

CANCER: THE LIVED EXPERIENCE OF THE OLDER ADULT

Marty Pentz

Submitted to the faculty of the University Graduate School in partial fulfillment of the requirements for the degree Doctor of Philosophy in the School of Social Work.

Indiana University

April 2002

Accepted by the Graduate Faculty, Indiana University, in partial
fulfillment of the requirements for the degree of Doctor of Philosophy
for

Martin Pentz

Doctoral Committee

Margaret E. Adamek, Ph.D. – Chair
Social Work

William H. Barton, Ph.D.
Social Work

David Moller, Ph.D.
Sociology

Valerie Nash Chang, Ph.D.
Social Work

Date of Oral Examination
February 11, 2002

Copyright © 2002

Marty Pentz

ALL RIGHTS RESERVED

Acknowledgments

This dissertation came about through the help of a number of individuals. Margaret Adamek, Ph.D., was tireless and quick with feedback and encouragement as my committee chair. Her insightful comments greatly increased the value of this dissertation. Dr. Adamek's passion for older adults helped me remain focused on the true heroes of any research project, the participants. Bill Barton, Ph.D., was indispensable as my primary advisor through my course work and research internship. David Moller, Ph.D., gave support and valuable feedback on my final product. Valerie Chang, Ph.D., was of great help with her feedback and advice on qualitative research.

My deepest thanks go to the thirteen participants who made this research possible. Three knew they were close to death and wanted to share their stories. The rest shared openly of their thoughts and feelings in relation to having cancer. It is to these thirteen men and women and all those who suffer from cancer that this dissertation is dedicated.

Without the support and grammatical editing of my wife Joy, this dissertation would not have been nearly as enjoyable to complete. Her love, support, and typing of participant's transcripts were wonderful. I also received help from my three children (Daniel, Emily, and Elise) in the form of their vast computer skills. I am deeply appreciative of my family's patience, humor, wisdom, and unabiding love.

Half of those who are diagnosed with cancer in any given year are over age 65.

Approximately 3.1 million males and 2.3 million females over age 65 became ill with cancer in 2000. The purpose of this study was to investigate the psychosocial experience of the older adult with cancer to enable social workers to better serve this population. It is not clear from previous research whether their lived experience in adapting to cancer is different from that of younger persons. Thirteen older adults with cancer were interviewed in-depth along with a focus group of three oncology social workers. Older adults are often viewed as frail and not able to contribute to society or continue to grow as a person. In contrast, the older adults in this study were mostly resilient and full of life, despite the possible devastation of cancer. The themes that emerged from the data were almost unanimously positive: 1) social support, 2) a positive attitude (acceptance, gratitude, keeping a present-focus), 3) spirituality-faith (belief in God, hope, and helping others), 4) positive coping (past coping, assertive behavior, reminiscing, and humor), and 5) loss (loss of weight and appetite, loss of energy and self-care ability, loss of social relationships, loss of activities, and loss of belief in one's competence). Practice applications, including reminiscence therapy and spiritual eldering, are discussed in relation to working with resilient and non-resilient older adults with cancer.

Margaret E. Adamek, Ph.D. – Chair
Social Work

William H. Barton, Ph.D.
Social Work

David Moller, Ph.D.
Sociology

Valerie Nash Chang, Ph.D.
Social Work

Table of Contents

Acceptance Page	ii
Acknowledgments	iv
Abstract	v
Table of Contents	vi
List of Tables	x
List of Figures	x
Chapter 1: Introduction	1
Chapter 2: Literature Review	5
Chapter 3: Philosophical Foundations and Research Methods	14
Initial Process	18
Criteria of Soundness in Qualitative Research	22
Description of Participants	24
Methods of Recruitment and Data Collection Procedures	25
Demographic Information	26
Data Analysis	27
Ethics, Social Work Research, and Protection of Human Research Participants ..	30
Participant Selection	32
Chapter 4: Participants	33
Albert.	33

David.	34
Glenda.	35
Judy.	36
Jeff	37
Larry	38
Bill	39
Hubert	40
Hank	40
Isaac.	41
Jack.	42
Mildred.....	43
Michael.	44
Chapter 5: Results.....	47
Social Support.....	48
Spirituality-Faith (Belief in God, Helping Others, Hope)	56
Positive Attitude.....	63
Acceptance	70
Lack of fear	75
Gratitude.	78
Keeping a present-focus	82
Positive Coping Strategies	84

Past coping	84
Assertive behavior	86
Reminiscing	88
Humor	89
Loss.	92
Loss of weight and appetite	92
Loss of energy and self-care ability	94
Loss of social relationships	97
Loss of activities	100
Loss of belief in one's Own competence	104
Chapter 6: Conclusion and Implications	107
Resilience	109
Pattern Analysis	116
Study Themes and Resilience	121
Social Support	121
Spirituality-Faith	124
A Positive Attitude	127
Positive Coping Strategies	131
Loss and Fatigue	132
Grounded Theory	137

Relevance for Social Work Practice and Interventions	143
Spiritual Eldering	144
Family and Relationship Counseling	146
Reminiscing	149
Building a Support System	150
Individual and Group Counseling	151
Volunteerism	154
Case Management	154
Summary of Interventions	155
Limitations, Recommendations, and Plans for Future Research	158
Conclusion	162
Postscript	165
References	166
Appendix A: Interview Guide for Older Adults with Cancer	179
Appendix B: Interview Guide for Focus Group of Social Workers	180
Appendix C: Older Adult Informed Consent	181
Appendix D: Social Worker Informed Consent	185
Appendix E: Open Codes Second Iteration	188
Appendix F: Open Codes Third Iteration	190
Appendix G: Axial Codes	191
Appendix H: Vitae	192

List of Tables

Table 1: Demographic Profile of Participants	46
Table 2: Consistency with Themes Found in Previous Studies of Older Adults	114
Table 3: Pattern Analysis Among the Major Themes	117
Table 4: Pattern Analysis of Extreme Fatigue	133

List of Figures

Figure 1: Grounded Theory of a Cancer Diagnosis/Treatment, Resilience, and the Subjective Experience of Older Adults	138
Figure 2: Interventions for Older Adults with Cancer	155

CANCER: THE LIVED EXPERIENCE OF OLDER ADULTS

Chapter 1: Introduction

Betty was a 67-year-old widower when she was diagnosed with cancer. Her husband of 41 years died of cancer five years prior to her diagnosis. She had been newly married for three months when she was diagnosed with lung cancer. Her husband returned to drinking, stating that he could not go through this again. His previous wife had also died of cancer. After her cancer diagnosis Betty did not have hope for a long and healthy old age. She told her social worker that she wanted to clean up her relationships with her children before she died. She also desired to spend as much time as possible with her children and grandchildren. She was able to accomplish these tasks with the help of a social worker, her family, friends, and her church. She reached another of her goals; she left this world as she wanted to, with some dignity and grace.

This research is about the “Bettys” of the world, older adults with a cancer diagnosis. Cancer risk increases with age. Half of those who are diagnosed with cancer in any given year are over age 65 (Monfardini & Yanick, 1993). McKenna (1994) estimates that nearly 1 in 4 males (23%) and 1 in 5 females (17%) between 65 and 85 years of age will become ill with cancer. This translates into approximately 3.1 million males and 2.3 million females becoming ill with cancer in 1999 (U.S. Bureau of the Census, 2000). Two-thirds of all colon and rectal cancers and half of all lung cancers are diagnosed in men and women over age 65. Fifty-four percent of all breast and uterine cancers in women and 80% of all prostate cancers in men are diagnosed at age 65 or older (McGill & Paul, 1993).

Cancer deaths by age were 263.6 per 100,000 population for 25-64 year olds and 1123.7 for those 65 and over in 1997 (U.S. Bureau of the Census, 2000). Just over 131,000 people ages 25-64 died of cancer in 1997 and almost 400,000 people 65-years-old and over died of cancer in the same year.

Considering death rates from cancer in relation to the growing population of older adults clarifies the magnitude of this issue. In 1999 there were 34.5 million persons age 65 and over in the United States. By the year 2010, it is projected there will be 39.4 million, an increase of 15 percent (U.S. Bureau of the Census, 2000). Using the 1997 cancer death rates (above) this translates into approximately 4.4 million cancer deaths in 2010 for the over 65 age group. Even with advances in cancer treatment, this promises to be a large number of cancer deaths. In the period 2010 to 2030, the older adult population will grow by 75% to an estimated 69 million. This growth rate exceeds that for those under age 65, raising the proportion of the older adult population from 13% to 20% of the total population (U.S. Bureau of the Census, 1992). These changing demographics will necessitate more social workers being trained in working with cancer patients and end-of-life care.

Older adults with cancer are typically studied from a medical model of illness, stressing the impact of cancer and medical treatment on the physical body (Varricchio, et al., 1996). Studies specific to the lived experience of older adults with cancer have a limited research base in the social science literature (Houldin & Wasserbauer, 1996; McGill & Paul, 1993; Varricchio et al., 1996). In a search of CancerLit from 1983-

1999, (using psychosocial, cancer, and elderly as search terms), I found only eight out of 870 articles that were specific to older adults. A number of studies included older adults, but did not focus on them. Research has also shown that older adult cancer patients often do not feel listened to by health care professionals (McGill & Paul, 1993; Tishelman, 1993; Varricchio, et al., 1996). Older adults perceive that they have less contact and feel less engaged with health care professionals (McGill & Paul, 1993; Tishelman, 1993; Varricchio, et al., 1996). Studies by Ackerman (1993) and Madan, Aliabadi-Wahle, and Beech (2001) found that cancer treatments varied substantially based on the age of the patient. The older the patient, the less treatment was recommended.

In sum, older adults comprise the fastest growing section of our population and are inflicted with a higher rate of cancer than younger adults. A theoretical understanding of the lived experience of older adults with cancer is needed to increase our knowledge of this population and their needs. This study sought to provide a beginning theoretical understanding.

This study describes, from the perspective of the participants, the lived experience of older adults with cancer. As with many qualitative studies, this study aimed to “understand and uncover” (Hoshmand, 1989; Polkinghorne, 1991; Reason, 1994) the meanings older adults with cancer assigned to their lived experience. A long-term objective of the researcher is to assist social workers to better meet the needs of older adults with cancer. By better understanding the lived experience of older adults with

cancer from their perspective, social workers will be better able to help them meet their needs.

Chapter 2: Literature Review

Few studies specifically address the psychosocial experience of older adults with cancer. Psychosocial aspects of a cancer diagnosis have been variously referred to in the literature as psychosocial factors (Heim, Valach, & Schaffner, 1997; Henderson, A., 1995; Shaker, 1992), adaptive tasks (Postone, 1998; Tope, et al., 1993), and the psychosocial impact of a cancer diagnosis (Nee, 1995; Winscot, 1993). For this study "psychosocial" is defined as interactions between the person and his or her environment and the internal experience of the person. This includes psychological, social, physical, and spiritual functioning within the context of their life and disease state (Goldstein, 1995; Tope, Ahles, & Silberfarb, 1993).

A number of authors have asserted that the psychosocial impact of a cancer diagnosis can be almost as traumatic as the physical effects (Harpham, 1995; Heim, et al., 1997; Singer, 1983). Cancer is associated with significant amounts of psychosocial morbidity (Postone, 1998). There are also studies that report a relationship between increased psychosocial functioning through counseling of various types and increased longevity and quality of life of cancer patients (Nee, 1995). A number of psychosocial factors are reportedly related to adaptation to a cancer diagnosis. Singer (1983) illustrated that a cancer patient and his/her family must deal with feelings of isolation and loneliness, dependence on others, changes in the family structure, and feelings of helplessness. One could expect that many older adults would already be dealing with

many of these factors prior to being diagnosed with cancer. Although not a focus of this study, how a diagnosis of cancer adds to these changes in later life is not clear.

In a qualitative study Krause (1993) studied 123 cancer patients to examine what problems they face. The participants ranged in age from 28 to 80 years, with a mean age of 57.5. The problems these cancer patients faced were not differentiated by age. Krause (1993) reported that fear impacted many of the cancer patients' sleep patterns, their ability to rest while awake, and their ability to manage finances. Coping with the reactions of "horror, shock, terror, surprise, anger, time standing still, emptiness, externalness, a sense of unreality, a punishment, or simply fate" placed more adaptation demands on the patient than anything else (Krause, 1993, pp. 34-35). Other factors that impacted psychosocial adaptation were 1) cancer's impact on activities of daily living, 2) uncertainty, 3) lack of information, and 4) home-care and rehabilitation issues (Krause, 1993).

Winscot (1993) examined the psychosocial needs of 70 cancer patients and their spouses. The cancer patients ranged in age from 32-82; however, the results were not specified by age group. Winscot (1993) used the Brockopp Needs Assessment Inventory (BNAI) and the Beck Depression Inventory (BDI). The BNAI has 25 statements and measures the psychosocial needs of hope, honesty, information, emotional expression, and discussion of dying and death. The most important needs were the need for information and emotional expression followed by hope, discussion of issues related to dying and death, and honesty, respectively.

The BDI is a summative scale that measures level of depression using the following categories: 1) normal/asymptomatic, 2) mild/moderate depression, 3) moderate/severe depression, and 4) extremely severe depression. Forty-nine (70%) cancer patients in Winscot's study were in the normal/asymptomatic range, 18 (25.7%) were in the mild/moderate depression category, 2(2.9%) were moderately to severely depressed, and 1 (1.4%) was extremely severely depressed. With the BDI being normed for adolescents and adults, but not older adults, (Beck, 1967), one might question the validity of these results for the older participants. However, differences by age were not specified.

Bloom and Spiegel (1984) found that social support was related to psychological well-being of cancer patients. In the same vein, family functioning is related to the psychosocial impact of a cancer diagnosis (Bordieri & Solodky, 1992; Fobair & Zabora, 1995; Nee, 1995; Winscot, 1993). Several studies demonstrated that perceptions of pain and pain control in cancer patients were also related to psychological well-being (Bloom & Spiegel, 1984; Henderson, A., 1995; Henderson, P., 1997; Novotny, Hyland, Coyne, Travis & Pruyser, 1984; Tope et al., 1993). Novotny et al. (1984) outline 10 psychosocial tasks that cancer patients often need to surmount to adapt to a cancer diagnosis. These tasks are 1) coping with illness and its associated problems, 2) coping with life as it is altered by the cancer, 3) adjusting to pain and incapacitation, 4) dealing with the hospital environment, 5) adjusting to special treatment procedures, 6) developing effective relationships with professional staff, 7) maintaining a reasonable emotional

balance, 8) preserving a satisfactory self-image, 9) maintaining relationships with family and friends, and 10) preparing for an uncertain future. It was not clear from this study if all or only some cancer patients deal with all ten tasks. Novotny, et al., (1984) also did not specify which cancer patients successfully completed these tasks and which did not. Illness-related issues that are known to impact psychosocial adaptation are feelings of alienation, concerns about possible mutilation, feelings of vulnerability, and thoughts about mortality (Novotny et al., 1984).

A number of authors have examined the differing psychosocial needs of cancer patients in various stages of the illness process. Blum and Blum (1988), using their experience as oncologists, identify four stages in the cancer process where assessment of needs is crucial: 1) the initial diagnosis, 2) completion of treatment, 3) treatment failure, and 4) communication of a terminal diagnosis.

At the initial meeting, when cancer patients are told of their diagnoses, a number of factors need to be assessed, such as, how they coped with past crises, the patient's and significant other's major concerns, individual roles and responsibilities, and who is helpful when the patient is upset. When treatment ends, the psychosocial assessment needs change (Blum & Blum, 1988). Issues to examine at this point are the patient's dependence on the health care system, the anxiety expressed when medical support is withdrawn, concerns about future symptoms, and the complication of life transitions brought on by cancer.

Another needs assessment is called for when treatment fails. Blum and Blum (1988) detail how patients need to deal with “realistic fears of increased symptoms and death” (p. 125). Patients are said to be at risk of experiencing rejection, depression, and anger. Confronting despair and bleakness is often needed at this point in the disease process. Many psychosocial factors come into play when patients are given a terminal prognosis. Further assessment of coping abilities is needed. Other factors to be assessed are the ability of the patient to be cared for in the home, and the availability, ability, and willingness of family and friends to help in the patient’s care. End-of-life issues such as artificial or mechanical support of essential life functions, palliative care, discussion of end time processes, and the sharing of feelings are critical to assess (Blum & Blum, 1988).

Heim et al. (1997) also tie psychosocial adaptation to the stages of the disease process. They studied 74 women with breast cancer with an age range of 35-88 and a mean age of 61. They found that whatever illness stage they were in, psychosocial support is a primary need. Henderson (1997) emphasizes the physical effects of the illness over time as a psychosocial factor. As one’s physical health declines, her or his psychosocial adaptation also declines.

In a quantitative examination, Boer, Elving, & Seydel (1998) examined the relationship between environmental psychosocial factors and mental health in cancer patients. They studied mental health as part of a larger study looking at quality of life and its relationship to quality of care. Boer et al., (1998) used the stress-coping model of

Lazarus (1966) as a framework. This model uses the objective health status of the patient and her or his appraisal of the severity of the disease in examining their mental health status. The study had 480 participants with an age range of 20-80 years and a mean age of 60.6 years. Results were not reported by age group. Mental health aspects of quality of life were measured using the RAND-36 (Van der Zee & Sanderman, qtd. in Boer, et al., 1998). The RAND-36 is an instrument to measure mental health, social functioning, role limitations due to emotional problems, and vitality. The psychometric properties of the RAND-36 were said to be sufficient, but how this was determined was not specified. Social support, degree of loneliness, general self-efficacy (power to produce results in one's own life), and social mobilization were also assessed.

