of Participant</u>	<u>Language of Researcher</u>
<p>1) Adjusting expectations of self to remain as productive as possible in different ways than before illness. Resentful vs. relieved about giving up career. Changing losses into gains through preserving independence. Prioritizing energy to include reading from daily devotions, scriptures, and book of encouragement. Has addressed end of life issues, doesn't want these issues to surface on daily basis. Enjoying recent addition of kittens to household. Gradually accepting chemo, radiation, appliances as friends vs. enemies, although balancing time off from untoward effects of chemo with knowledge of resultant proliferation of metastases.</p>	<p>1) Changing lifestyle to maximize productivity in significant events in life present.</p>
<p>2) Changing role from caregiver to receiver. More specific in requests; not as important to keep occupied as to keep useful. Little time alone; sometimes wants freedom to feel down, but appreciates high expectations of others to keep her rallied up. Shields loved ones from continuous exposure to changing medical condition. Support groups useful in living knowledge, understanding fear; feels has something to offer group. Strong belief in God's will; asks God daily to keep her useful, to not take her any sooner than He wants to, but not to stay any longer than has to, either. Struggles with wanting young adult children involved vs. not wanting to disrupt their lives. Grateful to have family and friends to depend on. Comfortable relationship within regular circle of health care providers; feels unrecognized as individual outside of circle.</p>	<p>2) Seeking balance of individual needs in meaningful relationships in keeping with the needs of others.</p>
<p>3) Concern over dying process and long-term suffering, but not fighting death; at peace with knowledge of God's will. Feels God takes weak things and brings out His glory. Hopes to continue to be a good example, knowing that there are a lot of people watching and listening. Makes daily notations on positive aspects so as not to lose sight of good things. Desires assistance with care during final days from outsiders to preserve family's happy memories. Concerned over spouse's quality of life once gone. Hopes that children marry Godly spouses who recognize their fine characters, and that they have learned important priorities; has prepared letters to each. Saving cards that have personal message so family members can know who she was through other people's eyes.</p>	<p>3) Living life present as positive example while preparing self for life beyond and others for life after.</p>

Proposition

The experience of living with advanced breast cancer is changing lifestyle to maximize productivity in significant events in life present while seeking balance of individual needs in meaningful relationships in keeping with the needs of others and living life present as positive example while preparing self for life beyond and others for life after.

Table 4  
Extraction-Synthesis of Participant Four

Language of Participant	Language of Researcher
<p>1) Feels cancer is just another challenge in life; cancer is not whole life. Awful knowing body is fighting itself, aware of its presence. Each day met with hope of feeling half way decent. Prioritizing activities for energy conservation, rallies up for special occasions. Days improved by sunshine, bubble baths, malts, and by doing things still has control over. Relinquishing pieces of lifelong independence; giving in to accepting help with mortgage versus giving up dream of having own place to come home to. Drastic changes in life; nothing mystical about experience. Chemo contributes and detracts from quality of life.</p>	<p>1) Shifting priorities to maintain independence in challenging situation.</p>
<p>2) Trying to prevent causing undue concern for elderly parent who has returned to role of caregiver. Annoyance versus acceptance of help; keeping control over independence, quiet time. Mutuality of neighbors: looking out for eachother in small ways without really knowing eachother. Loss of friends due to lack of understanding over inability to continue some former activities, but not all. Relationship with young adult child not as would like; difficult to empathize with trivial complaints. Resentment over fewer choices in situation being single. Difficulty convincing others about knowledge of own body. Confronting oncologist re: being real person, not “it” and healing through own measures. Concern over familial implications for other women in family.</p>	<p>2) Experiencing angst continuing meaningful relationships dependent upon life past as evolving new relationships reflective of life present.</p>
<p>3) Difficulty reconciling God’s intentions for her amidst decreased productivity. Not afraid to die; upon facing God, wants to be able to say used capabilities to fullest. Hopes for continued capacity to grow and learn with remaining time; important for the allowance of hopes and dreams. Doesn’t want old life back, wants to continue forward. Not blaming cancer for not making other changes in life. Grateful diagnosis comes at time children are older; feels role of mother fulfilled. Hopes for cure for younger people. Feels has greater capacity to enjoy life now than others with money as has less to lose. Feels contributed and played integral part in community. Uses imagery to deal with unpleasant experiences. Important to think well of self; owe self a better life by doing what brings happiness. Can contribute with small gestures to improve someone else’s day. Feels blessed in spite of cancer, not dealing with alcohol/drug problems. Wants to be remembered as former industrious self.</p>	<p>3) Contemplating growth opportunities inspired by successes of life past while anticipating life beyond.</p>

Proposition

The experience of living with advanced breast cancer is shifting priorities to maintain independence in challenging situation while experiencing angst continuing meaningful relationships dependent upon life past as evolving new relationships reflective of life present while contemplating growth opportunities inspired by successes of life past while anticipating life beyond.



## Propositions from All Researcher-Participant Dialogues

The propositions from all the researcher-participant dialogues appear below:

- The experience of living with advanced breast cancer is prioritizing choices daily while grieving losses of life past through the proactive balancing of giving and receiving in meaningful relationships with contemplation of life beyond tempered by desire to remain in life present.
- The experience of living with advanced breast cancer is making complicated choices to extend the ability to experience simplicity in life present and strengthening open meaningful relationships while forgiving those lost dependent upon life past with grateful preparation for death by living a good example in life present while yearning for an integral part in life future.
- The experience of living with advanced breast cancer is changing lifestyle to maximize productivity in significant events in life present while seeking balance of individual needs in meaningful relationships in keeping with the needs of others and living life present as positive example while preparing self for life beyond and others for life after.
- The experience of living with advanced breast cancer is shifting priorities to maintain independence in challenging situation while experiencing angst continuing meaningful relationships dependent upon life past as evolving new relationships reflective of life present while contemplating growth opportunities inspired by successes of life past while anticipating life beyond.

## Core Concepts

The propositions from all the researcher-participant dialogues yielded core concepts that were relevant to each participant's description of the experience:

- Grieving-adjusting remaining connected in ordinary life events.
- Reinforcing-distancing relationships preserving individuality.
- Choosing opportunities clarifying purpose.

From these core concepts evolved a synthesis of the meaning of the experience of quality of life for women living with advanced breast cancer.

### Structure of the Lived Experience

The answer to the research question then is: quality of life is grieving-adjusting remaining connected in ordinary life events through reinforcing-distancing relationships preserving individuality while choosing opportunities clarifying purpose.

### Heuristic Interpretation

Structural integration. Structural integration is connecting the structure of the lived experience with the theory. The finding of the study is the structure of the meaning of the experience of quality of life for women living with advanced breast cancer as written above. The structure of any lived experience, according to Parse (1990), is the paradoxical living of the remembered, the now moment, and the not-yet. Explained further, the remembered (the way it was as it is appearing now) gave rise to inventing the not-yet (specifying expectations of the “will be” in light of the now) as the now moment (everydayness) was incarnated through the all at once living of a directional movement (Parse, 1990).

This was evident in all participants as they spoke of living each day framed by the successes and failures of the past with ideas and hopes for the future in light of the mortality associated with metastatic breast cancer. The remembered, the now moment, and the not-yet were intricately woven in the reality of the experience for each participant and gave definition to her quality of life.

The weaving of the structure with the theory is connecting the empirical with the theoretical (Parse, 1990). This involves focusing on the core concepts that emerged from the propositions constituting the language of the structure.

The first concept, grieving-adjusting remaining connected in ordinary life events, is the meaning given to the situation as the participants shifted priorities in the process of becoming. Physical limitations from the disease process has resulted in all the participants looking for new ways to get the most out of each day through conservation of energy for preferred activities. The loss of previous abilities makes way for maintaining connectedness to daily life events through acquisition of new priorities.

#### Participant Statements

“It was difficult giving up sharing a room and a bedroom with my husband. I had to have a hospital bed because of my back. That was difficult, but on the other hand, it makes it possible for me to adjust my head level and so on without having to ask him to get pillows, and again it keeps you more independent.”

“When I fly, I always arrange ahead of time to have a cart...it was kind of hard except for I knew I didn’t want to waste the amount of time I could be on my feet in the airport, I wanted to have it when I saw my (family).”