The results suggested that the mental health of cancer patients was only slightly lower than that of the general population; differences were not statistically significant. Generalized self-efficacy and feelings of loneliness were found to have the greatest effect on the mental health of cancer patients. This study did not report any differences by age of the cancer patient.

There are a number of reactions to cancer that some view as pathological. Postone (1998) reported that 50% of cancer patients suffer from symptoms of depression and 30% have elevated levels of anxiety. In another study, 47% of cancer patients were reported to have a psychiatric diagnosis (Derogatis, Morrow & Ferring, 1983). Diagnoses included adjustment disorder (68%) and major affective disorder (11%). In a

related fashion, cancer patients are shown to adapt more effectively when their psyches are treated (Boer et al., 1998; Postone, 1998; Rowland, 1994).

Using a stratified probability sampling method, Shaker (1992) studied the psychosocial variables of psychological functioning, social networks, religiousness, self-rating of health, and social support. The first interview was an in-home structured interview focusing on predetermined psychosocial factors. The second interview was a 15-minute phone interview. Shaker used a pre and post-test with a three year interval. Patients with more advanced disease were shown to have poorer cognitive functioning, lower participation in activities, lower levels of private religiousness, and higher unmet emotional needs than those with less advanced disease.

Shaker (1992) also found higher depression scores for those with cancer than the general population. Those with cancer also reported greater unmet emotional needs than the control group without cancer. Social networks of cancer patients were not impacted more than controls. Of the 281 older adult cancer patients, 123 (43.8%) survived until the second interview. Analysis of demographic data revealed that older cancer patients and those who were not working at the time of the first interview were less likely to survive to the second interview. This was the only study found to exclusively focus on older adults with cancer.

In summary, a number of factors are related to effective adaptation to a cancer diagnosis. Consequences of a cancer diagnosis include feelings of 1) isolation and loneliness, 2) helplessness (Singer, 1983), 3) fear and uncertainty (Henderson, A., 1995;

Krause, 1993), 4) alienation, and 5) vulnerability (Novotny, et al., 1984). Although many older adults have some of these feelings (Hooyman & Kiyak, 1998), it is not clear from previous research whether their lived experience in adapting to cancer is different from that of younger persons. In addition to these emotions, other factors which affect adaptation are 6) dependence on others (Singer, 1983), 7) changes in family structure, functioning, and social networks (Bloom & Spiegel, 1984; Shaker, 1992; Singer, 1983), 8) perceptions of pain and pain control (Bloom & Spiegel, 1984; Henderson, A., 1995; Henderson, P., 1997; Novotny, et al., 1984; Tope, et al., 1993), 9) concerns about mutilation (Novotny, et al., 1984), 10) the need for information (Boer, et al. 1998; Henderson, A., 1995; Henderson, P., 1997), and 11) religiosity and spirituality (Gear & Haney, 1990; Shaker, 1992). Some studies stress the importance of assessing for mental pathology in the experience of cancer patients (Boer, et al., 1998; Derogatis, et al., 1983; Postone, 1998; Rowland, 1994). And lastly, hope, honesty, discussion of death and dying, and self-rating of health were outcome variables among cancer patients (Winscot, 1993).

A majority of the reviewed studies examined the negative aspects of a cancer diagnosis. Cancer is usually seen as a difficult, stressful, and depressing experience. None of the authors spoke of any positive outcomes associated with a cancer diagnosis. Yet, as Frankl (1970) found in Nazi concentration camps, it is possible that some good can come from any negative experience. With only one study examining psychosocial functioning with older adults (Shaker, 1992), it is clear more work needs to be done with

this population. The studies that include cancer patients over 65 are largely quantitative in nature and do not differentiate between constructs that may be particular to this population. While much valuable data has been gleaned from these quantitative studies, a more in-depth examination of the cancer experience of older adults is clearly needed. It is possible that older adult cancer patients have different needs than younger cancer patients (McGill & Paul, 1993). Research designed to understand the whole cancer experience is needed (Tope, et al., 1993). This research partially remedies this lack.

Chapter 3: Philosophical Foundations and Research Methods

This study focused on older adults for several reasons: their greater likelihood of getting cancer (Monfardini & Yanick, 1993), the growing number of older adults in the U.S. (U.S. Bureau of the Census, 1992), and the lack of research on older adults with cancer. My interest in this population stemmed also from my long history as a clinical social worker in nursing homes and my current teaching load in gerontological social work. Another reason I chose older adults is that a younger cohort is too close to home. In December of 1997 a person I was very close to, my 36-year-old sister Julie, died of colon cancer. In January 2000, my 50 year-old brother Steve died of pancreatic cancer. The methods used for countering possible inherent biases will be detailed later.

Many of the works on adaptation to a cancer diagnosis are theoretical in nature or are simply literature reviews (Blum & Blum, 1989; Harpham, 1995; Henderson, P., 1997; Novotny et al., 1984; Postone, 1998; Rowland, 1994; Singer, 1983). There have also been a number of studies using a post-positivist approach (Bloom & Spiegel, 1984; Boer et al., 1998; Bordieri & Solodky, 1992; Fobair & Zabora, 1995; Heim et al., 1997; Henderson, A., 1995; McGill & Paul, 1993; Nee, 1995; Shaker, 1992; Winscot, 1993). It is probable that the theoretical papers, literature reviews, and post-positivist research missed some of the perspective and lived experience of older adults with cancer.

A driving theory of this research is that of symbolic interactionism (Blumer, 1969; Charon, 1995). A symbolic interactionism perspective is used to arrive at the meanings of the participants. The symbolic interaction approach rests on the assumption

that there is a reality out there, and through our interpretations and perceptions we construct concepts and categories to arrive at shared meanings. Humans actively participate in the construction of their reality and we can arrive at explanations of these constructions. This is in contrast to a pure constructionist view that all reality is constructed and the critical theorist who seeks to explain an objective reality. Likewise, the epistemological argument between qualitative and quantitative research need not interfere with research and knowledge acquisition about the lived experience of older adult cancer patients.

Symbolic interaction is important to the analysis and theory development in this qualitative research study. Blumer (1969) states the three premises of symbolic interactionism as follows:

The first premise is that human beings act toward things on the basis of the meanings that the things have for them. Such things include everything that the human being may note in his world-physical objects, such as trees or chairs; other human beings, such as mother or a store clerk; categories of human beings, such as friends or enemies; institutions, as a school or government; guiding ideals, such as individual independence and honesty; activities of others, such as their commands or requests; and such situations as an individual encounters in his daily life. The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. The third premise is that these meanings are handled in, and modified through, an

interpretative process used by the person in dealing with the things he encountered. (p. 2)

One critical component is that the meanings a person has for an object are central in their own right. Interpretation is not an automatic process, but one where the individual uses a formative process in “which meanings are used and revised as instruments for the guidance and formation of action” (Blumer, 1969, p. 5).

In symbolic interaction the self is an object a person makes of her or himself (Lal, 1995). A person is free to assume any self he or she chooses, but is constrained by the choices of others (Katovich & Reese, 1993). From this perspective it could be argued that older adults with cancer, and older adults in general, are constrained in defining themselves by the actions of a society practicing ageism (Hooyman & Kiyak, 1998). The self is created in a socialization process (Lal, 1995) that continues until death. Thus, the self rises out of interactions (Katovich & Reese, 1993). Older adults continue to interact with their environment and how this environment interacts with them has the potential to impact their view of themselves.

In a study of lesbian motherhood, Skvoretz and Fararo (1996) used symbolic interaction to explain these mothers' relation to society as a whole and to those in their lives. With lesbian mothers being marginalized in our society, Skvoretz and Fararo (1996) found that with the sense of self being created by interactions with society it could be, and often is, negatively impacted. The interactions older adults have with society and those close to them are often negative (Hooyman & Kiyak, 1998; Kart, 1997). The

individual confronts a world that must be interpreted in order to act (Blumer, 1969). With this dynamic it is easy to see that an older adult with cancer could have his or her sense of self impacted by interactions with the environment. Hequembourg and Farrell (1999) discuss this changing sense of self as identity negotiations.

Meaning arises out of interactions with others (Blumer, 1969), and this meaning is attached to relationships. Due to the difficulties associated with cancer, it might be especially challenging for older adults with cancer to maintain continuity in relationship management. This may be similar to the struggle in relationship management experienced by lesbian mothers (Skvoretz & Fararo, 1996).

Symbolic interaction is about perspective and not attitude (Charon, 1995). Charon (1995) defined attitude as an attribute of a person while one's perspective is a guide to definition. Cancer in an older adult often brings on a new perspective (Tishelman, 1993) and a new perspective means new realities are constructed (Charon, 1995). Charon (1995) goes on to say "actions toward self depend on one's perspective. . . and this perspective comes from significant others, a generalized other, and reference groups" (p. 86). These interactions, perspective changes, and changing sense of self in older adults with cancer are investigated in the results and analysis sections below. The symbolic interaction perspective allows the researcher to study a phenomenon through interaction with it. The lived experience of older adults with cancer will be examined from their point of view. A theoretical understanding of the lived experience of older adults with cancer was pursued without a prior definition of that experience.

In line with the grounded theory approach of Glaser and Strauss (1965, 1968) and Strauss and Corbin (1990, 1997), I pursued answers to how older adults with cancer construct meaning in their living with cancer as it relates to their lived experience. With limited research on older adults with cancer and their unique needs (Shaker, 1992), we lack a theoretical understanding of the lived experience of older adult cancer patients from their perspective. I used a systematic set of procedures to arrive at a theory about this phenomenon. “A grounded theory is one that is inductively derived from the study of the phenomenon it represents” (Strauss & Corbin, 1990, p. 23). An assumption of this approach is that all the concepts pertaining to a phenomenon are conceptually undeveloped or are yet to be identified (Strauss & Corbin, 1990). The lived experience of the older adult cancer patient falls into this category of being an under-developed phenomenon.

Initial Process

Grounded theory techniques and strategies I used were field observations and interviews, literature review, open and axial coding of interviews and observations, and selective coding (Glaser & Strauss, 1968; Strauss & Corbin, 1990, 1994, 1997). Open coding is the initial analysis of the data looking for concepts, categories, and patterns. Axial coding is arranging the discovered concepts, categories, and patterns in new ways to arrive at a theoretical understanding. Selective coding is analyzing old and new interviews looking for the theory from axial coding and doing negative case analysis (looking for cases that go against your developing theoretical understanding). The field

observations and interviews were conducted in the private homes of the participants. The focus group of oncology social workers was conducted at the Wellness Community of Central Indiana. The aim of this study was to describe and formulate a theoretical base of the lived experience of older adult cancer patients. A long-term goal is to help social workers better understand and enhance psychosocial adaptation of older adults with cancer.

Grounded theory research requires a high level of immersion in the data as one continues to examine his or her research process (Glaser, 1994; Strauss & Corbin, 1994). Creswell (1998) stated that “a central concern for rigor in qualitative research is evidentiary adequacy—that is, sufficient time in the field and extensiveness of the body of evidence used as data” (p. 301). Of the 13 participants, six were interviewed once, seven were interviewed twice, and of that seven, six were interviewed a third time. Theoretical saturation was reached after those third interviews. There were 20 hours of taped interviews and all were transcribed verbatim. Accountability was maintained by these three sets of interviews and consultations with my committee chair. An active search for disconfirming evidence was conducted. Memos were created that charted my personal responses to the data analysis and interviews. Other than heightening my ability to hear and see the feelings being expressed verbally and non-verbally by the participants, I do not believe that my experiences with my siblings’ cancer biased the collection and analysis of data. The sadness of some participants and the gratitude of others were palpable. This dichotomy was fascinating.

The interview questions chosen were a product of my experiences, literature review, and the IRB process. Out of the six questions in the initial interview guide (see Appendix A), the three that produced the most valuable data were the following: 1) How has having cancer changed your life? 2) What are the most difficult things about living with cancer? and 3) What could someone else learn from your experience? Using selective coding, which is based on analysis of initial participant interview data, three questions were developed for follow-up interviews: 1) Has your faith been of help to you in coping with cancer? 2) What can you tell me about emotional ups and downs since diagnosis? and 3) What do you hope for?

Both qualitative and quantitative frameworks can inform questions on the lived experience of older adults and cancer. As a qualitative researcher, I wanted to understand the complexity of the situations faced by the older adult cancer patient and not attempt to control for every variable. Franklin (1998) stated that “quantitative methods rely primarily on deduction in theory building, prediction, measurement in data collection, and statistical methods for building evidence for one’s observations” (p. 57), while

Qualitative methods rely primarily on induction in theory building; understanding narrative forms of data collection such as interviewing, participant observations, and case records; and interpretive processes such as grounded theory, narrative analysis, dimension analysis, and other methods that allow the discovery of empirically derived categories by systematically comparing multiple sources of data. (pp. 57-58)

Triangulation (Denzin, 1978) was used to enhance the validity of the data. Triangulation was achieved by face-to-face interviews with participants, a focus group of oncology social workers, a further literature review following data collection and most of the analysis, and using the theory of symbolic interaction (Blumer, 1969; Charon, 1995).

Systematic observations are an integral part of qualitative research (Marshall & Rossman, 1995). Sociologists have long done systematic observations in the laboratory and in the field (Popenoe, 1995). In order to achieve a broader understanding of participants, observations of settings and the context of the participant's life were recorded immediately after each interview.

As stated earlier, I became interested in this topic after my sister's death to colon cancer and the experience I had with her the last one and a half years of her life. This included living in hospice with her for the five days she was there. In January of 2000 my brother died of pancreatic cancer. It is possible that my interactions with the cancer patients in my study and my personal experiences with cancer affected the views and experiences of the participants and my interpretations of the interviews. This aspect of critical subjectivity was tracked by journaling and memo-writing throughout the process of interviewing and analysis of data, especially immediately after each interview and data analysis section. Further amplification of how this bias was accounted for is explained below. Rigor was established by adhering to the following criteria for soundness in qualitative research.

Criteria of Soundness in Qualitative Research

The criteria for excellence in qualitative research differ from the criteria for excellence in quantitative research. The criterion of credibility is used to demonstrate that the subject was accurately described and identified. Was the inquiry “credible to the constructors of the original multiple realities” (Marshall & Rossman, 1995, p. 296)? Using member checks, i.e., confirming with the participants the accuracy of the interpretation of their statements, is one way to increase the credibility of the inquiry. Member checks could be problematic due to the often-increasing difficulties with communication encountered among patients whose cancer is progressing. This was accounted for by member checks soon after the interviews were transcribed and initially coded. The member checks consisted of bringing the analysis of the data back to the participants in subsequent phone interviews.

The second criterion of soundness is transferability. The burden of demonstrating the applicability of transferring one set of findings to another study rests with the investigator who would make this transfer (Marshall & Rossman, 1995). The context of each participant’s life, and their interview responses, are described in detail (the “thick description” presented by Denzin, 1989) to allow another investigator to make an informed decision about how much pertains to others (e.g. type of cancer, prognosis, family involvement, etc.). This is analogous to making the decision that a scale normed for one population would be appropriate for another.

The third criterion is dependability. This criterion sees replication as problematic. In a dependable qualitative study the “researcher attempts to account for changing conditions in the phenomenon chosen for study as well as changes in the design created by an increasingly refined understanding of the setting” (Marshall & Rossman, 1995, p. 145). An increasingly refined understanding came through initial and ongoing data analysis.

Confirmability is the fourth criterion of soundness in the paradigm of Lincoln and Guba (1985). Can another confirm the findings? This criterion attempts to address the issue of researcher subjectivity. Marshall and Rossman (1995) define seven controls for balancing bias in interpretation:

1. A research partner or a person who plays “devil’s advocate” and critically questions the researcher’s analyses.
2. A constant search for negative instances.
3. Checking and rechecking the data and purposeful examination of possible rival hypotheses.
4. Practicing value-free note-taking, then taking two sets of notes, one with more objective observation and another that allows the researcher to impose some conceptual scheme or metaphor, and to be creative with the data in ways that might prove useful for more formal analysis.
5. Devising tests to check analyses and applying the tests to the data, asking questions of the data.

6. Following the guidance of previous researchers to control for data quality
7. Conducting an audit of the data collected and analytic strategies. (Marshall & Rossman, 1995, pp. 145-146)

To enhance the confirmability of the findings, I used most of these controls. The committee members played the “devil’s advocate.” I read and reread the data to search for negative cases. I searched for rival hypotheses. Analysis started with critical incidents being the primary hypothesis. After further analysis, critical incidents gave way to the more accurate hypothesis of resilience. The pattern analysis in Chapter 6 is an example of asking questions of the data by using a test. During data analysis, I also followed the example of many qualitative researchers (Glaser & Strauss, 1968; Marshall & Rossman, 1995; Strauss & Corbin, 1990). Possible bias due to my experiences with cancer in my family members was examined through journaling and consultations with committee members.

Description of Participants

Participants were to be older adults (65 and over) with a cancer diagnosis. Participants were of diverse racial, gender, ethnic, cultural, and spiritual/religious backgrounds. There were two different groups: one with participants who had been diagnosed with cancer for less than six months (N=6) and one who had been diagnosed for more than six months (N=7). Older adults were identified at different stages in their illness in order to represent a variety of perspectives. A mini-mental status exam (Folstein, 1998) was administered just prior to the interview. As a licensed clinical social

worker I am qualified by the state of Indiana to administer this exam. No participants had cognitive impairments that prevented their participation in the interviews. One person who originally agreed to participate through her caseworker later declined to be interviewed when I approached her. With human beings able to acquire any of about 100 kinds of cancer (World Book, 1999), I limited the participants to cancer of the lungs, prostate, and the digestive system (i.e. esophagus, liver, pancreas, colon, rectum, and stomach), two of which are some of the most aggressive cancers (Kart, 1997).