“You try to save your strength for what is important to you, whether it be just a short walk with my dog, you know, to go outside, that’s important to me. It’s important to see my family and still have them know that I wanted to be there at the graduation. This is my god-son, my sister’s boy, I’m his god-mother, so it was important for me to be there. And my priority just about the whole week centers on, you know, just something like that what you have to do.”

Grieving-adjusting remaining connected in ordinary life events is the shifting of priorities, which is interpreted as *valuing* from the first principle of Parse's theory (Parse, 1997).

The second concept is the reinforcing-distancing of relationships preserving individuality. This is the cocreating of rhythmical patterns. Reinforcing-distancing relationships is the incarnating of disclosing hiding meanings all at once. All four participants discussed the changing of relationships in light of the knowledge of having breast cancer. While all expressed becoming closer to certain individuals, even those relationships had elements of shielding from pain and preparing for life without the participant. Relationships were sought that were reflective of being an individual first, then as an individual who happens to have cancer.

#### Participant Statements

“...I go into any medical situation with medical people and I know what I want. I know that I want to have a feeling very strongly that they are looking at me, and that they have kind of stopped in the rush of the day, and that they are really paying attention to me, and in some cases that's what happens from the start, and in other cases where I have my doubts it's gonna happen, I try to structure it, I take the initiative to structure it.”

“There are some friends who have backed away because they don't know how to deal with it, and I think about that and I think that kind of hurts a little bit – she doesn't want to call me and hang out with me because I'm sick - but I understand. If they can't deal with it, it makes them sad, or if they are protecting themselves for when I do die so they won't hurt so much because they've been

hanging around with me, I can understand why they would want to do that and that's okay, too. I live a full life, it's not like I'm lonely and home by myself or crying for friends or anything, so if they don't want to deal with it, that's okay, it's just their problem, it's really not mine."

"...there are about a hundred people who want to know what my last CT was...if he (spouse) has to listen to a phone call that I need to make or, you know, it's rough on him, I try to make those and take some of the calls in privacy. If he's in the shower and I know that I need to make a phone call, and we can go over something he's heard ten times already, I always wait until he's in the shower and then make that call."

"There are some people that have trickled out of your life because they're not strong enough to act normal around you or whatever it is just to be. You know, I still like movies, I still like cheesecake. My mouth is sore and I still like to go fishing, and I still like to be told I look nice, you know, when you make an effort to get dressed. Why some people find it so hard to talk to you, but we don't have to talk about cancer. I'm here today like you and want to talk about past things."

Reinforcing-distancing relationships preserving individuality is the incarnating of disclosing hiding meanings all at once, which is interpreted as *connecting-separating* from the second principle of Parse's theory (Parse, 1997).

The third concept, choosing opportunities clarifying purpose, is related to changing the way of becoming with a situation. All the participants hoped to keep happy

memories alive in the minds of loved their loved ones. They all were preparing for death through reflections of spirituality, a sense of carrying on after physical death.

### Participant Statements

“I kind of wonder what I’m supposed to be doing with this time. It just really worries me. I talked to one of the counselors at (hospital) about it. I really haven’t been shown any bright light or visited by a guardian angel or anything I can grasp that I know what I’m supposed to be doing with this time. I really don’t know other than trying to get by. That doesn’t seem quite good enough...I’m not afraid to die, I don’t know why you’re supposed to be even, I don’t know why you would be. Probably because we don’t know what to expect - - the unknown, but I don’t think you should be scared...”

“I would rather have non-relatives taking care of me, and then my own family and friends come and see me, you know, and have better memories of me than just the sad memories of taking care of a shriveling up body, and that’s all very noble and wonderful, but I really don’t want my husband’s last memories of me to be like that.”

“Oh I would (take chemo again), I’d have to, my life does not belong to me, I have children. If I were single and if I had no children, I wouldn’t go through this for nothing. I would just say ‘bye,’ I’d check out, I’d die. But my life doesn’t belong to me anymore. I’ve brought kids into this world, and it would be really, really selfish of me to just say ‘sorry this hurts too much, I don’t want to.’ I can’t do that. My kids are... you never stop needing your mom. I’m forty-one years old and I still need my mom, so I’m gonna do whatever I have to do.

Now, I will not become a burden to my children, you know what I mean? I'm not going to go on until I'm blind and crippled and, you know, can't move and they have to take care of me. I'm not gonna do that, because I don't want to be remembered like that either....even if I'm not physically able to do things, as long as I can still smile and be happy with this, I'm still being their mom."

Choosing opportunities to clarify purpose is the transcending with the possibles, which is interpreted as *powering unique ways* from the third principle of Parse's theory (1997).

Structural integration is connecting the structure of the lived experience with the theory. The meaning of the quality of life for women living with advanced breast cancer, then, is the shifting of priorities as disclosing hiding meanings all at once while transcending with the possibles.

Conceptual interpretation. Conceptual interpretation specifies the integrated structure of the lived experience with the concepts of the Human Becoming Theory. The structure of the meaning of quality of life for women living with advanced breast cancer then moves up the ladder of abstraction to the theoretical structure of the Human Becoming Theory: quality of life is *valuing the connecting-separating of powering unique ways*. This progression of abstraction to conceptual interpretation can be seen in Figure 1.

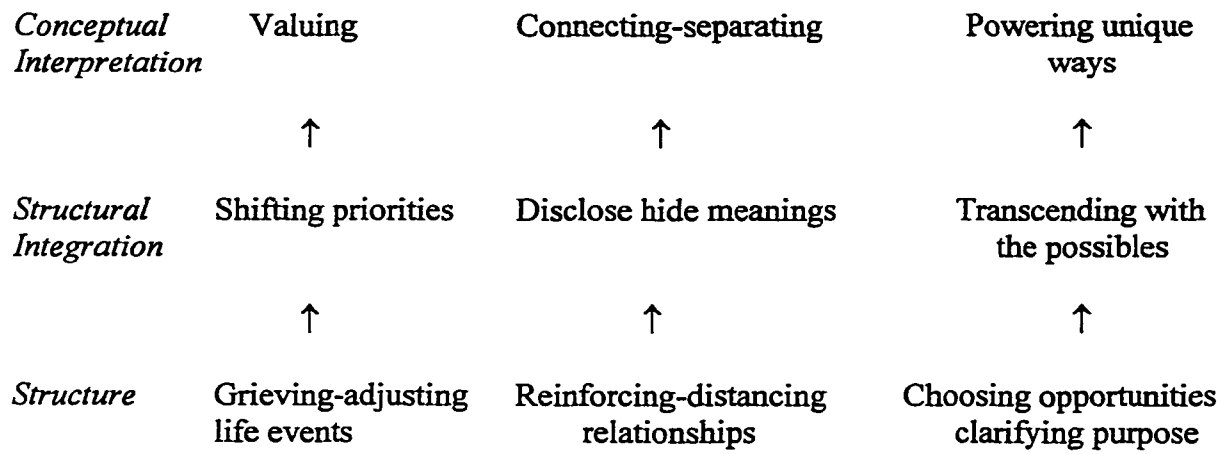


Figure 1. Progression of abstraction to conceptual interpretation.



## CHAPTER V

### DISCUSSION AND IMPLICATIONS

#### Discussion of the Findings

Review of the literature was performed to determine if the three core concepts emerging from this study were also described in other quality of life (QOL) studies. Studies involving the structure of the meaning of QOL in women living with advanced breast cancer were not found. Other qualitative studies involving the lived experience of women with breast cancer have been done (Carter, 1989; Carter, 1993; Chiu, 1999; Coward, 1990; Nelson, 1993; Pelusi, 1990), but none have specifically described the phenomenon of the structure of the meaning of QOL. Searching-for-meaning-in-life (Chiu, 1999), self-transcendence (Coward, 1990), and meaning of survivorship (Carter, 1989, 1993; Nelson, 1993; Pelusi, 1990) were the focal phenomena under study in those inquiries.