Methods of Recruitment and Data Collection Procedures

Fourteen participants were purposively chosen using the above criteria. All were from the Richmond and Indianapolis area. One declined to participate. Data collection continued until theoretical saturation had been reached (Glaser & Strauss, 1968; Strauss & Corbin, 1990, 1994, 1997). In-depth face-to-face interviews with 12 participants and a telephone interview with a thirteenth participant were conducted using an unstructured interview guide. Follow-up interviews were conducted by telephone. The interviews were audio-recorded with participants' permission and were transcribed verbatim. Copious notes were taken during the interview for two participants who, due to their breathing difficulties, spoke too softly for the recorder.

Data were collected through participant interviews, a focus group, literature review, memo-writing, observations, and field notes. I conducted a focus group of three oncology social workers to inquire about their perspective of the lived experience of older adults with cancer. The focus group took place in a private office after most of the

data from the participants had been analyzed. Results of the analysis of participant data were not revealed to the focus group members until after the group interview. Each member signed an informed consent acknowledging that only the researcher would report on what was said in the group and that they would never be identified in any report or publication. I also kept a log of my own reactions, thoughts, and thought processes throughout the study.

The following demographic information was collected to assure the participants fit the stated qualifications for the study.

Demographic Information

1. Current age (65 or over)
2. Cancer site
3. State of physical, cognitive, and psychological health – from the patient's perspective. Cognitive health was ascertained by a mini-mental status exam (Folstein, 1998) just prior to the interview and took five to ten minutes. This is an instrument that is widely used with geriatric populations. This information was needed to determine if the data obtained was trustworthy.
4. Gender
5. Racial or ethnic group
6. Stage of illness (diagnosed for less than six months; diagnosed for more than six months)

7. Social class (ascertained by observation of the participants' living conditions)

The following interview guide was developed to provide a beginning focus to the interviews. After a certain amount of rapport building, the interviews centered on the lived experience through the following questions:

1. How has having cancer changed your life?
2. What are the most difficult things about living with cancer?
3. What needs do you have?
4. Are your physicians, social workers, nurses, and family members meeting those needs?
5. Who can you count on for support when you need it? (family, friends, minister, lawyer, neighbors, support group)
6. What could someone else learn from your experience?

See Appendix B for the social worker interview guide.

Data Analysis

Data analysis in grounded theory research is similar to that in other forms of qualitative research. The major difference from other qualitative methods is the emphasis on theory development. In grounded theory data analysis researchers are usually looking for substantive theory (Strauss & Corbin, 1994). In the analysis of data I was searching for the concepts themselves and plausible relationships between concepts and sets of concepts (categories).

The qualitative data analysis program Ethnograph and line-by-line open coding as described by Strauss and Corbin (1990) were used to analyze the data. This beginning coding began after transcription of the initial two interviews. Coding is the task performed to break the data down into manageable concepts and categories, and to then put them back together in new ways. Initial coding is simply a line-by-line examination of the data to begin arriving at concepts and categories that will lead to a substantive theory. I was looking for leads in the data. This included examining the data for the relative importance the participants placed on certain aspects of their experiences. I also looked for what is missing in the data and for imagery that adds power to the participants' descriptions. What was "missing" in the data was explored in subsequent interviews.

In the second phase of coding I took "a limited set of codes that were developed in the initial phase and applied them to large amounts of data" (Charmaz, 1994, p. 102). This phase of coding is where the process of putting the data back together in new ways was undertaken (Strauss & Corbin, 1990). The codes that came out of the line-by-line analysis were organized into categories. After this phase of coding the first two transcripts, I interviewed more participants looking for these concepts and categories as well as others for negative case analysis. This is an accepted method for grounded theory research (Charmaz, 1994; Strauss & Corbin, 1990).

After coding the remaining data in the same fashion, the data were further reduced to a more manageable level. The numerous categories were compared with each other to see how they group or converge. I was looking for underlying uniformities. When the

main concepts or categories were apparent, they were examined to see when or where they were likely to occur, and if they were important to the emerging theory. At this time, I selectively sampled (theoretical sampling) further participants and collected more data to see if the emerging theory was supported. I returned to the data and looked for evidence that supported or refuted the developing theory. This process included negative case analysis and was used to broaden my understanding of the data.

As stated earlier, the theory of symbolic interactionism was used to inform data analysis, especially in relation to the concepts of critical incidents and resilience. I was looking for the symbols and meanings behind participant narratives. More about the impact of symbolic interactionism on data analysis will be discussed in Chapter 6.

When it was quite clear that further analysis or data collection would not yield further important categories, I moved the data analysis to the final stage. In the final stage of analysis, as with the previous stages, I maintained an attitude of skepticism. Prior to writing up the data and theory, I stepped back and determined if there were further questions to ask of the data. This stage is where member checks were useful to increase the chances that the perceptions, categories, and associations I found in the data matched what the participants said and not what I wanted to find. The constant comparative method of “joint coding and analysis” (Glaser, 1994, p. 182) was used to: 1) compare incidents applicable to each category, 2) integrate categories and their properties, 3) delimit the theory through the use of negative case analysis, and 4) write up

theory realized from the data. Using the journal and memos, I examined the possible impact of my experience with my sister and brother's deaths to cancer on data analysis.

Ethics, Social Work Research, and Protection of Human Research Participants

Research needs to be helpful to participants, society, and others like the participants. A researcher needs to hold to rigorous standards when doing research on human research participants. A cardinal premise in social work research is the protection of human research participants. Minimizing the risk to participants to zero is probably not possible, but I lessened the risk by following some basic guidelines. A risk-benefit analysis attempted to balance risk with the possible benefits of the study. The participants knew going into the interview that we were going to talk about their experience of cancer. The risks involved the possibility of a participant experiencing psychological and emotional pain. One participant believed such an interview would cause too much emotional pain and declined to participate. No participant decompensated emotionally and/or psychologically during or after an interview. This was ascertained at the time of the interview and through a follow-up telephone call with a number of the participants. Research on talk therapy has shown a number of benefits for the client (O'Hanlon & Martin, 1992; Rubin, 1985; Thomlison, 1984). Although these interviews were not therapy, they could possibly have had some level of therapeutic benefit (Rowland, 1994). This possible benefit of the interviews was accounted for in the analysis and interpretation of the data.

Confidentiality of participant information was strictly maintained. The participant's real names were not used and no identifying information is reported. Using informed consent forms was another way to minimize risk to the participants (see Appendix C for participants and Appendix D for social workers). All participants were able to understand and sign the consent forms. As per all research at Indiana University, I proceeded through the standard Institutional Review Board (IRB) procedures. IRB approval to proceed with the study, (# 0007-01B) was obtained on August 25, 2000. Amended approval to include those with prostate cancer, to ensure greater male participation, was received on October 13, 2000. I also abided by section 5.02, Evaluation and Research, of the NASW Code of Ethics (1996) to help minimize risk to participants.

When investigating the lived experience of the older adult cancer patient, I needed to be aware of the stereotypes that society places on older adults and my own thoughts and feelings about aging, cancer, dying, and death. I also need to acknowledge my thoughts, feelings, and perceptions of diversity. Social work researchers, as all social workers, have an ethical responsibility to be culturally competent. The social work values of truth-telling and self-determination needed to be honored with a critical eye toward protecting the participants' rights without being paternalistic. The value of truth-telling was not problematic. I had knowledge of the participant's time since diagnosis, site of the cancer, and cognitive health status through the use of the Folstein (1998) mini-mental status exam. Honoring the participants' values was critical. The values and

ethical principles of NASW make it clear that human participants are to be protected and their protection is to be the first consideration when research decisions are made. Following the ethics of NASW and Indiana University were of paramount importance.

Participant Selection

A number of possible participants were identified through professional contacts in the Richmond and Indianapolis area. Prior to my contacting them, all participants gave permission to be interviewed. One person declined to be interviewed. All the participants read and signed an informed consent form. The first part of the interview consisted of rapport building and discussing the nature and purpose of the research study. All the participants spoke freely of their experience with cancer. All of the face-to-face interviews were conducted in the participant's place of residence. Theoretical saturation was reached after analysis of the last three interviews did not reveal any new themes or categories.

Chapter 4: Participants

This chapter presents a brief description of each participant. The participants whose diagnosis was less than six months in duration (N=6) are described first, followed by those who were diagnosed for more than six months (N=7). There were ten men and three women. Twelve were white and one was African American. All participants were oriented times three (person, place, and time). Names have been changed to protect the identity of the participants. Social class is based on researcher impressions of participants' living conditions. Prognoses for Albert, Glenda, Hubert, Hank, Isaac, Jack, and Larry were obtained from their medical charts. Prognoses for Bill, David, Jeff, Judy, Mildred, and Michael are based on participants' perceptions.

Albert. Albert is an 89-year-old Caucasian widower who was diagnosed as having prostate cancer with metastasis to his thyroid within the six months prior to the interview. The interview was conducted in his cluttered and plainly decorated apartment. He lives alone in a middle class retirement community in an assisted living apartment. Prior to retiring in 1970, he taught high school biology and physiology. He did not talk about his family members when asked. Albert struggles to breathe and is on oxygen, has trouble swallowing, said he feels bad all the time, and has urinary incontinence. His vocal cords were paralyzed three years ago due to thyroid treatment for another problem, and he speaks through his neck with a tracheotomy. Besides cancer, Albert has angina, Parkinson's, pneumonia, and an upper airway obstruction. Albert is confined to a wheelchair. Other than trips to the hospital, he seldom leaves his apartment. He spends

most of his time watching TV. A home health aide provides assistance with his activities of daily living (ADL's). Albert is on numerous medications. He stated "I am ready to die, but do not want to rush it." He was alert throughout the interview. His cancer diagnosis did not seem to faze him. In light of his multiple medical conditions, this might be expected. His prognosis appears to be poor.

David. David is a 73-year-old Caucasian widower who was diagnosed with prostate cancer within six months of being interviewed. Within the previous year he lost his wife of 44 years to cancer. His loneliness and continuing grief came through in statements like the following: "Of course I was trying to get used to living alone here. That was much tougher than anything else." He was often tearful when speaking of his wife and her recent death. David and his wife worked together since the early 1960's.

The initial interview took place in his upper middle-class home, which sits on a lake with a beautiful view of the water. His house was well-kept; he stated that he has had the same housekeeper for over 20 years. He said that he does not think much about having cancer due to his grief over the loss of his wife. David has a younger brother who lives in California. His 98-year-old mother lives in a nursing home in New York State. Prior to retirement he owned a small engineering firm with 15-20 employees. His wife was the office manager. They never had any children and this still bothers him. He is an active man who works out at a gym 3-5 times per week. Other than urinary incontinence (which he refers to as a "plumbing problem") due to the prostate surgery, he has no apparent adverse physical effects from the cancer. At the follow-up interview two

months later, he related still being frustrated by his “plumbing problem.” David’s response to his diagnosis was accepting:

I had just the attitude that if it got me it’s all right. I’m 73, and I could go on and be with Beth or if the Lord decided to keep me well, then I’d go on and do what I could for Him. I’ve been fortunate in that I’m in pretty good health. In cancer of the prostate, if you get it early enough it’s curable, I hope. So I didn’t have a lot of trauma with the cancer portion of it or the fact that it could get me. I figured if that doesn’t, something else would.

At times he appeared resigned to whatever fate or God had in store for him. His cancer appears to be gone. David believes that his prognosis is good.

Glenda. Glenda was a 91-year-old Caucasian female who suffered from cancer of the pancreas, diagnosed within six months prior to the interview, and was in hospice care. The interview took place in her room in a nursing home. Her private room was sparsely decorated with photographs of family and pictures of birds painted by her late husband. She had been a widow for 20 years and had one daughter who was present at the beginning of the interview. Glenda never re-married. She lived on a farm most of her life and would be considered middle-class. She spoke extensively and with fondness of her life on the farm. She quit high school early to help her dad on the family farm. Glenda worked for 20 years in a hospital after her daughter entered school, and then eight years in a furniture store. Glenda experienced constant pain that was managed somewhat by liquid morphine. She complained of not having an appetite. Glenda first thought she could beat the cancer, but then appeared accepting of the fact that it would probably kill

her. She was fully aware that she was in hospice and that means there was nothing more medicine could do to “cure” her. She was alert throughout the interview. Glenda was interviewed on October 26, 2000 and passed away on December 4, 2000. Her daughter, sister, and brother survive her. She received her wish of dying before her brother so as to not watch another sibling die. At her death, family surrounded Glenda.

Judy. Judy is a 67-year-old Caucasian who was diagnosed within six months of the interview with inoperable lung cancer. Judy was a smoker for over thirty years and quit when she was diagnosed with cancer. Other than the cancer, she reports being in good health and is oriented to person, place, and time. She lives in a lower middle-class neighborhood with her husband of more than 40 years. The initial interview took place in her home with her husband in another room. Her home was neat, clean, and had a well-manicured lawn. She was alert throughout the interview. Judy has a son and daughter with whom she reports having a close relationship. Her husband, daughter, or son go with her to all her doctor and treatment appointments. Her parents, siblings, and grandchildren often visit Judy. Judy still has ongoing relationships with the “children” (now adults) that were raised in this same neighborhood with her children. They still come and give her hugs when visiting their parents. After her kids were in school, Judy worked as a telephone operator for a local bank. Her love of talking to people made this job very “enjoyable.” She operated one of the old phone systems that you had to plug a line into to transfer calls. When she was forced out of this job by technology, she worked

as a church secretary and then as a records keeper for the U.S. Army. Judy reported that she really liked tracking down missed payments in her job with the military.

Judy shared that when she was first diagnosed she went numb to her feelings and did not feel like herself. She stated she did not believe this could happen to her. What finally brought cancer home to her was seeing other people receiving chemotherapy in the common treatment room. Judy expressed that she expects more time, but that her cancer will eventually kill her. At the follow-up interview three months later she reported doing “pretty good,” but still had lots of fatigue and was unable to do what she used to do. Her treatments were over at the time of the interview, though the cancer was not gone. She was in a recovery period from chemotherapy before they could do more treatment.

Jeff. Jeff is a 72-year-old Black male diagnosed with cancer of the lung three months prior to the interview and cancer of the prostate six months prior. He stated that this has not been a very good year for him. He reported being a life-long smoker. He was alert throughout the interview. He lives in a middle-class neighborhood and the interview took place by telephone. By the sounds in the background there were many people in the room with him. For most of his adult life Jeff worked for a steel company as a loading dock foreman. He was active in the Masons before cancer made this “impossible.” Jeff is married, has nine children and seven siblings, six of whom are still alive. When first diagnosed with lung cancer he was in the hospital for 29 days. His reaction to the initial diagnosis was, “I have no control over this so why get upset.” This

has been the attitude he has kept ever since. He has also had diabetes that has been controlled for over 15 years. He is still taking chemo-therapy and does not know if the cancer is lessening. Jeff stated that the doctors will not give him a prognosis. He said he expects to die from lung cancer. At a two month follow-up he said he was still taking chemo, but thought he was at the end of treatment for a time due to getting more fatigued, having problems with his vision, and finding it difficult to read. According to Jeff, his prognosis for a cure appears to be poor.

Larry. Larry was a 70-year-old Caucasian who was diagnosed with lung cancer less than six months prior to his death. He smoked from his teen years until being admitted into the nursing home just prior to the interview. He had two roommates in the nursing home. One roommate moaned throughout the interview. Larry stated that this goes on all the time. The room smelled of urine, but was cleaned upon my request. Larry retired 15 years ago from his job as an auto mechanic. His cancer recently robbed him of his one hobby, working on cars. He is too “tired and sick.” He said he has not seen his children in years and was taken care of by his “girlfriend” until his admission into the nursing home. His girlfriend was too sick to come visit him. He struggled to breathe and was on oxygen all the time. He stated that walking was hard for him. Larry could not take care of dressing himself, washing himself, or most of his basic daily needs. His feelings at diagnosis were unknown. He said he knew he would never go home again and expected to die in the nursing home where the interview took place. It was difficult to hear him so copious notes were taken instead of tape recording the interview. He was

alert and responsive throughout the interview. Larry died less than one month after the interview and was reported to have had no visitors during his entire stay in the nursing home.

The next seven participants were diagnosed for more than six months prior to being interviewed.

Bill. Bill is a 71-year-old Caucasian and was diagnosed with lung cancer in 1997. The interview took place at the AA clubhouse where he has worked as the manager since his retirement. We were in a large meeting room with the AA twelve steps and slogans on the wall. Prior to retirement he was a division manager for a chemical company that made chemical products for hospitals. He lives at home with his wife. He said he wants to “help people” the rest of his life. He describes himself as lower middle-class. He is alert and believes he has no other major health problems, although, he recently had an aneurysm. When asked about his feelings at diagnosis he shared:

Kind of here we go again. The aneurysm was done on an emergency basis, and suddenly this was going to be done. I had super-confidence in the surgeons and the idea of surgery. I didn't have any confidence in chemotherapy and not much in radiation. And then there was at least one guy in the club here that had had lung surgery for lung cancer, and I felt that was the way to do it. Get rid of it, take it out. Then you're clean and you can start over again. It just worked out real well. He got through it fine. He's still in good shape, good health.

Bill was originally only given a short time to live, but with surgery and 68 doses of radiation, the cancer went into remission over one year ago. With no sign of cancer, Bill's prognosis appears to be good.

Hubert. Hubert is a 87-year-old Caucasian widower with cancer of the prostate. The interview took place in his assisted living apartment where he lives alone. When I entered the room he was sitting in the dark in a corner. Hubert spoke softly and was difficult to hear. The room was filled with pictures of his family, many of them grandchildren and great-grandchildren. He has been in middle-class assisted living for five years. Hubert worked for 18 years as a Junior High School teacher and then went into banking to “make some money.” He reported having only occasional visits from his younger grandchildren and no visits from his children, older grandchildren, or any of his great-grandchildren. He would not speak of his late wife other than to say she passed away. He was 82 when diagnosed with cancer and said the diagnosis did not overly worry him. Hubert said the cancer probably changed him, but in subtle ways he could not readily recognize. He had radiation when first diagnosed and currently reports no symptoms of cancer. Hubert stated that his mind feels free due to cancer being gone. Hubert also said he is resigned to whatever happens. He stated this with no hint of worry in his voice. It appeared that he was tired and yet okay with whatever life brought at this point. He was alert throughout the interview. According to his medical chart, his prognosis appeared to be good.

Hank. Hank is a 89-year-old Caucasian who was diagnosed with prostate cancer in 1992. The interview took place in his middle-class assisted living apartment where he lives with his wife of 68 years. She was present throughout the interview and answered a number of questions for him. His apartment was neatly furnished with pictures of his

family throughout. There was a picture on the wall of their former house painted by one of his sons. In the 1930's he attended a business college in a small Midwestern city. After college he went to work as an accountant for a large finance company where he worked until he retired at age 65. When asked what went through his mind when told of the diagnosis Hank said, "Well, I thought it was a pretty serious proposition. I sort of figured I didn't have much time to go, but then it worked out a little better than that." Judging by his facial expressions, Hank appeared to be resigned or accepting of whatever life brought. He reports no current symptoms, but is still taking chemotherapy. According to his medical chart, his prognosis appears to be good.

Isaac. Isaac is a 91-year-old Caucasian diagnosed with prostate cancer and cancer of the testicles when he was 80 years old. When asked if his diagnosis scared him he responded, "No, I was 80 years old. . . I don't worry about it" (dying). He doesn't know if the cancer changed his life or not. He lives alone in a middle-class assisted living apartment and feels he is in good health for his age. The interview took place in his apartment. The room was sparsely decorated, but clean and tidy. Isaac was asleep on the floor when I came for the interview. At first I thought he was dead. He stated he often sleeps there because it is more comfortable than his bed. Isaac said he often wonders why he is still alive and not with his wife of 52 years who died ten years ago. Isaac said he is ready to die and go to heaven. He appeared resigned to live his life as he is until he dies. He seems ready to go any time. Prior to his retirement he delivered milk for a living. He is the oldest of four children who are all still alive. Throughout our time

together I often had the impression that he was a very lonely man. He said he misses his wife a lot. They met when he was three years old. He stated he occasionally spends time with other residents, but is fearful of going outside because of the risk of falling. Isaac spends most of his time alone. He was alert throughout the interview. He reports no current symptoms of cancer, but does sometimes think about it. His doctor told him that he probably would not die from his cancer.

Jack. Jack was a 66-year-old Caucasian diagnosed a year before the interview with cancer of the liver. Jack was alert throughout the interview. The interview took place in his apartment, which was cluttered, but clean. Jack had a home health aide who came three times per week and a hospice volunteer who visited once a week. He used an electrical lift to climb the stairs into his apartment. He said this lift took most of his savings. He had been divorced since 1965. Cancer forced him to retire after working more than thirty years for a division of a large manufacturing company. From the time of his diagnosis until just prior to dying, Jack was determined to keep a positive attitude. His oft-repeated phrase was “I don’t have time to die.” Even as his health declined he continued to do what he could for himself and others. Jack became a hospice volunteer after signing up for hospice for himself. This was a first for this hospice organization. Jack reported having little or no support system prior to having cancer, but he said that cancer had “enlightened” him and given him many people that he now loves. For the most part, his social supports were built after having cancer. Jack is survived by an ex-wife whom he still talked to, a daughter (age 42) who has Down’s Syndrome, and a son

(age 37) with MS. His ex-wife and children all live more than a four hour drive away. Jack lived alone in his own apartment, but was receiving hospice services. He has lived in this apartment above an insurance office for 35 years. His past life-style would be considered lower middle-class due to his apartment's location in a poor section of town. Jack owned a place on a lake near where he lived where he would fish at least weekly until he was too sick to care for the place and had to sell it. He struggled to breathe and was on oxygen all the time. At a one month follow-up he said he was doing "okay." He needed nursing home care for a couple of weeks. He died less than a month after the interview on December 1, 2000.

Mildred. Mildred is a 69-year-old Caucasian diagnosed with lung cancer about one year before the interview. The cancer is in both of her lungs and has recently metastasized to her liver. She lives in a middle-class home with her husband. The interview took place in her kitchen, which was clean and tidy. I was struck by the liveliness and bright colors in the house. Her lawn could be on an ad for fertilizer.

Mildred has a son and two brothers who have been helpful and supportive. She was a dental assistant for twenty years prior to her retiring at age 62. She continues to stay busy with volunteer activities. The nine months of treatment were difficult due to nausea and "extreme" fatigue. Mildred continues to take chemotherapy that does not have bad side effects for her. She stated that she feels fairly good, except she cannot climb stairs without getting worn out. She said that at diagnosis her attitude was that "I beat this before, I can beat it again." Twenty-two years ago she had a mastectomy due to

breast cancer. This positive attitude remained throughout the four months of chemotherapy that left her with daily nausea and extreme fatigue so bad she could hardly function. Even in the midst of the worst nausea, she said she focused on the present-moment and the fact she was still alive. Since the end of the difficult chemotherapy, most of her strength has returned and her life is somewhat back to normal. Her attitude remains positive and she was alert throughout the interview. Although doing well at the time, Mildred said she expected to get worse and eventually die from lung cancer. She said this with a note of resignation. At the two month follow-up she stated she was “still doing okay” and was “enjoying each and every day.”

Michael. Michael is a 67-year-old Caucasian male who has cancer of the prostate and bladder. He was told they are different kinds. He was first diagnosed with both types of cancer when he was 58. Michael was alert throughout the interview, which took place in his upper middle-class home. The interview was in a room that overlooked a beautiful pond with ducks. His wife and dog were in and out of the room as the interview progressed. The room and the house were dark. Michael formerly was a successful real estate salesman and Mayor of a small Midwestern town. His current wife is much younger than he and this worries him due to his impotence from prostate surgery. He has four daughters ages 21, 26, 37, and 41. He stated that his youngest daughter is the only one who will talk to him about cancer or his feelings about his cancer. He attributes this to her studying counseling in college and the fact that she was a young

girl when he got sober in Alcoholics Anonymous and he was able to be the father to her he was not able to be with his other daughters. Like Larry, Michael was perpetually negative about his cancer. Michael spoke of the mental impact of having cancer.

Nobody really knows until...nobody really knows the mental impact when the doctor says, hey, you've got it. Wh..wh..wh..I got what? . . .It's a real drawback. It knocks you for a loop. The first thing you think about is get it out of there, get rid of it. So we tried. It didn't work, obviously.

His anger and bitterness remained through the follow-up interviews. He stated that he is physically healthy except for the cancers. Michael said he has no energy and cannot do anything he used to be able to do. I came away from the interview with the impression that Michael expected to die from cancer. At the three-month follow-up he said his continued urinary incontinence "sucks" and that if he lost his car and drivers license he would have nothing.

A demographic profile of the participants is presented in Table 1.

Table 1. Demographic Profile of Participants (N=13)

NAME	AGE	GENDER	RACE	MARITAL STATUS	SOCIAL CLASS	MONTHS SINCE DIAGNOSIS	TYPE OF CANCER
Albert	89	Male	Caucasian	Widowed	Middle	<6	Prostate
Bill	71	Male	Caucasian	Married	Middle	>6	Lung
David	73	Male	Caucasian	Widowed	Upper Middle	<6	Prostate
Glenda	91	Female	Caucasian	Widowed	Middle	<6	Pancreas
Hubert	87	Male	Caucasian	Widowed	Middle	>6	Prostate
Hank	89	Male	Caucasian	Married	Middle	>6	Prostate
Isaac	91	Male	Caucasian	Widowed	Middle	>6	Prostate Testicles
Judy	67	Female	Caucasian	Married	Lower Middle	<6	Lung
Jack	66	Male	Caucasian	Divorced	Middle	>6	Liver
Jeff	72	Male	African American	Married	Middle	<6	Lung Prostate
Larry	70	Male	Caucasian	Divorced	Lower Middle	<6	Lung
Mildred	69	Female	Caucasian	Married	Middle	>6	Lung
Michael	67	Male	Caucasian	Married	Upper Middle	>6	Prostate Bladder

Chapter 5: Results

Initial face-to-face interviews lasting from one to two hours were conducted with 12 participants. One interview was conducted by phone with a thirteenth participant and lasted approximately one hour. Eleven follow-up interviews were conducted with six of the participants by telephone. The interviews resulted in 358 pages of transcripts. The focus group with three oncology social workers lasted one and half hours and produced 32 pages of transcripts. The interviews were conducted between September 14, 2000 and February 4, 2001. The focus group of oncology social workers was held on January 25, 2001.

Initial open coding of the older adult participants' transcripts produced 307 distinct code words or phrases. After combining words of similar meaning and omitting misspellings, these were reduced to 108 code words or phrases (see Appendix E). Looking through these codes, re-reading the transcripts, removing codes that were only mentioned once, and having others read the transcripts, I identified broader categories within the data. I then collapsed the data into 66 axial code words or phrases (see Appendix F). With 66 still being too large a number to manage I went back into the data, re-read and wrote memos on the data, and conducted member checks. I was looking for overall themes within which most of the data would fall. Five major themes emerged from the data (see Appendix G). The major themes and sub-themes were: 1) social support, 2) spirituality-faith (belief in God, hope, and helping others), 3) a positive attitude (acceptance, lack of fear, gratitude, keeping a present-focus), 4) positive coping

(past coping, assertive behavior, reminiscing, and humor), and 5) loss (loss of weight and appetite, loss of energy and self-care ability, loss of social relationships, loss of activities, and loss of belief in one's competence).

The first four themes are positive in nature and were mentioned most often and emphatically. Losses were mentioned frequently as well, but the data will show that other than with Michael and Larry, these losses were incorporated into the participants' lives and they remained positive people. Responses to the focus group with the three oncology social workers were coded after the participants' transcripts were coded; their data is interspersed within the presentation of findings.

In the following presentation of data, names have been changed to protect the confidentiality of the participants. The following abbreviations stand for the respective participant and the interviewer: JZ=Jack, G=Glenda, L=Larry, HS=Hank, HP=Hubert, I=Isaac, A=Albert, MG=Mildred, B=Bill, MR=Michael, JB=Jeff, JK=Judy, D=David, and MP=interviewer. The focus group of social workers are S=Susan, SH=Sherry, and G=Greg.

There were originally ten themes, but after further analysis and consultation with members of my dissertation committee, the theme of physical consequences of cancer was collapsed into the theme of loss and the themes of lack of fear/acceptance, gratitude, and present-focus were determined to be sub-themes of positive attitude.

Social support

One of the most critical factors in the lives of all the participants was social

support or lack of it. Most had a fairly strong support system. A few did not. I will first describe the ones with strong support. Jeff's social network included his Masonic brothers and his wife and children:

JB: I have a lot of friends. People are always asking me what can they do for me, you know. I'm a Mason. My Masonic brothers, they are really truly my brothers. I got a white brother; he takes me to all my doctor appointments because he wants to do that, you know. Not all of them, most of them.

MP: Masons has been a very good thing for you then.

JB: To me, yes.

MP: Throughout the years, yeah. I haven't met a Mason yet who was not completely happy with their experience.

JB: Yeah, it's a unique thing. They're always calling, "What can we do?" Nothing. There really ain't nothing to do, just keep calling me and talking to me. You'd be surprised at the people calling telling me they're praying for me. Prayers help. Prayers do help.

MP: Yeah. If nothing else, it helps to know that people are thinking about you.

JB: I got quite a few of them. Like I say, I try to be the same guy all the time. I always try to be this way, and I'm glad I am.

Judy described receiving extensive support from her husband and daughter:

MP: So you have been able to talk openly with your husband about it whatever may happen?

JK: Oh yeah. I'm a person that does talk openly about it. I would never be one where anyone close to me would be afraid to talk about it. And I've been able to go to stuff at church. We've gone to that Andy Griffith class. We went this summer. We very rarely missed church on Saturday night, so it's been kind of nice.

MP: So you get support from your husband and your two kids and some friends?

It sounds like it's a pretty good support system for you.

JK: It is. It is. You couldn't ask for better, really. I've been fortunate.

MP: Does he go with you when you get treatments?

JK: Yeah, but he doesn't sit back there. They don't care if they're not real crowded, but when they're crowded, it's too hard for you to take your family in there. My daughter went with us. Frank (husband) always goes in the doctor's office, because it's good to have somebody with you. Then my daughter went one time because she wanted to know and be sure if we had any question that we didn't understand, maybe she heard something that we didn't or we heard something she didn't.

Judy also received social support from a neighbor:

JK: . . . Like this little girl down the street--I say little girl--she's forty, but she grew up with my kids. She was down at her mother's. She came down and just threw her arms around me and kissed me. Well you know that's a nice, nice thing for you.

MP: So physical touch is important.

JK: Absolutely. I mean it was like, she said, oh Judy, I think about you all the time. Those things I know they don't sound like anything, but they are everything.

David's social support took many forms.

MP: So other than that, it hasn't changed your life much at all?

DR: . . . I was fortunate that Beth's best friend from Florida came up and stayed with me for four or five weeks, something like that, because she has a great outlook on life. Her husband and I were close friends. He died of a heart attack years ago. . . I have a lot of friends. . . And of course Bill died in February, so Betty and I have been kind of hanging out together, since she knew Beth real well and of course I knew Bill real well. And that's the way I'm trying to get along with this, is trying to help people. . .

MP: So you have a lot of...a pretty good support system?

DR: Yeah. Personal friends, the church people...I must have gotten a hundred cards. Everything from get well, thinking about you. You go around church and people would say hey David, you doing all right. Some people I hardly ever knew. It's very good. Then my close friends really rallied. The neighborhood. Speaking of some of his former employees, David stated:

. . . They still call me once in a while when they get into something and can't remember what happened. They also call me just to see how I am, particularly the girls from the office are real great. I've had a lot of support.

Mildred's social support was also from family and friends:

MP: Do you have people you can count on for some more support as far as that?

MG: Yes, yes. I feel I do.

MP: Who would that be? Would that be your son and...

MG: ...and Roy (husband) has been wonderful through it all. And our son too. He's single, as I say, but ...I have two brothers. He has a brother yet, so...I've been truly blessed and I'm very grateful because I do have that support. Like I said earlier, they don't have anybody. No family, no one. I'm sure that's a whole different situation when you don't have somebody to kind of lean on once in a while.

MP: Yeah. That's one of the things I've found with folks is having people in their life is a big thing.

MG: Oh yeah. Yes. As I say, your own immediate family, and I have some wonderful friends that just...well they have just been wonderful. I feel truly blessed to have friends like that.

MP: You mentioned earlier that you are not sure how this is going to progress, but I think you mentioned you expect it to get worse.

MG: Uh huh. And I'm sure it's my situation and my environment that has been able to make me feel that way, you know. I've always had good support and help

and consideration and all those good things that go with it, so I'm sure that that has some bearing.

Most of Bill's help comes from AA and the club he runs, as demonstrated in the following interchange:

MP: It sounds like you have a lot of support from the people here at the club and your wife and your doctors and nurses...

BN: Yeah. It's like the guys won't let me pick up much weight around here. They see me trying and they'll come help, grab it and get it away from me. I try but I don't push myself. I remember on one occasion, I picked up a hundred pound box of ice chaser off the truck and put it on the front steps. One of the guys watched me do it. This was before my operation. I don't do that kind of thing anymore. . . My wife and I do things together. It's like we'll go out to breakfast every Saturday and then go to the grocery together. That used to be my golf time. Now I spend it in a different way. I really enjoy it more. I think she enjoys it. She's two years older than me. She's 74. Actually 2 and a half. I'll be 72 in December. We go out to dinner at least once a week. We've got three children living here and one in Evansville.

Glenda had the support of hospice and her family. The hospice social worker informed me that her family surrounded Glenda when she died. Jack's social support was different than all the other participants. He built his social support *after* being diagnosed with cancer and entering hospice. The following conversation illustrates Jack's support system.

JZ: Oh, let me just tell you, if it wasn't for Hospice, I wouldn't be living. They made me...not that they need me to live. They made me want to live. I like to help people myself. Actually, I like to have a positive attitude. If I had a negative attitude, I'd have been dead two weeks after I heard that. . . I'll bring it up while I'm thinking about it. Having cancer has really enlightened me on a lot of things. If it hadn't been for this cancer, I wouldn't have met a lot of people I really love.

MP: So your doctors and nurses and everybody else have been pretty good for you?