Numerous QOL studies have been conducted with cancer patients in general involving elements of qualitative inquiry, such as semi-structured interviews or open-ended questionnaires (Cella et al., 1993; Ferrell et al., 1992a, 1992b; Ferrell, Dow, & Grant, 1995; Haberman, Bush, Young, & Sullivan, 1993). Extensive studies regarding cancer patients discuss the utility of QOL assessment scales or employ their use (Aaronson, 1988; Calman, 1987; Chamberlain, 1985; Clark & Fallowfield, 1986; Clinch & Schipper, 1993; Cohen, Mount, Tomas, & Mount, 1995; deHaves, deRuiter,

Temperlaar, & Pennink, 1992; Donovan, Sanson-Fisher, & Redman, 1989; Ferrans, 1990; Grant, Padilla, Ferrell, & Rhiner, 1990; Guyatt, Feeny, & Patrick, 1993; Holmes & Dickerson, 1987; Kaplan, 1993; Levine et al., 1988; Moinpour, 1994; Osoba, 1991; Padilla, Grant, & Ferrell, 1992; Schag & Heinrich, 1990; Schipper, 1990; Sprangers, Cull, Bjordal, Groenvold, & Aaronson, 1993; Tchekimedian & Cella, 1990; Williams & Wood-Dauphinee, 1989).

Literature review for this study involved a two-step process. The three core concepts of this study are discussed in light of similarities to concepts of other studies, while theoretical development is strengthened through comparison of the structural and/or conceptual levels of abstraction of this inquiry to previous studies utilizing Parse's research methodology.

Grieving-adjusting remaining connected in ordinary life events. In general, the literature on the phenomenon of coping describes the core concept of grieving-adjusting remaining connected in ordinary life events as illustrated in this research. Lazarus and Folkman (1984), in their conceptual framework for the Adaptational Outcome of Coping, describe how a threat presents itself to a person, who then appraises the situation and develops strategies to manage the situation resulting in an adaptational outcome. This coping process can be seen in the grieving reaction of the woman with breast cancer facing the mortality of her diagnosis and subsequent life changes, then adjusting by shifting priorities in order to remain a part in those events that are meaningful to her. In a study by Krause (1993), coping in cancer patients was comprised of active-cognitive and active-behavioral methods in which continuing with work, activity, and relationships with friends and relatives played an important part.

Grieving-adjusting remaining connected to ordinary life events was structurally interpreted within the Human Becoming Theory as shifting priorities, and conceptually integrated as *valuing*. A similar outcome was described in a study by Smith (1990), describing the struggling through a difficult time for unemployed persons. In this study, a core concept was grieving the loss of what was cherished. Grieving was found to be separating from what was, while connecting with it in a different way through restructuring its meaning within an ever-unfolding context. A woman faced with the physical, spiritual, and emotional implications of metastatic breast cancer grieves the loss of life unencumbered by disease, the loss of what-was and some dreams of not-yet. This is related to Parse's concept of *valuing* related to structuring personal meaning. Valuing is a process of choosing and affirming what is most important; shifting priorities to keep connected to what is most important thus becomes significant. According to Smith (1990), the abrupt loss of something valued shatters the personal matrix that frames all that is imaged from one's multidimensional experiences, transforming personal reality. Grieving is creating anew the personal value matrix through reassigning meaning to what is lost within the context of the totality of emerging life experiences. Through adjusting priorities, a means of coping with the new reality occurs.

Reinforcing-distancing relationships preserving individuality. In a study by Carter (1993), the concept of authentic self was uncovered which describes elements of this study's concept of reinforcing-distancing relationships preserving individuality. Carter describes how women in the study interpreted cancer as a protest about something in their lives that gave them the permission to be more authentic. They described the emergence of a more authentic self that was then shaped over time through interactions

with others. Many women emerged from the cancer experience with a clearer sense of self, gratitude for life, and strength and confidence in their ability to manage life crises (Carter, 1993). The experience of living with breast cancer has caused them to re-evaluate relationships; to develop those that are significant, to let go of those that are no longer fulfilling, thus honoring the individual's emerging self through the experience. A study on healing through art with women with breast cancer also reflected this emerging authenticity: women who at first were reluctant to express themselves through creative works about the cancer experience eventually "...reported a liberation from the burden of unexpressed emotion once they committed their innermost thoughts to a tangible form through art" (Predeger, 1996, p. 52). The healing-art group provided a safe place away from the facades often needed to survive among well-meaning family and friends (Predeger, 1996).