JZ: Oh yeah. I wouldn't be living if it wasn't for them. It's just fellowship and friends.

MP: What have you found most helpful from people?

JZ: People.

MP: Just having people around?

JZ: Yeah.

MP: Is there anything specific they do?

JZ: Being nice.

MP: Anything else you want to tell me?

JZ: No. Like I said, I've met a bunch of wonderful people.

Jack's only family was his two disabled children, but I was informed by his hospice social worker that friends and hospice workers and volunteers surrounded Jack when he died.

Michael's support system is some men in AA, his 21-year-old daughter, and his dog.

MP: . . . So do you find other ways to do that...to feel like you fit and contribute?

MR: It's difficult to do. I drink coffee every morning at 9:30 with a bunch of guys. That's the only contact I have with people.

MP: Outside of the family?

MR: Outside of the family, yeah. I go at 9:30 every day. I'm back here at 10:30, and take care of the dog. That's about it.

His last comment about support was the most telling. "I get all the support I need on TV."

The social workers in the focus group talked about the importance of family to older adults with cancer:

MP: What is it they most want in life at this point?

S: To spend time with families. Over 65?

MP: Yeah.

S: I would say almost exclusively over 65, to be with their families, people that they love.

MP: Same thing, Greg?

G: Yeah, I think so. I don't know if there will be another question addressing that or not, but I think for some people there is some grief attached to that because they want to spend time with their families, but just because they have cancer does not mean that their families have become more emotionally available to be with them in essence.

MP: So the process of being with them might be painful to begin with because they can't be present to whatever their needs are, that kind of thing?

G: Well, just, I don't know....I'm going to go back thinking about the older women I've had in my groups. They kind of go through this process of changing, and wanting to be more connected and so forth. And how many stories have I heard about husbands who-- at least the story I get from the women is that they are emotionally blocked up, and can't make that connection, and that makes it very difficult when the women are ready and really wanting to spend that time, and the husband's not emotionally available.

The social workers also discussed the importance of social relationships:

SH: I know some of the ladies that I see at Wishard, the older ladies, they look forward to coming to the support group, just to have something to do. And they talk about that. They talk about how important it is to have something to look forward to, to have a schedule, an everyday schedule. Whether it's just getting up and doing the dishes, or gardening or whatever, how important it is for them to have a schedule and follow it, and to have something to look forward to like the support group. . .

G: The only other point that came to mind for me is I occasionally become frustrated working with someone who is older. They have grown up in a generation where it wasn't ok to talk about your emotions and feelings and to discuss your private stuff. Granted, I said occasionally because by the nature of what we do here, people are drawn here because they are probably more willing than the general population to have those discussions. There are still older people that I can think of, I think they saw this as a social support kind of thing. It really took a lot of doing by the group to help them open up a little bit and get some of the benefits of talking on a feelings level, and some, I can think of one or two older people who didn't hang out here very long. My guess is that because they quickly learned that because that was the nature of this—it wasn't just a place where you come and talk about your medical treatment. It's not a purely social. . .

S: It's hard to facilitate that. That is hard work.

SH: The culture also impacts that because having worked with Wishard. Wishard groups are primarily African American, and they tended not to talk about their emotions. It's one of those kind of mixing it up type groups because their support is kind of in socializing. Every once in awhile I mix it up with the emotional stuff they are resistant to, but they wouldn't just come and do the emotional disclosure you are talking about without mixing it up because they have that need. The culture is so much different. It was hard for me to facilitate it in the beginning because I was trying to do it like I did with the primary groups here, and it took real learning what that culture needs.

MP: So there's a real cultural aspect to the way some folks deal with cancer too?

SH: Definitely.

In sum, social support is possibly the most critical factor in the quality of life of these older adults with cancer. Jeff, Judy, David, Mildred, Jack, Glenda, Hubert, Albert, Hank, and Bill all had strong positive support systems. In contrast, Isaac had a positive

support system, but it was not very strong. Larry's only social support was from an overworked social worker and a girlfriend who was too ill to visit. Finally, Michael had access to a large support system in AA, but appears to have not connected to any of its members in a way that could help him work through his feelings about having cancer. Michael concentrated on not being heard.

Spirituality-Faith (Belief in God, Helping Others, Hope)

Eleven of 13 participants mentioned the importance of their spirituality-faith. Larry and Albert were the only two who did not mention anything about a faith in God or Higher Power. Michael spoke of the importance of his Higher Power in his 12-step program of AA. The participants found meaning in their faith. For a number of the participants meaning was found in helping others. Jeff, while not an active church member, did have a belief in God and found meaning in helping others.

JB: Well, I can understand that because see, before I got sick, it was my job to call people that was sick and stressed, you know. Go to the home of people who were survivors of death. This is what I done. I can't do that no more, so someone else has got to do this.

MP: So one of the things that have helped you throughout life is helping people and finding meaning in doing things like that?

JB: Well, I have been doing this for quite a while, quite a while. I still tell them, call them and tell, hey so-and-so is sick. They called me and told me they was sick. I told them don't call me no more because I'm sick. But that's the way it has been for awhile.

When talking of his spirituality, Jeff shared about the helpfulness of prayer:

MP: Are you a religious or spiritual person?

JB: Basically no. Do I believe in God? Yes. . . I was brought up in church. My family is in church, but I'm not.

MP: Does that belief in God help you at all?

JB: Heck, yeah! You'd be surprised at the people calling telling me they're praying for me. Prayers help. Prayers do help.

The topic of prayer was also touched on in a follow-up interview with Jeff: "MP: Is faith important to you? JB: Oh, yes. All my friends pray for me every day. . ." Jack also found meaning in his faith.

This following comment about his doctor was said with a note of awe and wonder in his voice.

JZ: Let me get this in. My doctor also comes up and reads the Bible to me every Tuesday plus checks me out. And he doesn't charge me anything.

MP: So he doesn't charge you for either one of them?

JZ: No.

Later, when talking about his spiritual beliefs he again emphasized their importance.

"MP: Do your spiritual beliefs help you? JZ: Oh yeah. They do. I'm definitely spiritual.

I got faith. You don't have faith, you don't have...you can't make it." Mildred only spoke a little of her faith, but she emphasized its importance. "MG: I have God in my life, and what more do I need." In a follow-up interview, Mildred shared about her faith:

MP: How important is your faith?

MG: Very. It's not in my hands, and it's not in the doctors that are taking care of me, Marty. They help me and they have done an awful lot for me, but it's that guy upstairs that does the final deciding.

MP: Do you pray every day?

MG: That I do. I thank God for another day. . . but I just think, you know, you can win these things, but you have to have confidence. You have to have faith, and we don't have control over this, Marty. It's the guy upstairs that controls these things.

Judy's faith was important to her and she expected it to take on more importance if her cancer worsened.

JK: But the thing is, I think that time is what has to happen. And see it's early for me.

MP: What do you mean by time? What do you expect time to do?

JK: Well, I think then the spiritual feeling can really, really be your partner wholeheartedly. Right now...oh listen...there's been days when I've just been angry, resentful. Like I'm mean. But I think time, as you go along. I have found in life that usually that's what it takes.

MP: Have you experienced that already in the time since you've been diagnosed?

JK: A little. A little. And you...

MP: When you say spiritual, are you talking about being at peace with whatever happens?

JK: Right. Right.

Judy also talked about the importance of attending church: "And I've been able to go to stuff at church. . . We very rarely missed church on Saturday night, so it's been kind of nice." During a follow-up interview, Judy reiterated the need for her faith:

MP: During this whole thing, how important has faith been for you?

JK: Oh, a great deal. A great deal. Unfortunately, there's people... that tend to be what happens...it takes something really serious for you to become more faithful, and you do.

MP: Did that happen to you?

JK: Sure.

MP: So you have become more of a person who prays?

JK: Well, you think of it more. It becomes more important in your life. And a lot of your priorities change, you know. Things that seemed important, aren't as important.

Glenda, Isaac, Hank, and Hubert only briefly mentioned their faith. Isaac's only comments about God were as follows: "MP: How long do you want to live? IS: Well, I don't care. You know, that's a question that I'll leave up to the man above. I don't care." Hubert stated that having cancer deepened his faith. Hank's only mention of church or faith was that he and his wife still attended church every Sunday. When asked if her spiritual life was important to her, Glenda stated: "Oh yes, yes. I'm not going to be fanatic on it, but when I was coming up, we went to Sunday school when we were just little kids." Bill stressed the importance of his spiritual life, and that it was strong before the cancer.

MP: Is there anything that's changed in your life because of having cancer?

BN: Oh...No..um...I think intangibly, sometimes when you have a brush with death, why, it changes you a little bit, but Anne (wife) and I have never been religious people, particularly, and we started back to church oh, five or six or seven years ago. I don't think it had any connection with the previous surgery. I think it was just...the twelve steps gives you a pretty good way to live, whether you realize it or not. I'm sure you do. As far as being churchy is concerned, she's more churchy than I am. I'm not very churchy (laugh). I'd say it changed that aspect of my thinking.

MP: Your spiritual life you mean? Is that what you're talking about?

BN: Yeah. Well, of course I keep spiritual separate from religious. My spiritual life is real strong, and has been for a long, long time.

MP: Has it been strengthened by having cancer?

BN: It wasn't weakened. Of course if I had died, I'd have felt like maybe I'd gotten short-changed, but... (laugh).

Bill later shared that helping others through managing the AA clubhouse was important to his spirituality. In a follow-up interview he shared more about his faith:

MP: Yeah. How important is faith to you?

BN: That's the basis of the whole thing.

MP: Okay.

BN: If I didn't have that I wouldn't have anything.

MP: So your whole life, basically then is based on your faith and your actions follow from that?

BN: Right.

David was the only participant who talked of an active faith coupled with a very active church life. His faith was intricately tied up with helping others:

DR: I did a lot of meals-on-wheels and so forth with those folks. Of course, they do a lot of scholarship stuff. It's kind of an organization that fit into it--what I wanted to do.

MP: So the way you find meaning in all this is to get out and help other people?

DR: That's exactly right. . . That's right. I want to get this behind me. I want to go home and see my mother and try to help her out. I was home over the spring. Then my brother spent the month of August there trying to look out for her. But we need to get her moved. We lived in a small town of about 600 people. I'm fairly active in that church. It's called a Federated church, a combination Presbyterian and Methodist church. In a small town, the churches were built

provisionally in the early 1800s and they both fell apart in the 1850s. The town is primarily Irish. There's barely enough people in the town to have a Protestant church, let alone two of them. The Catholic church is there, which is fine. So this Federated church which was built...a man died and gave them enough money to build a real nice church. But like small churches, there are only maybe 100, 150 at the most people, and they struggle, so I just try to help them.

David continued to talk about helping others:

DR: Well, there's one thing that I...maybe more from Beth's death than from cancer, but with cancer too. I feel that I can communicate better with people about their problems. And you go to them and look them in the eye and say I know, I've been there. And they know it. That's why I've got quite involved with Jack and his care group (church affiliated). I can go and talk to people that are losing somebody or got it themselves or something. I understand. I kind of jumped in and tried to help the Smiths who are struggling right now. Any of them. And of course it doesn't necessarily have to be cancer, but if you've been through a death or something...I can imagine you'd understand that because you've been there. You just feel you really understand, and people know you understand, and they accept it a little better.

David also donated \$25,000 to furnish a hospice in honor of his wife. Helping others has been a major foundation throughout his life. Having cancer appears to have enhanced his ability to help others.

MP: And you're helping people.

DR: Yeah. I can't seem to find any satisfaction outside of that. I almost have to drive myself to do that. Not that I don't want to do that, but I mean I have to push to do that. When you don't have somebody close that you do things for every day, then you have to look around and work at it. It just works out well for me.

Fortunately with the church and with Sertoma (a voluntary civic organization designed to help those with speech and hearing disorders; Sertoma stands for SERvice TO Mankind) and with my close friends, some of them running into trouble, there's lots of opportunity and I appreciate that.

MP: You said you have to drive yourself. Sometimes it's hard to go do it?

DR: Yes, yes. Jerry and I have talked a lot about this. We talk about the courage to care. Jerry's kind of picked up on that. I just accidentally just said that one day. You got to be careful you don't get lazy. It's easy to get lazy and you could lay back and let the world go by, but you got to stick your nose in. You got to try to do things that can help.

When asked what somebody could learn from his experience, David shared about his Bible study group:

DR: So people need to keep interested in people. You know this Bible class of men I'm in. There are four or five guys in there probably in the same boat I am. The passion for me is to get some guys...there's three or four in there because I just insisted they come and let us help them. And one of the reasons we have a pretty good group of guys...there are five or six guys who have lost their wives...you often think about women being by themselves...but in some ways it's just as difficult for men...in some ways a little more maybe.

In a follow-up interview, David reiterated the importance of his faith:

MP: I know your faith is tremendously important to you, but could you put that into words for me?

DR: Well, I had faith in the Lord when I went into this thing, no matter how it came out that I was going to be a winner. If I got the cancer and so forth, that I would be able to stay here and help other people and try to do the Lord's work. If I didn't make it, I would go to Heaven and be with Christ and also Beth and many

other friends up there. So going into this thing was the spirit I had was a win-win situation.

MP: You had a 100% chance of being okay.

DR: Yeah, yeah. I think so. The Lord felt that I needed to stay here and do some things yet.

The oncology social workers mentioned faith in the context of coping strategies:

MP: What coping strategies do you see them using day-to-day? What do they talk about? Not just hope, but other things?

S: That's a good question. A lot of them pray. A lot of them pray. Not all of them, but a lot of them do.

G: I think that may be more prevalent among the older people.

S: Yeah. I have a lot of praying people. A lot.

With eleven of 13 participants commenting on the importance of their faith, it is clear this is an important coping strategy. The implications of this for social work will be discussed in Chapter 6.

Positive Attitude

Acceptance, lack of fear, gratitude, and keeping a present-focus all seem to be sub-themes of a broader theme of positive attitude. While participants expressed both positive and negative attitudes, many emphasized the importance of keeping a positive attitude. Jack talked about having "no time to die," and Glenda was "determined to beat it." A number of participants talked about taking life one-day-at-a-time.

A participant's attitude (positive or negative) appeared to have a significant influence on how cancer impacted them emotionally. A number of these older adults with cancer had an attitude that one could call "very positive." Two of the three (Jack

and Glenda) who believed they would soon die nevertheless had positive attitudes.

Glenda spoke of what she loved in life.

“MP: You like bluebirds?

G: I love birds period. I love birds. My husband painted those. Those are two of the pictures that I kept.” Much of our time together was spent with her reminiscing about her life and her family. She displayed a positive attitude about the hardships she endured growing up on a farm and living through the Depression and two world wars.

MP: So you’ve seen the world go through recession, Depression and world wars, two of them.

GA: Recession wasn’t easy, but we laughed. We had to shuck corn for people. We lived in their house after we were married. I had one daughter, was all the children we had. We shucked corn for a dollar a day and paid our rent. He had five old hens, and we chased them around the chicken house.

Glenda’s reminiscing appears to display satisfaction with a life well-lived. Jack also had an amazingly positive attitude. He credited his survival beyond what the doctors predicted to his positive attitude:

JZ: I’m going downhill, but I’m going to get better. I’m too damn ornery to die. They gave me 6 months to a year to live, but I’ve gotten through it. I’m getting better, getting stronger. But you’re still determined to keep getting through it. You can’t have a negative attitude.

MP: Do you have liver cancer?

JZ: That’s what they...yeah. Definitely, yeah.

Hospice social worker: Our medical director, for instance, is totally amazed. I mean on paper, you shouldn’t be here.

JZ: I know that. I’ve been told that.

Hospice social worker: I know I can say that because you said it to me and it's amazing.

MP: Liver cancer is one of those things that generally you don't stay around as long so...yeah. What do you attribute staying around this long to?

JZ: Determination for one thing, and a positive attitude. That's all I can say about that. A positive attitude, that's it. Lot of people I see, even people who don't have terminal cancer...they give up a lot of things.

MP: Is there anything somebody could learn from your experience with cancer?

JZ: Have a positive attitude. Don't give up. I might kick and fight about it but I wouldn't want to give up.

MP: So you are one who wants to go out kicking and fighting?

JZ: Yep. I don't sit around and feel sorry for myself. I ain't gonna do that.

MP: So self-pity is not a good thing if you are sick?

JZ: No. You'll die quicker that way than anything else if you sit around and dwell on something.

Jack later stated: "Actually, I like to have a positive attitude. If I had a negative attitude, I'd have been dead two weeks after I heard that" (referring to his being told he has 6 months to a year to live). Mildred also portrayed a positive attitude:

MG: Uh huh. And as I say, I just take each day, and I am grateful for each day. I'm sure in time that it's going to get worse. I mean, I have to be realistic about these things, but I feel I can be in remission for some time. As I say, I feel very fortunate.

MP: So would that be your main way of coping, looking at things as just today I'm fine?

MG: Yes, yes. I'm not...I don't feel I'm depressed about it at all. I've never had that feeling. I don't know. It isn't anything you're happy to hear, naturally, but it has never gotten me to the point that I'm so depressed that I can't cope with each

day. That's not a problem at all. I basically get up every morning, and this is today. Great! Today! I don't worry about tomorrow, as I say, and yesterday is gone, so...

Two other participants with mostly positive attitudes were Bill and David. Bill's upbeat attitude and lack of fear came through in the following interchanges:

MP: Did that (the radiation) affect your body in any way other than going after the cancer?

BN: No, I don't think it did. They said a lot of people get tired, but I think that was mostly psychological and I decided I wasn't going to get tired, so I didn't get tired. I made friends with the technicians, and we kidded around and joked and made a good time out of it. . . . At first I stayed in bed quite a bit, and there was never any real pain. There was discomfort, but no real pain. It was all right here in my shoulder. I didn't have any inside or my back or any place like that. . . .

MP: Did you have any fear when you found out about having cancer?

BN: Not really. And I never had any fear with my aneurysm either. I knew I'd be knocked out. I told them knock me out, keep me out. In fact I said to one of them, don't let me know I'm dying, just keep me out. They said they'd do that. I don't have a fear of death. I think that's only because I'm not close to death. When I get to the point where I really know I'm going to die, I'll probably be scared-er than hell. But as of right now I don't have any.

David found it much more difficult to accept his wife Beth's cancer than his own:

MP: Yeah. I can see how that could be a lot harder than being sick yourself.

DR: You know that's right. That's right. That doesn't bother me at all. And I am thankful that it looks like we beat it, but if it comes back again we'll deal with it, whatever happens. . . . with Beth it was hard to handle and it's still bothersome. I guess because I was under the shadow of that, I took this as inevitable. If it

weren't for the urinary problem I have, I wouldn't...it's kind of like having a bad cold.

Judy also demonstrated a positive attitude:

JK: So, I don't know how this will turn out, but I try to be positive.

MP: None of us know how it's going to turn out. That's for sure.

JK: We don't. And like my husband and I talked about it and he said, well none of us know.

Jeff demonstrated mostly a positive attitude, but also resignation.

MP: What would you say is the most important thing that keeps you going?

JB: That keeps me going?

MP: Yeah.

JB: My attitude. Ain't nothing else but that.

MP: Yeah. What do you mean by your attitude?

JB: Well, what do you mean, what do I mean by my attitude?

MP: I mean, are you talking about a positive attitude. Or is it live one day at a time...

JB: My attitude is hey, it's here. I can't do nothing about it, and I go to get the treatments. The treatments are supposed to be helping me. I don't know how...it could be helping me. I don't know how long I'm going to live, you know. I've asked these questions. They can't give you no definite answer. They just hope you get better. . .

Interestingly, only a few of the participants focused on anything negative. David was only negative about having to wear diapers. At a follow-up interview when talking about wearing diapers, David said: "Yeah. I have some days, I get pretty frustrated. The last couple of weeks, life has been on a tear." Michael was the only participant that came

across as mostly negative. He was openly angry. His attitude and emotions were expressed with an angry tone of voice:

MR: And I kept telling them hey, you caused a problem with me. And he said we may be, but we are getting it. I said that's okay, get it! That is all I have ever said, get it. Get it out of there! . . .

MP: Is that anger you're talking about or just annoyance?

MR: No. It's frustration. I just get frustrated. People don't hear you and when they hear you they don't pay attention. So I don't know, do they hear or what?

He also seems depressed:

MP: One of the things that a lot of the people I've talked to experience is a fair amount of ups and downs. Have you experienced anything like that?

MR: Yeah. Sure have.

MP: So do your moods go fairly quick from feeling okay to why in the heck is this happening to me?

MR: Yeah. Right.

MP: What kind of emotions do you experience?

MR: Oh, depression, mainly.

The social workers talked about the emotional contrast between older adults with cancer and younger people with cancer. The social workers expressed the view that older adults with cancer were less angry and more accepting than younger adults with cancer. The following quote demonstrates this contrast.

MP: When you say philosophical, do you mean more accepting?

S: Yeah, in some kind of, it isn't that they accept that their life's being threatened. They don't exactly, but it's almost like, the way they talk about it, it's like, well, you know at this age, I have to expect something's going to get me. They don't

always say it quite that way, but that's kind of how they come across a lot of times. Maybe it's more accepting because by then they've got other kinds of physical problems usually that they've been starting to cope with, and they are already starting to think about some kinds of lessons in time. I'm 58, and I think about it some, so I think it's just the meaning of it is different in some ways. I don't think they are any more willing to die, though. They talk about it different. Yeah. It's not like when you are 30 or 40 and you still got a whole lot of stuff left undone. A lot of times they've already done a lot of the things they had hoped to do.

SH: There's not as much anger.

S: I agree.

SH: I have young people come in and talk about the anger that they feel because all their plans for the future are threatened. Some people will talk about it when I ask, when I invite others to share if they have had the same experience of anger, a lot of people will say, no, that they are not angry about having cancer because they don't feel as disappointed that all their plans for the future have been changed.

MP: Is that because their plans for the future are limited in any way?

SH: Yeah. Because I think they pretty much already felt they have lived full lives or that there is not as much, you know families, they often times don't have small children so they are not angry about the possibility of leaving them. I think probably a lot of that is acceptance. I'm not exactly sure of what, but I just know that there is less anger among the older people who have been diagnosed with cancer.

The social workers also contrasted emotional ups and downs between older adults with cancer and younger adults with cancer. There was some disagreement among the social workers when they spoke of these emotional ups and downs.

S: I think that's practically all we hear about is the ups and downs, about being on a roller coaster.

G: I'm not totally sure I agree. I'm trying to think through my experience. I may have heard fewer ups and downs with older people. I don't know if it's just a matter of their life experience kind of kicks in and it all helps them cope. I'm not entirely sure, but that's what it feels like. . .

S: I agree with the physical part of it, but the emotional part, I think the ups and downs are around limitations and being cut off from things that they like to do, not having energy to have the things they like to do. Relationship stuff a lot. You're right. It's not the same kinds of ups and downs that I hear people 30s, 40s, 50s. They're more concerned, it's more the cancer piece that's the up and down for them. I don't know. It doesn't seem to be cancer. It could just as easily be heart or something else...

MP: Is it like the effects of the cancer you mean, the fatigue?

S: Yeah. Being fatigued, not feeling good, or feeling sick, not being able to drive, being dependent, or having a life situation change, or having to stay with somebody or having somebody stay with them. A lot of independence issues, but I don't think it's a cancer issue itself.

Acceptance. Only Larry and Michael displayed a lack of acceptance of the course their lives were currently taking. Bill, Hubert, and Hank showed acceptance by an attitude of "whatever happens is okay." Albert said he was ready to die, but did not want to rush it. Glenda displayed her acceptance by her long discourses down memory lane. Whenever asked about her cancer she would briefly answer the question directly and then reminisce at length, demonstrating what appeared to be acceptance of a life well-lived. Jack displayed acceptance while talking about funeral arrangements.

JZ: I've already made funeral arrangements and everything. Also my gun and stuff, I got a young fellow wants to buy guns, so I'm going to donate it to him. My jewelry is going to be going to my boy and all that kind of stuff. Also my funeral arrangements are all paid through my insurance policy.

Knowing she survived for 22 years since having cancer the first time has tremendously helped Mildred with acceptance:

MG: I'm sure it has (having survived cancer previously) because, you know, everyone was saying, you know, we've put you on our prayer list, and we are thinking of you. I'm sure that has played a great part in it. A great part, to be able to accept it as well as you can accept something like that, but I find that not a problem, I really don't. . . I just have...everything is fine the way it is. I have fun. We do...I have a wonderful husband, and I have a home to live in, have all the material things we need. There isn't anything, anything...I wouldn't change anything.

Judy was not as accepting as Mildred, but could see herself moving in that direction:

MP: What do you mean by time? What do you expect time to do?

JK: Well, I think then the spiritual feeling can really, really be your partner wholeheartedly. . . now...oh listen...there's been days when I've just been angry, resentful. Like I'm mean. But I think time, as you go along. I have found in life that usually that's what it takes.

MP: Have you experienced that already in the time since you've been diagnosed?

JK: A little. A little. And you...

MP: When you say spiritual, are you talking about being at peace with whatever happens?

JK: Right. Right. Where you can accept it better. Because you do go through stages and I think it's just like anything you go through stages, a divorce or whatever. You go through emotional stages.

MP: What is it you hope for?

JK: Well, that you will, I don't know if you call it beat it, but you would learn to live with it and be able to, that it wouldn't be so horrendous, where you wouldn't be so sick.

David spoke of acceptance:

MP: What could somebody learn from your experience with your own cancer?

DR: Well, if people could learn to accept it I think, like I did. Somehow my cancer didn't seem to be difficult for me. It was just something that was there, you could take care of it, it was like you had appendicitis or something like that. I really was never afraid of dying. I may still die from it. I don't know, but I had no fear whatsoever. I'm not sure everybody can do that, but if you could just accept it as another disease.

Jeff spoke of acceptance even in the face of his cancer spreading:

MP: How did your CT scans come out that you had the other day?

JB: Well, the CT scan—there's another mass in my body.

MP: Oh man!

JB: I don't know and they don't know, and I got to go back and have another CT scan.

MP: Well, I'm sorry to hear that.

JB: Me too. But I can't do nothing about it.

Jeff's acceptance came through in a follow-up interview as well:

MP: The first question has to do with emotional ups and downs. A lot of the people I've interviewed have had some very wide swings, and I was wondering if you've experienced anything like that?

JB: My mood swings?

MP: Yes.

JB: Well, I've had some bad times, and some good times.

MP: Yeah. I'm sure you would.

JB: But, I try to keep the same attitude all the time, man. It's something I have no control over, and I can't do nothing about it, so there's no sense in getting upset about it.

MP: Is it on your mind a lot?

JB: It's not on my mind at all. I don't know why. See, I've got this attitude, man, like I told you before. This is something that happened to me and I have no control over it. My mother passed from cancer. My brother died from cancer. Now, these people were close to me. I was in the hospital with both of them. My mother and I were in the hospital...she was on one floor, and I was on another floor. They brought me down when she was dying.

The social workers also had a lot to say about acceptance:

G: Sometimes in the later stages, the hope can take the form of not suffering in the process of dying.

MP: That's pain control, you mean, or is it also emotional?

G: I think it's really both.

S: It depends how late it is, though, because they get to a place of acceptance more than they are really worried about pain control and being dependent on somebody. You know, having somebody have to take care of them.

The exhaustion of fighting cancer was thought to bring on acceptance:

MP: I've known people at the end to be just ready. They have had so much of the fight that they just don't want to fight it anymore.

S: Well, they are exhausted. By the time somebody dies of cancer, they are just so worn out.

MP: Nothing left to fight.

SH: Yeah. Nothing left to fight, and nothing left to fight it with. We had this conversation at Wishard because somebody said they quit fighting or gave up, and

I don't like that connotation because it's like giving up. Basically, what I said, could you look at it that they chose to prepare for what's next. It's not that they've given up, it's just that now, they've made a different choice. No longer going to do the chemo, no longer going to do whatever. I hate that connotation.

S: Yeah. I always reframe that. I'm constantly reframing that at groups around fighting for recovery. What is recovery? Does recovery always mean cure? If not, what else can it mean? I do that all the time in my groups. I'm constantly bringing it in because I agree. Fighting for recovery, people are encouraged or allowed to think that you've got to fight. You have to continue to fight, but there's all kinds of recovery. If you know that you are not going to have a physical recovery, there is still plenty of things in yourself and in your life that you can recover. Until they know they are going to die, they are always fighting to live, always. But then living takes on a whole new meaning. There's all kinds of ways of living, even if you know you've got measured time.

What older adults with cancer are preparing for and their different choices will be discussed in Chapter 6. Acceptance was also talked about in relation to quality of life:

MP: So you are talking about quality of life. Your focus changes to a different area of life.

S: And it does even if we intervene or not. I've had a lot of people die, and it's really an amazing thing to watch to see people go from being told they are terminal, which we don't talk about around here, but there's nothing left, you can go into hospice, this disease is going to kill you in some sort of predictable amount of time. People go through an amazing transformation. It's quite humbling to watch.

They also spoke of the tremendous value in having older adults with cancer in their groups:

MP: Anything else you can share about your experiences with people 65 and over?

S: I think for me, for my purposes in the group, they serve a pretty unique place in terms of just their overall wisdom and their life experience, so I think they bring a great deal to groups. Not every single one of them, because having cancer, being older doesn't predict people being better. I mean, you can just as well be old and stupid as young and stupid, but generally speaking, older people bring a great deal of balance. A lot of not exactly peace, but just balance. They bring a lot of that.

Lack of fear. Acceptance of their illness came out in the participants' lack of fear.

Conventional wisdom would have us believe that cancer victims are uniformly fearful. In contrast, with the exception of Michael and Larry, the participants expressed no fear in dying and were actually accepting of what was happening to them. Interestingly, Michael and Larry were the only participants with limited social support. Michael's fear of dying came through in everything he said about his cancer. Along with the fearful expression on his face, Larry's worry was apparent with every labored breath. Remarkably, the other 11 participants expressed a lack of fear related to cancer. Albert, Hank, Isaac, and Hubert all stated that they did not fear dying or their cancers. Isaac expressed his lack of fear as follows:

MP: How long do you want to live to be?

IS: Well, I don't care. You know, that's a question that I'll leave up to the man above. I don't care.

MP: So whatever happens, happens.

IS: Yup. That's the way I feel about it.

Isaac shared that he did not worry about his cancer:

MP: Did it scare you at all?

IS: No. I was 80 years old when I had it, and I just thought, well, heck, I've got it, if it takes my life, that's it. That's the way I felt about it. Maybe that's the reason I've been living so long (laughs).

MP: You don't worry about it.

IS: I don't worry about it. I used to, but since I lost my wife and all, I don't worry about it.

MP: So you used to worry about dying, but you don't anymore.

IS: Yeah.

MP: Do you think about it sometimes?

IS: No, not really. Somebody says something to me about it, I think about it, but I don't worry about it.

Jeff displayed little fear when talking about his cancer:

MP: Do you have any fears or that kind of stuff?

JB: Fears?

MP: Yeah.

JB: Not really. I'm resigned. What's going to be is going to be. I got a lot of friends that's got cancer. A lot of them have left here (died).

The conversation continued:

MP: Is it on your mind a lot?

JB: It's not on my mind at all. I don't know why. See, I've got this attitude, man, like I told you before. This is something that happened to me and I have no control over it.

Jack's lack of fear was shown in his oft-repeated phrase "I don't have time to die."

MP: What is the most difficult thing about having cancer?

JZ: Well, not really anything is really difficult. A lot of, I just got to learn to expect to die. I know I'm not going to...I'm not really afraid of it yet, but I know I'm going to not raise heck about dying, but I know when it happens I'm going to be scared when it comes right down to the final interval, I'll be chicken probably.

MP: (laughs) You'll be chicken. You're not going to do it?

JZ: I don't have time to die.

If Judy experienced any fear of dying it seemed related more to aging than to having cancer:

MP: I remember you said you sometimes think about dying. Does that still come to your mind?

JK: Well, sure. Sure. But I'm not so sure some of that isn't age too. I think people do as they tend...a lot of my friends say that, that they have had that experience too.

MP: Is that a scary thing for you?

JK: Sometimes. Sometimes, but not always. I think it's the fact that you're kind of scared of the unknown.

I was unable to find fear in any statement made by Mildred. When asked about her thoughts at diagnosis, Mildred said: "Well, I beat it before, and I figure, well, I'll beat it again." A lifetime of survival seemed to prepare Glenda for her cancer diagnosis:

MP: When the doctors told you you had cancer, what went through your mind?

GA: That I could defeat it. . . I knew then it was my turn. I knew it so. I'd been having some pain, not severe or anything. I told my doctor and he did a CAT scan out here in the hospital. And he didn't see anything he said, but the pain didn't go away, so my doctor sent me down to Dayton for another doctor to do a CAT scan, and he found it. It was in the pancreas. So he called the surgeon down there, Dr. Smith, and he did the surgery. It was farther along than he thought it

was, so he took the pancreas and the bile ducts and went across and took out the gall bladder.

MP: Do you have any fears?

GA: No, no. I'm ready any time, as far as that goes.

David's lack of fear appeared tied to his age: "So I didn't have a lot of trauma with the cancer portion of it or the fact that it could get me. I figured if that doesn't something else would." I was truly struck by the lack of fear in the participants. Lack of fear and acceptance appear to be closely linked or perhaps are components of the same construct.

Gratitude. In the same vein as acceptance, eleven of the 13 participants spoke of gratitude. Only Michael and Larry did not display any gratitude in their interviews. Albert said he has everything he needs and he is grateful for that. Isaac was grateful for his long life, and was ready to die. Hank was grateful for the life he has been able to lead to this day. Having cancer has not changed his gratitude for life. Hubert appeared grateful for the health he has remaining after cancer and living 87 years. Jeff's gratitude came through when talking about his kids:

MP: Well, your daughter told me I'd have an interesting conversation with you, and I agree with her.

JB: That was Charlene?

MP: Yeah, that was Charlene.

JB: That's my baby daughter. My baby's a boy. But I don't have any babies. I'm the only one can get away with calling them babies because they are all in their forties and fifties.

MP: I have an eight year old, and I can't call her baby.

JB: They don't want to be called that anymore. Those are my children. I got nine of them, and I can call them anything, but I don't. I just call them...They call me all the time, you know. It's good to have a family that loves you and you love them.

His gratitude also came out in a follow-up interview.

MP: Is there anything you are grateful for right now?

JB: Hey, man. I'm grateful to be here! I tell everybody that every day. My situation has not changed. My program has not changed. This is the way I feel about it. Can't do nothing about it.

MP: That's good to be able to find some gratitude, isn't it?

JB: Yes.

Jack's gratitude was expressed in his thoughts about the people in his life:

MP: So you met people you never would have met before.