Reinforcing-distancing relationships preserving individuality was structurally interpreted within the Human Becoming Theory as disclosing hiding meanings all at once, while conceptually integrated as *connecting-separating*. Numerous studies have similarly described connecting-separating as an element of a lived experience (Allchin-Petardi, 1998; Bunker, 1998; Parse, 1996b; Parse, 1996c). Connecting-separating is a rhythmical pattern of moving with, while simultaneously moving away from, specific phenomena. Allchin-Petardi (1998), in a study describing persevering through a difficult time, further describes connecting-separating as one travels through life living health and specifying quality of life, one continuously chooses to move with certain phenomena. This naturally means moving away from certain other phenomena simultaneously. The women in this study described strengthening meaningful and rewarding relationships

while letting go of those based upon a false reality. Within meaningful relationships, disclosing- shielding was occurring as a testimony to the authentic self.

Choosing opportunities clarifying purpose. The phenomenon of transcendence in the literature aptly describes the third concept of this study, choosing opportunities clarifying purpose. Coward (1990) and Pelusi (1997) described women facing a terminal cancer diagnosis with feelings of transcendence. Frankl (1969), in his study of Nazi war camp prisoners, describes the ability of individuals to transcend difficult experiences and make meaning in their lives. According to Frankl (1969), individuals transcend in three ways: a) giving to their world through creative works, b) taking from their world through receptivity to others' care and appreciation of the world around them, and c) adopting an attitude of acceptance in situations that cannot be changed. Steeves and Kahn (1987) described transcendent experiences in hospice patients that were a source of comfort and meaning during a time of suffering. The women in this study displayed transcendence by choosing opportunities to connect with loved ones or nature, by actively leaving a legacy, by questioning meaning beyond themselves, by accepting the support of others, and by living to the fullest in the moment.

Choosing opportunities clarifying purpose was structurally interpreted within the Human Becoming Theory as transcending with the possibles, while conceptually integrated as *powering unique ways*. Smith's study (1990, p. 23), describing struggling through a difficult time for unemployed persons, similarly describes the concept of powering in a lived experience:

Just as the sculptor uncovers a masterwork with an amorphous medium through receptivity and faith in personal creativity, the individual struggling through a

difficult time uncovers a new path, direction, or way of being within the rhythms of change through surrendering faith to the flow of events. This uncovering is cocreated through affirming personal worth, strengths, and talents as the person forges new ways of becoming with the ambiguity.

Choosing opportunities clarifying purpose is transcending with the possibles through asserting self in the rhythms of becoming, thus powering unique ways of being.

The three concepts derived from this study are in keeping with similar concepts from other studies. Concepts previously undefined were not uncovered in this study for this particular population.

#### Limitations of the Study

The homogeneity of the sample in regards to age, racial background, and education may limit the scope of uncovering other themes related to the quality of life for women living with advanced breast cancer. Consideration must also be given to the idea that the participants' willingness to be in this study may distinguish them from others living with advanced breast cancer who did not want to be part of a dialogue.

#### Implications for Research

To further enhance understanding of the structure of the meaning of quality of life for women living with advanced breast cancer, other studies might be initiated that focus on the meaning of the core concepts. For example, a qualitative study could be developed on the lived experience of grieving-adjusting remaining connected to ordinary life events, reinforcing-distancing relationships preserving individuality, or choosing opportunities clarifying purpose. These studies would add to the knowledge base of lived experiences and the Human Becoming perspective. It would also add to the knowledge

base of QOL literature. Uncovering the structure of the meaning of quality of life for different populations may or may not support the concepts outlined in this study.

Examples of populations might include the QOL of women facing a terminal illness of a different sort, men facing a terminal illness, individuals from across the lifespan facing a terminal illness, and individuals from different cultural perspectives facing a terminal illness. It is not the intent of studies describing a lived experience to be able to completely define a situation for all people. However, a better understanding of the complexities surrounding any one lived experience increases the individual's likelihood of becoming through a supportive environment.

The potential also exists for research combining elements of this qualitative study with quantitative methodologies. Incorporating elements of the three core concepts into QOL assessment scales may strengthen reliability and validity parameters while encompassing more dimensions of the experience.

#### Implications for Practice

According to Daly et al. (1996), Parse's theory of Human Becoming offers nurses the opportunity to explore and expand understanding of how persons define and live quality in day-to-day life from a discipline-specific perspective. Nursing practice that is rooted in nursing theory more closely encompasses phenomena of nursing concern and guides practice in ways that are meaningful to persons who are in the care of nurses.