JZ: Yeah. I really love and appreciate, that's something you really got to be grateful for, in fact, I got to be grateful for more than that. I'm not happy I'm going to die, but I decided these people I know...I think it's neat.

MP: Anything else you want to tell me?

JZ: No. Like I said, I've met a bunch of wonderful people.

Mildred oozed gratitude. It came out mostly as gratitude for the people in her life, but also that she had beaten cancer once before. In a follow-up interview, she reiterated her thoughts on gratitude.

MP: Yeah. I remember you talked a lot about gratitude for family and friends and that kind of stuff.

MG: Yeah. I had wonderful, wonderful friends and family through all of this. I think that plays a pretty important part.

Judy was grateful that other than cancer she was healthy. She was grateful for the respect with which she was treated by her doctors and nurses. She was also grateful for her family and friends.

JK: I'm so fortunate to have...you know I thank God every day that I've got my family there and that's wonderful, grandchildren...and I think to myself they are healthy and we've really been very, very fortunate.

In a follow-up interview, Judy again talked about her gratitude for her family: "MP: At this point in your life, what are you grateful for? JK: Oh, my family and things like that. Things you've accomplished like raising children. It's a good feeling."

As with the other themes, Glenda's gratitude came out in the stories she told. She displayed gratitude for her husband and an enjoyable life.

MP: What gives you meaning today?

GA: That I could live as long as I've lived, that I had my husband as long as I did. I'd have loved to have him a lot longer, but he had an aneurysm of the brain, and that took him.

MP: Are those the kind of things that keep you going? Those memories...

GA: Yes. And going places. We used to square-dance a lot back in those days. We didn't have much money to go on, but back in those days, you could square dance for 50 cents.

David was grateful for many things including appearing to have beaten cancer:

DR: I'm just thankful that it appears that we got all the cancer. My PSAs have been normal, so that's an indication the cancer has not spread. He did a lot of bone scans and cat scans.

He is also appreciative for the people in his life. “And I’m very appreciative of what people have been able to do for me and so forth.” David even found gratitude in his hospital experience: “Although the trip to the hospital was pretty tough as it turned out and for several days I was very sick. But actually people looking out for you and so forth, it was a nice experience.” David spoke more about his gratitude in a follow-up interview:

MP: Okay. Is there anything in all this you are grateful for?

DR: Well, I’m grateful for my life. I’m grateful for my doctors. And I’m grateful that I have some good friends that would take care of me when I was really down. I have many things to be grateful for.

Bill also talked about gratitude in a follow-up interview:

MP: What are you grateful for?

BN: Well, like I said, my job. My home, my family. My kids are all doing great. The grandchildren are doing pretty good. I’m grateful for all those things. The health that I do have, and the fact that I got that cancer taken out of me, makes it bearable.

While only one social worker spoke of gratitude in older adults with cancer, the participants expressed a great deal of gratitude. It came out as gratitude for a life well-lived, for family and friends, for each day, for each breath, and for the life they have been able to live. The implications of this attitude of gratitude for social work practice will be discussed in Chapter 6. The next sub-theme is likely related to keeping fear at bay and being grateful, i.e., staying focused on the present.

Keeping a present-focus. Being able to stay focused on the present moment helped a number of the participants. Jeff said: "Every day is different with me. Every day is different. Because no two days are the same." He took every day as it came. Mildred had the most to say about keeping a present-focus.

MP: What kind of things do you hope for compared to what you might have a few years past?

MG: Well, I have to think about that. I don't know. I don't really think I've changed that much. I've always kind of taken things day by day, just thankful for the blessings that I had each day. To appreciate your friends and to appreciate things that people do think about for me when I was ill. And I don't really think it's changed that much.

Later, Mildred stressed her present-focus attitude again:

MG: That's right, and as I say, I had an aunt that was a good example of that, and I just take each day as it comes and appreciate it. I don't dwell on it at all. Sometimes I don't even think...sometimes I think why aren't I back at work instead of sitting here at home doing nothing (laughs). But I'm very comfortable with life at this point. I would not choose or make it any different.

MP: So when you say you expect it to progress and probably get worse, do you think about dying at that time when you say that, what that may be like?

MG: Not really, no.

MP: So your focus really stays today.

MG: Yeah, and even when I was so awfully ill, I never thought about dying. I just thought, I'll just get through the day. Yesterday is gone, so I've got that day behind me. And my philosophy has been pretty much like that throughout my life. . . And like I say, I can't say it enough. I've been very, very fortunate in life. Today is here, and I had a nice day, and that's all I'm worried about.

MP: What are your hopes for these days? What do you hope for in your life?

MG: Oh gosh, Marty. Well, I just hope that things continue as they are. As I have said many times before, I really don't look two years down the road. I'm always saying, I'm here today. I'm enjoying today. Yesterday is gone, and I don't worry about it. That's my philosophy.

This last line from Mildred sums up her whole philosophy. "I thank God for another day." When asked what somebody could learn from her experience with cancer she had this to say:

GA: A day at a time. A day at a time.

MP: Are you pretty good at that?

GA: Yes, I am. Once in a while my nerves get the best of me, but I don't let it get to be too long at a time. I snap out of it pretty quick.

David did not have any clear statements that he lived life with a present-focus, but a large portion of the conversation was about what he could do for others today. He said he often dealt with his incontinence one diaper change at a time. Bill's present-focus appears tied to his spiritual beliefs.

BN: . . . I'll enjoy what life I've got while I got it, but when it goes I really...I always figure, I think it's Robert Schuler that says it. We were over on the other side for millions of years before we were ever born. Now we got here and we have to go through this life. Then we're going back over where we were before. We must have been warm and comfortable and safe and everything when we were over there before, why not when we go back? I think that's kind of my philosophy.

For at least seven of the participants it was important to stay focused on the present-moment. With this being verbalized by seven of the 13 one might expect this to be

important to some of the others as well, but this question was not specifically asked of them. The social workers did not address keeping a present-focus when asked how older adults coped with cancer.

In sum, the participants experienced a range of emotions and attitudes. Michael was the only one that was almost exclusively negative. Judy, David and Jeff had their negative moments, but were mostly positive. Bill, Mildred, Jack, and Glenda were upbeat and positive throughout the interview. Larry and Judy expressed some fear. A number of participants shared some anger, but this did not appear to be a major focus for any of them besides Michael. The importance of one's attitude in relation to cancer will be discussed in the implications section of Chapter 6. Positive coping strategies were exhibited by most of the participants.

Positive Coping Strategies

The title of the theme of positive coping strategies sums up a lot of what these participants taught me. Except for Michael and Larry, they were all highly positive people. The discussion that follows details four sub-themes (past coping, assertive behavior, reminiscing, and humor) that did not come out as overall themes, but were important examples of positive coping strategies.

Past coping. Mildred used the memory of beating cancer 22 years ago to help her cope with her current situation. Glenda also demonstrated the importance of past coping. She told stories of her life during the Depression and ways in which they coped.

GA: Well, I never gave it a thought. I was always a happy-go-lucky person throughout life. Enjoyed, like I said, dancing and going places. During the Depression, there were couples of us, none of us had any money, but we'd get together and play cards. Things like that. Enjoyed that. Maybe popped some popcorn. It was fun.

The social workers spoke of past coping being important.

SH: Some of my older women at Wishard talk about looking at the things they have to be grateful for, and they look back on how they have coped through... I mean, some of these people have come through the eras when it was very difficult. I work with a lot of women who lived through a lot of different things, and they pull on those same coping skills to get through this too, so they talk about being grateful for all their experiences, and looking at all they have to be grateful for. Some of that is all the stuff that they have been able to overcome in their life.

The social workers continued to discuss the importance of past coping with life's difficulties:

MP: So using previous coping skills that they've used over the course of their lifetime, whatever they happen to be.

S: Yeah. Just having been through the fire, many people when they are older, they've been through a lot in their lives, regardless of what their lives have been like, most of them have been through losses and...

MP: You get to be 65, you've been through losses.

S: Yeah. They do draw on that a lot. There's a lot to be said for having survived a lot of stuff, because you know you can. I'm not talking just physical survival, but emotionally getting through stuff. . .

SH: I agree. Again, I have to go back to the work I've had that has to do with the elderly I worked with at Wishard. They tend to have less ups and downs because they draw on the strength of their experience. They've been through hard times before, and this is just another hurdle, so they tend to have less ups and downs because of their faith and their own healthy self-talk.

MP: So, it's kind of like this is what's next to deal with, so let's deal with it?

SH: Yeah.

Assertive behavior. Only two of the participants displayed assertive behaviors.

Bill's assertive behavior was demonstrated in his choice of surgery over chemotherapy. He did not trust chemotherapy. Jeff displayed assertive behavior when dealing with his doctors and his treatment.

JB: They diagnosed the prostate cancer as cancer inside the prostate, and they was going to operate in July. July 10. I cancelled that. I said no, no. I'm going to be taking chemo. I'm taking chemo now and I won't be taking no operation. Not like that. . . Well, like I said, like my wife says, it depends on whether it's contained or not. If it's inside the prostate, then you don't have no problem. But if it gets outside, then it spreads to everything.

MP: Yeah. If it's just there, they can take it out and you are done with it.

JB: Well, yeah. They wanted to do that to me too, but I didn't want that. Because they told me, they said in ten years...this thing could go on for ten years and not have to be touched. In ten years, I'll be 82 years old. Why would I want you to be cutting something out on me that ain't going to have no effect on me if it's inside the prostate?

MP: Especially when you are already being treated for lung cancer.

JB: Well, I told them. I said, hey, I'm already being treated. The funny thing about this. These two guys are in the building. . .he's in the same building as my

lung cancer doctor. He's right around the corner from that guy, and they know each other. I told them, no, no, you're not going to be cutting on me.

In contrast, the social workers spoke of the lack of assertive behavior among older adults with cancer in their groups:

SH: That brings up the fact that older people tend to be . . . until they get into the group and really learn, they tend to be less patient active. They tend to be less assertive with their medical team because they have grown up under this "the doctors are God" scenario. Until they find out from others that its ok to fire your doctor and go someplace else or question or request a different nurse to take blood out of a port because you don't know how or something. They don't tend to be as patient active with their medical team, and they resist sometimes, some of them...

S: I think most of them. I don't think most of them are anywhere near as patient active...

SH: Yeah, and even when they know they can, they don't. They see the medical profession as more of a profession, I suppose, where they've been in the same level as the doctor.

S: You know, I'm thinking of some specific people we've had in here who were elderly, who were professionals, and they didn't question much in the treatment. They just trust what is told to them.

MP: Is that a good thing or a bad thing?

S: Depends how you look at it.

MP: Yeah?

SH: And it depends what's going on. If they are getting great care, then...it just depends how you choose to look at it.

MP: Or how they choose to look at it.

SH: I do think the medical profession tends to dismiss older people more because they feel like, well, they've had a good life, so ...

Becoming more assertive may help older adults with cancer when dealing with the medical profession and others.

Reminiscing. Thinking and taking about the past was critical to most of the participants. Memories were important to Glenda, David, and Isaac. Isaac and David spoke longingly of their many years with their respective wives. Glenda shared often about her life, especially her childhood:

GA: Yes, I did. I worked at the hospital for 20 years. Before that, I was my daddy's boy. He always called me Curley. He said, "Curley, you are going to have to be my boy. Lavern's going to leave me. So I had to quit school then, drove a tractor and chopped wheat and did all the hard work. Back in those days it was hard work. I enjoyed it. Mound hay back in the hay mound, drove horses. We had horses, and my sister next to me, she got old enough that we both had a team of horses we plowed on and did all that kind of work. It was a lot of work.

Glenda continued to reminisce about her life:

GA: I can remember when my daddy bought his first car, a Model T Ford, and I was 12 years old. He let me drive, and we went to church that Sunday morning. I went to turn around to park in the parking lot, I didn't know how to stop it. I didn't know which pedal to push. There was three pedals. The middle one was to reverse, see. The one on the left hand side was to go, and the one on the right side and the one on the left side, you pushed both of them part way to stop. I didn't know how to stop it. (Both laugh). They have kidded me a lot about that.

MP: Those are good memories aren't they?

GA: Yes, they are.

MP: They help you a lot today, don't they?

GA: Oh yes.

When the social workers discussed older adults with cancer reminiscing, one of them

expressed frustration with this aspect of their coping.

G: Something that occurs to me. We might put the label maladaptive coping on this, but it's still a coping style to not talk very much about the cancer experience. To come to group and talk about anything else under the sun.

S: Uh huh. That happens a lot with older people. You're right.

G: That happens a lot with older people, and it drives me nuts a little bit as a facilitator, but it's still a way of coping with the experience.

Humor. Humor was present in a number of the interviews and it was clear that this was an important coping strategy for many of the participants. There was no humor in the interviews with Larry or Michael. A number of the participants found humor in difficult situations. David and Bill displayed a sense of humor in statements about dying. "DR: There are a lot better ways of dying. I kid people and say, well, I'd like to live to be 90 and then get shot by a jealous husband. (both laugh). That's my idea of a way to go, see?" Bill displayed his sense of humor when he was talking about spitting up pieces of his lung cancer and he was laughing about it. Bill displayed his sense of humor again when speaking of his spiritual life:

MP: Has it been strengthened (his spiritual life) by having cancer?

BN: It wasn't weakened. Of course if I had died, I'd have felt like maybe I'd gotten short-changed, but (laugh).

David also found humor in his "plumbing problem:"

DR: Well, I think they can put some sort of a valve in. I know a little about that. I hope it isn't something with a handle on it. If I could get a solenoid valve put in, where I pull my ear, that might be alright. Yeah.

Mildred also had a light-hearted attitude about her illness:

MG: But as far as energy and everything, I'm sure I wouldn't be very good running or anything any more, but my every day living has not changed much at all. I can still shop all day (laughs), all the important things.

Hank used humor when talking about his surgery:

HS: Then he decided (the doctor) to take me off of that, and he castrated me (prostate surgery). (Laughs). Took me out of circulation.

MP: Put you out to pasture? (All laugh).

HS: I think I was already out.

Judy did not laugh during the interview, but she did speak about the importance of humor in her life. "Oh, if I didn't have my sense of humor, I wouldn't get through it. Well, you wouldn't get through life I don't think." There was a lot of humor during the interview with Jack.

JZ: Remember this? I'm talking about the picture hanging on the wall. You want to come around here? You got time?

MP: I've got all day.

Hospice social worker: I know this one. Is this the talking fish or singing?

MP: The dancing fish.

JZ: Watch this. He'll talk to you. (all laugh as fish sings)

Hospice social worker: Yeah, I've seen them in the stores. (Fish sings) Oh, my God, Jack.

JZ: That's my gimmick.

Hospice social worker: You haven't had him very long, have you?

JZ: No. About a week. Someone got it for me, so I just had to...I couldn't resist that.

Later in the interview there was more humor:

MP: You own this building?

JZ: No, no.

MP: So you rent this apartment?

JZ: I got a key to downstairs if something happens. I check after the place all the time, see.

MP: That insurance company been here as long as you've been here?

JZ: They haven't been here as long as I've been here, but...I was here before dirt. (All laugh). There's still a lot of that around.

MP: Still a lot of dirt around?

JZ: Yeah. Still a lot of dirt around.

Jack continued to find humor in life:

MP: Like the fishing and chasing girls actively (which Jack mentioned earlier)...

(All laugh)

JZ: Whatever.

Hospice social worker: You just look at them as they walk out of the room.

JZ: When you stop looking, you're dead.

While these sub-themes of positive coping were not necessarily common among the participants, they seemed to be effective in helping some of them cope with their illness and treatments. The social workers did not speak of the importance of humor, but they did talk about the benefits of and need for assertive behavior.

Loss of one kind or another was mentioned by ten of the participants. These losses are chronicled in the discussion of this last theme.

Loss

As one might expect there were many losses associated with a cancer diagnosis. The types of loss experienced were: 1) loss of weight and appetite, 2) loss of energy and self-care ability, 3) loss of social relationships, 4) loss of activities, and 5) loss of belief in one's competence.

Loss of weight and appetite. A number of participants experienced appetite problems due to chemotherapy and cancer itself. Jeff lost the taste for food:

MP: Do you have any nausea from the chemo?

JB: I don't have any. I could have it, but I take the nausea pills. I definitely do that because the food don't taste right most of the time. My wife is a damn good cook. I know everyone else is enjoying that food, and I...it tastes like cardboard. But she understands. My consumption of food has been cut down to half because I don't get a lot of food on my plate because I never know if I'm going to be able to eat it all.

He expressed concern about the upcoming Thanksgiving meal:

MP: Well, Mr. Brown (pseudoname), I really appreciate your time, and I hope your chemo goes well and you have a great Thanksgiving.

JB: Well, I hope so too. My chemo is over right now until the end of this month. Then I start on chemo again. They spaced it this time so we wouldn't be taking it during Thanksgiving. I just hope I can eat my meal right.

Speaking of her appetite during chemotherapy, Mildred said:

I have some wonderful friends here in the neighborhood, and they'd just come down with everything and anything they could think of to, you know, possibly that I would eat. I had no appetite. Nothing sounded good. I could go all day and

never miss eating at all. As I say, you just have to force yourself to do that because of course you can't survive if you don't eat something.

Judy also had trouble with her appetite:

JK: I've gone through stages, like a day or two, this can produce anorexia where you cannot eat. That's the last thing you want to do is eat.

MP: Especially if you have nausea, I imagine.

JK: Uh huh. So you keep trying and trying to eat and drink Ensure.