Theory-based nursing practice evolves by filtering nursing theoretical structures through practice methodologies congruent with the ontology (Smith, 1990). The three principles of the Human Becoming Theory involve paradoxical rhythms that describe the human's way of living. These paradoxical rhythms are ways humans structure meaning,

cocreate rhythmical patterns, and cotranscend with the possibles through powering (Parse, 1997). The theoretical structure, developed from the findings of this study to guide practice is: The meaning of quality of life for women living with advanced breast cancer is the shifting of priorities as disclosing hiding meanings all at once while transcending with the possibles.

Applying theoretical structure to practice, then, the nurse engages the individual in a discussion of the meaning of the health situation while being fully present. This requires attentively dwelling with the uniqueness and dignity of the individual. Knowing that grieving-adjusting to remain connected in ordinary life events is an essence of the quality of life for women living with advanced breast cancer, the nurse bears witness to the loss of what was and encourages exploration of the meaning of the loss so as to cocreate new meaning in the adjusting of priorities for the present and will-be.

The nurse is sensitive to the paradoxes in the health experience. Reinforcing-distancing relationships is a paradoxical rhythm and having knowledge of its expression can assist the individual in illumination of understanding what seems to be opposing forces. "Glimpsing both sides of the experience leads to a powerful insight that contextualizes the struggling in a new way and provides a fuller perspective on the range of choices that are available" (Smith, 1990, p. 27). Disclosing one thought automatically hides another, and the choice remains as to which to reveal for purposes of authenticating relationships.

The nurse also can encourage the individual in exploring the possibles to move beyond the what is. Knowing that choosing opportunities for clarifying purpose is an essence of the quality of life for women living with advanced breast cancer, supporting



those endeavors that have meaning for the individual aids in transcending the limitations of the health situation to a state beyond boundaries. Personal meaning unfolds in the experience, and the nurse can give validation to the experience. The process of healing can occur in the absence of curing. "Learn to tolerate the darkness without fixing it, and by lighting the candle of understanding, help someone see his or her way" (Radziewicz, 1997, p. 1694).

### Summary

The purpose of this study was to uncover the structure of the meaning of quality of life for women living with advanced breast cancer. Through use of Parse's research methodology based upon the Human Becoming Theory, the findings of the study were discussed in relation to some other research and some practice implications were surmised. The study itself furthers nursing science by enhancing the Human Becoming knowledge base.

## APPENDIX A

## Script for Potential Participants

Dear Co-participant:

Thank you for expressing interest in my study. My name is Maureen Mika Eberly. I have been a registered nurse for the past 17 years. I am currently back in school at Grand Valley State University working towards a Master's degree in nursing. I plan to become a nurse practitioner, and my area of interest is in women's health.

I am doing a study for my thesis requirement. My interest is in the quality of life of women living with breast cancer. I would like to learn more about how the experience of cancer is changing your outlook on life.

I am interested in this subject because as a nurse practitioner, I will be in the position of providing health care to women. I want to learn from you things that have made a difference on your quality of life. In that way, I can try to support women during difficult times by encouraging those situations that provide help and comfort to them. I have experienced the loss of my mother to breast cancer, and I wish I had known then how to be more supportive of her inner needs and desires as she was living with cancer.

To be a part of this study, there are a few requirements:

1. If you agree to participate in the study, you will be asked questions about your life since you have been diagnosed with breast cancer. Those ten questions are included at the end of this letter.
2. You need to be able to meet with me to have the interview. This would be one meeting, lasting as long or as short as you like, at a time and place of your choosing that allows for privacy. A second time can be arranged if you prefer to complete the interview in two sittings.

3. You can choose to stop the interview at any time for any reason without it affecting the care you receive.
4. You can choose not to be in the study even after the interview, and I will supply you with names and phone numbers of people to contact if you have any concerns.
5. The interview will need to be audiotaped so that I can spend time going over it. You can also write down your thoughts before the interview if that would help you to explain your thoughts and feelings, although this is not necessary to participate.
6. There are no right or wrong answers.
7. Your name will not appear on any of the papers to keep things confidential.
8. Before the final report is printed, you will be asked if you want to review how I categorized your answers to see if they correctly reflect your thoughts and feelings.
9. You may request a final summary of the study.

Hopefully, you, too, will feel the benefit of expressing some of your deepest thoughts, and in knowing that you are contributing to the science of nursing so that we can better meet your needs.

Thank you for your time and willingness to listen to me. If you are interested in being a part of my study, you can let me know today, or you can contact me later. My name, again, is Maureen Mika Eberly. My home phone is 616/842-2860, and I do have a message machine if I'm not there. You can write me at home; my address is 14738

Indian Trails, Grand Haven MI 49417. Or if you prefer, you can reach me by e-mail, and that address is [eberlym@river.it.gvsu.edu](mailto:eberlym@river.it.gvsu.edu) .

Interview questions:

1. What is life like for you?
2. What contributes to your quality of life?
3. What may diminish your quality of life?
4. What are your priorities right now?
5. Who is most important to you?
6. What changes in your routine or relationships might change your quality of life?
7. How would you like to change your quality of life?
8. What can you do to make this happen?
9. What are your concerns?
10. What are your hopes and dreams?

## APPENDIX B

## Consent Form

I understand that this is a study of how living with cancer has changed my outlook on life, and especially those experiences that have helped me deal with my diagnosis. The knowledge gained is expected to help health care professionals, such as nurses, to provide health care in a manner which will better meet the needs of women experiencing a life-altering event.

I also understand that:

1. participation in this study will involve one interview regarding my experience of living with breast cancer and how it has affected how I deal with life. It can be as short or as long as I would like.
2. the interview will consist of describing this experience to my satisfaction, and that the researcher (Maureen Mika Eberly) will encourage me to talk as much as I want to. A second interview can be arranged if I prefer to answer the questions in two sittings.
3. I will be interviewed in a place of my choosing and at a time convenient to me.
4. I have been selected for participation because I feel I am able to describe my experience of living with breast cancer.
5. it is not anticipated that this study will lead to physical or emotional risk to myself and it may be beneficial to have someone to listen about my experience of living with breast cancer.
6. the information I provide will be kept strictly confidential and the data will be coded so that identification of individual participants will not be possible.
7. once my interview has been studied by the investigator, I will be encouraged to review her interpretation of my thoughts for accuracy. Maureen Mika Eberly will contact me in the future to discuss this.
8. a summary of the results will be made available to me upon my request.

I acknowledge that:

“I have been given the opportunity to ask questions regarding this research study, and that these questions have been answered to my satisfaction.”

“In giving my consent, I understand that my participation in this study is voluntary and that I may change my mind at any time and decide not to participate. If I

decide to no longer participate, I just need to inform Maureen Mika Eberly of my decision.”

“I hereby authorize the investigator to release information obtained in this study to scientific literature. I understand that I will not be identified by name.”

“I have been given the phone numbers of the researcher and the chairperson of the Grand Valley State University Research Review Committee. I may contact them at any time if I have questions.”

I acknowledge that I have read and understand the above information, and that I agree to participate in this study.

\_\_\_\_\_  
Witness/Date

\_\_\_\_\_  
Participant’s Signature/Date

\_\_\_\_\_ I am interested in receiving a summary of the study results.

Researcher: Maureen Mika Eberly, RN  
Kirkhof School of Nursing  
Grand Valley State University  
212 Henry Hall  
Allendale, MI 49401  
616/895 – 3558

home address:  
14738 Indian Trails  
Grand Haven, MI 49417  
616/842 - 2860

If you have any questions about your rights as a subject in this study, you may call:

Paul Huizenga, Chair  
Grand Valley State University Research Review Committee  
Allendale, MI 49401  
616/895 - 2470



## APPENDIX C



GRAND VALLEY  
STATE UNIVERSITY

1 CAMPUS DRIVE • ALLENDALE, MICHIGAN 49401-9403 • 616/895-6611

February 10, 1999

Maureen Mika Eberly  
14738 Indian Trails  
Grand Haven, MI 49417

Dear Maureen:

Your proposed project entitled "*Quality of Life Through Self-Transcendence in Women Living with Advanced Breast Cancer*" has been reviewed. It has been approved as a study which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,



Paul Huizenga, Chair  
Human Research Review Committee

## LIST OF REFERENCES

## LIST OF REFERENCES

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