Glenda also spoke of her loss of appetite and enjoyment of food:

Hospice nurse: How's the appetite?

GA: Terrible. I don't have no appetite.

Hospice nurse: What did you have for breakfast this morning?

GA: I had fried eggs and a piece of toast and prune juice, but I didn't drink the prune juice. After last night, I didn't feel like I needed it.

Hospice nurse: Okay.

GA: I had a glass of milk.

Hospice nurse: Did you eat all that?

GA: I ate the eggs and the toast, and I ate a few bites of cereal, corn flakes. I didn't eat very much of it, just a few bites. I'd rather drink milk.

Hospice nurse: Do you have nausea or vomiting that keeps you from eating or is it just...

GA: I'm just not hungry. . .

MP: So, it has slowed you down.

GA: It's slowed me down, and eating, I don't have an appetite. I've been living on mostly this Ensure, a supplement, and very, very good. It's not bad, and they put ice cream in it, and it takes the sweet taste away. Every day at noon and every day at suppertime, I get a glass.

Glenda and Mildred experienced problems with weight loss:

GA: Of course, before I came out here, I was putting a lot of ice cream in it to keep my weight up because I didn't want to lose. I was up as high as 134, and I wanted to stay there. I haven't been weighed since...it's been close to a month now...and before this last time, I weighed 109. Last time it was still 109, so I hadn't lost and I hadn't gained. I told my daughter I feel like I may have put on some weight because my wrists seem a little bit bigger.

Mildred shared that her doctor had concerns about her weight loss:

Once I stopped that and had a little chance to...of course the weight loss was tremendous...and that was another thing that the doctor was concerned about. She said of course everybody loses weight when they do the chemo, because you can't eat. But I wasn't very big to start with and she was very concerned. When I got down to 93 pounds she said we are going to have to do something. I was averaging a pound or two a day. That's a lot of weight. I've not ever been too big anyway, so I didn't have too much I had to shed.

While only four participants mentioned appetite or weight problems, by the way they emphasized these problems, it appeared to be a big issue for them. Problems with appetite and weight loss can lead to a loss of energy and, for some, a loss of the ability to care for themselves.

Loss of energy and self-care ability. A number of the participants suffered a loss of energy and the ability to independently care for themselves. Larry and Albert needed help with their activities of daily living (ADL's). Albert lost the ability to care for himself and he needs help with all his ADL's. By the end of their lives, Glenda and Jack

needed help with all of their daily needs. Michael and Jeff spoke of their not being able to do yard work anymore. Jeff spoke fondly of his past gardening. Judy's loss of energy impacted her desire to cook and attend previously enjoyed activities of her grandchildren. Michael has taken his losses very hard. He appears to have taken them personally. He talked about his loss of mobility due to loss of urinary control:

MP: You still have to wear those pads?

MR: Yeah, still do.

MP: That's kind of a bummer.

MR: Tell me about it.

MP: How often do you have to change those?

MR: Three, four times a day.

MP: Oh, that's not too bad. One of the guys I talked to has to do his about every hour.

MR: Only problem is I have to change clothes.

MP: So you have to either be close to your home or take them with you. That takes some pre-planning.

MR: Right. I have to do that for the golf thing. I carry it in my bag. Sometimes I disappear for a half an hour or something.

Mildred experienced loss of the ability to care for herself due to chemotherapy: "I was hardly able to get into the shower and do that by myself. It really takes a lot out of you."

Jack experienced a loss of mobility:

That bothers me, that's the only thing that really bothers me. And you know, I have a hard time walking, getting around. When they see you some place they want to stop and talk to you. I say, well I can't stay too long, I can't stay out that long. And..."You need help to walk up to your car or something?" I don't need

that help. Just get the hell out of my way, I'll get there okay. (All laugh) I'll tell you, that's aggravating.

Glenda also spoke of her mobility restrictions and the loss of an active lifestyle:

Hospice nurse: Well good. Are you still out walking in the hall?

GA: Yeah. Not as much as I'd like to be. Before I got sick I was walking four miles a day.

Hospice nurse: I heard that. My goodness.

MP: So that's one thing being sick has done, it's lessened your activity a lot.

GA: Yes, yes. . . Let's see. I really don't know. Walking. I want to keep doing that as long as I can.

MP: So how has cancer changed your life?

GA: Well, mostly, just, I'm not walking like I was. . . I used to have pretty big wrists. My mother had large wrists.

MP: I imagine all that farm work you did...

GA: Oh yes. Mounding that hay back. That wasn't an easy job. I had a lot of muscle.

The social workers spoke of the loss of independence:

MP: One of the things you've touched on already, and that I have found is important, is that every one of the people I interviewed, is the importance of activity—being able to do something. Is there anything more you can say about that? And to them, it's meaningful activity, whatever meant something to them.

S: I think there is just a raging need to be independent. And to be able to do things for themselves. To be able to drive. To be able to get around. . .

The need for older adults with cancer to remain independent came out when the social workers were speaking of hope. When asked what they see older adults with cancer hoping for, Susan had this to say: "A lot of things. They hope to not be dependent. Their

biggest fear is that they not get dependent.” Nine of the participants spoke of the negative impact of the loss of energy. For many, this loss of energy led to a loss of independence, social relationships, and other activities.

Loss of social relationships. While in the nursing home Larry had no visits from his girlfriend and he had long since been estranged from his children and the rest of his family. He died alone. It is unknown if Larry was a loner prior to having cancer. Isaac was experiencing the loss of his wife. He is waiting to die and “to go be with her.” Michael was the one participant who seemed most bothered by his losses.

MR: I haven’t been able to work. And where I had cancer I go to the bathroom time and time again I just go. I never know when. I have to wear a pad all the time.

MP: Other than not being able to work, how has cancer changed your life? I mean has it slowed you down in other ways?

MR: Well, I went from a 13 to a 29 handicap.

MP: Oh, so your golf game went way down.

MR: It went to hell. Let’s see. Sex life is in hell. Impotent as hell.

MP: Is that because of the prostate?

MR: Uh huh. The surgery.

MP: How has that affected you?

MR: It ain’t good. It’s affected Pam more than it’s affected me. She’s pretty healthy. But she’s hanging on.

MP: What do you mean by hanging on?

MR: Without, I don’t know...sex, I guess.

MP: I see what you mean. Has it affected your masculinity then, the way that you look at yourself?

MR: Yeah.

Jeff previously found great meaning in helping others. These relationships were negatively impacted by his having cancer:

JB: Well, I can understand that because see, before I got sick, it was my job to call people that was sick and stressed, you know. Go to the home of people who were survivors of death. This is what I done. I can't do that no more, so someone else has got to do this.

MP: Okay. Is there any importance in finding meaningful things to do? Is that important for you?

JB: Well, the thing about this. I belong to several organizations. I'm a Mason, and there's plenty to do as a Mason. I belong to the Canton Old-Timers. You don't know nothing about it, but it's a club that's been affiliated for 38 years, and I've been there a long time.

MP: That's good.

JB: I have things to do. I joined in 1973. I belong to the June Knights.

MP: Are you still able to be active in those groups?

JB: Not like I'd like to be. They inform me of everything. They talk to me on the phone all the time. I just can't go and do.

MP: Right.

JB: My Masons went to Dayton today. I wish I had been able to go.

MP: What were they doing in Dayton?

JB: They had a guy taking degrees, and they give the degrees in different places. I definitely wanted to go, but I couldn't because my health is not like it used to be.

MP: Right. Is that from the fatigue, and that kind of stuff?

JB: That's strictly fatigue.

When speaking about dying and leaving his friends, Jack said: "I just don't have time to die. I just have too many friends I don't want to leave here. I've lost too many friends

already since I've had cancer that died, and I didn't expect them to die." Her feeling different also impacted Judy's relationships.

If they just knew to just listen and if that person wants to talk about it you know, great. If they don't, you go on with something else. But you do feel different and I don't like that. I like being part of the pack you know.

Judy was saddened by not being able to do as much with her grandchildren.

MP: Do you find ways to be part of the pack?

JK: I try to, very much so, but the trouble with when you are taking chemo...the trouble with it is...and I'm very fortunate with it because I'm healthy...is the fact that it takes a lot out of you and it has a lot of side effects. You can't do a lot of things that you've been used to doing with your friends and family and so forth. And I'm a grandmother. I like to do things with my grandchildren. They are on teams. One kid's a track star. They grow. It's just things you just love to be involved in, but I don't always feel like going...

Glenda spoke a lot about her memories and loss of social relationships:

MP: What are the more difficult things you find about living with cancer?

GA: Well, I can't go like I did before. I used to go a lot of places. My sister that's three years younger than me, we used to go fishing every summer. When it was nice, she'd call me and say, "Get your sandwich fixed, we're going fishing." Away we'd go...catch the crappies. I miss that a lot and I miss her too.

Interestingly, the oncology social workers spoke more about loss than did the participants. This could be due to their working with older adults with cancer in a problem-focused group setting that is designed for open and deep sharing. Loss can take many forms. For some, loss is what they will be missing in the future. Greg said: "All I would add to what Susan said is sometimes the hope can be even more concrete. They

hope to live until their grandchild's birthday. Something like that. It's incredible how many times you see stuff like that happen." According to the social workers there was pain associated with the loss of social relationships:

S: Yeah. I don't see anger as much. I see a lot of pain around it. It depends on how old they are. If you're talking 65, I mean, I've had a lot of people 65, 70, 72 in there that are really disappointed because their retirement plan's been interrupted. They've had all these plans to travel, they were going to this, they were going to that, and all of a sudden one of them gets cancer, and they're not going anywhere. At that age range, there's a lot of pain around that, and I see a lot of pain with people around their grandchildren. They're past having their kids raised, but now they've got their grandkids, and some people have great-grandkids, and they talk a lot about seeing these kids grow up, and see them do this, see them do that, so there's always that family thing Greg was talking about...

MP: Do you mean sadness when you say pain?

S: Depends on where they are. I think it's pain up until they are actually actively dying, and then I think it's really sadness.

SH: Emotionally? You're talking about emotionally?

S: Yeah. It's just like anticipatory grief, sort of, that they may not get to see these little ones. People are incredibly attached to their grandchildren.

For some of the participants these accumulating losses lead to the loss of participation in favored activities.

Loss of activities. Larry lost the ability to participate in his one hobby, working on cars. Michael talked about what he could no longer do:

MP: Are you able to do anything around the house like you used to, like cut the grass or...

MR: Not really. I've got a riding lawn mower in the back end I've never used. We got a pool we just had put in, and it eliminated some of the grass, a lot of the grass, but yet you have to take care of the pool. Pam takes care of the pool. I hate pools.

Jeff experienced activity restriction as well:

MP: How would you say cancer has changed your life?

JB: Dramatically. I can't do anything I used to could do. Nothing. And I try, and I still can't do nothing that I want to do because it's my body.

MP: Things like yard work...

JB: I can't do it no more. My wife don't even require me to do it no more. She just goes out there and do it. . . I can't do no yard work. I went out there to try to plant my garden. I have a garden every year. This is the first year that I went out there in the garden, and could not plant my garden because of my problem.

MP: So physically tired?

JB: All the time. I don't have to do nothing and I get tired. If I do anything I get tired-er.

MP: I remember you said before that it was almost overwhelming how tired you get sometimes.

JB: Well, the thing about it, anytime I try to do something, anything, wash dishes. I tried to help my wife, and I washed dishes this morning. I got some down time, my back. And then you got to sit down. It's just sad.

Judy also mentioned not being able to help others:

MP: So what needs do you have that might be different than they were before or even the same?

JK: Understanding and know there are just going to be times you are not going to be able to do things you had planned to do for somebody.

As he got sicker, Jack lost his place at a lake:

JZ: Yeah. I had a place at the lake I had to sell because I couldn't get around good enough.

MP: What lake?

JZ: St. Mary's.

MP: Is it pretty? I've never been there.

Hospice social worker: That was a tough one, wasn't it, to give that up?

JZ: Yeah.

MP: You've only given up what you absolutely can't do. That's what I'm hearing. JZ: Yeah.

Mildred, ever the optimist, spoke little of loss. Speaking of chemo's impact she stated:

Oh, yes. Very tired, very very tired, you know, immediately after and for a couple of days, you just feel like somebody just...I was not in pain...but oh, you know your body just felt so tired and I thought if I could just sleep. I could sleep. I didn't have any trouble, but you know, I never felt rested when I would wake up. But as I say, I did...I was still nauseated, but I didn't have the violent vomiting that some people have. Oh course I lost hair, naturally.

Continuing about chemo she stated:

Yes, I was very, needless to say, that was from January until probably the latter part of April or May before they stopped the chemo. At that time, I, social, or nothing we did, I couldn't drive.

Judy spoke of slowing down:

MP: So that slowing down part, is it the chemo or the cancer that slows you down?

JK: Probably the chemo does a lot of it.

MP: More than the cancer itself?

JK: The unfortunate part with chemo is, he's got me on this taxol which is supposed to be a great, it has a high rate of cure, but I've been sensitive to it. He's had to water it down, but I think it destroys a lot of the good cells. They rebuild you know, but at the time it's happening, it takes a lot out of you. I don't sleep as good at night because of these treatments and all, and it's on your mind all the time and you don't want it to consume your life.

Loss of urinary control has kept David from flying out and helping his mother. He said: "I want to get this behind me. I want to go home and see my mother and try to help her out." This lack of urinary control has impacted David's activities in other areas as well:

DR: Yeah. I have to change. I was just thinking this morning. I went out and bought some more. I'm using about 100 a week, and that's a lot of changing because they are just... you know...I may be going right now. I don't know. That's a real nuisance. I go to a meeting and I have to get up and leave the church. I have to do a lot of things. . . Oh, yeah. When they take out the prostate, they go in and interrupt the urinary tract. Then they tie it together, because the prostate is right up against the...as you know older people have prostate troubles and they can't go.

Loss of activities was experienced by 9 of the thirteen participants. Activities were lost

due to the effects of cancer treatments and the cancer itself. Most of the cancer treatment effects were due to chemotherapy for Judy, Mildred, and Jeff and prostate surgery for David and Michael.

Loss of belief in one's own competence. It appears that Michael identified himself with his work. With his work gone, his view of himself as a competent person seemed to suffer.

MP: What have been the most difficult things in living with cancer?

MR: Not being able to work.

MP: Is it the money part of that or is it just the busy, feeling like you contribute.

MR: Yeah.

MP: It's that kind of stuff? So do you find other ways to do that...to feel like you fit and contribute?

MR: It's difficult to do. . . Yeah, I used to be in the real estate business. I had my own company. I started to grow it here, then I had to watch it go. . . And I tried to get disability and them folks that have the power say huh uh. I say, well what'd you gotta do? Well I was 62, so they said, well you can have that Social Security anyway. I said, well, what if I don't want it? What if I just want disability? I'm disabled as far as I'm concerned. I can't do things I'm used to doing. Say tough.

MP: You were used to pretty much doing everything yourself.

MR: Oh yeah. Always. I took care of the house... MP: Well, you were head of a real estate company and mayor of a town. You pretty much had a lot of things your way.

MR: Yeah. Right, and now you don't have anything.

MP: Now you feel like you don't have anything.

MR: Uh huh.

I was left with the impression that not being listened to also impinged on Michael's sense of himself being a competent person:

MP: So when you say people don't listen, does that mean you feel like you are not heard?

MR: Yeah.

MP: What is it you are trying to say that they don't hear?

MR: I honestly don't know. To be specific, to the point, I don't know. But they just don't pay attention to me.

MP: Is that different than it used to be? Did people used to pay attention to you?

MR: Some people, yeah.

MP: And so now they don't. Is that when you talk about things like cancer or how you feel?

MR: I don't talk about it.

MP: You don't talk about it?

MR: I just quit.

MP: What got you to quit talking about it?

MR: No response.

MP: So they weren't...it was not that you didn't want to keep talking, it's just that no one was listening?

MR: Nobody wants to hear that. Unfortunately, I didn't want to hear it either.

Sherry, one of the oncology social workers, had an interesting take on male cancer patients not being heard.

SH: Then I kind of wonder too, how much of that is their own awareness that nobody is listening to them as opposed to before they never had that awareness. What I have found is that people tend to be more intensely connected with their emotions, and part of that being whether they are respected or listened to or heard. We can go on kind of automatic during the day not really paying attention to whether anyone is listening to us or not, because we just kind of go through the motions. I'm wondering from my own experience, from what the people have said in the group, older and younger, is their increased awareness or sensitivity to people listening to them more. I don't know.

MP: So they may not have been heard before, but either way, they are aware of it now, and it really bugs them.

SH: Yeah, because now more than ever, they want to be heard, they need to be heard.

In sum, participants experienced a variety of losses as a result of their cancer. Even with these losses, all except for Michael and Larry were mostly upbeat. Glenda, Jeff, Judy, and Mildred suffered the loss of their appetites and this seemed to bother all of them. Glenda and Mildred experienced weight loss. Judy, Jeff, Glenda, David, Mildred, Larry, Michael, Albert, and Jack suffered varying losses in their levels of energy, self-care ability, and involvement in social relationships and activities. Jack, Glenda, Michael, Judy, and David experienced the loss of belief in their own competence. Glenda, Jack, and Larry were facing the loss of everything, even their lives. Cancer patients often lose their appetite due to chemotherapy or the cancer itself. This often leads to weight loss which can decrease a person's energy level for going out and enjoying things they used to do. These losses appear to be cumulative with the loss of life being the final loss suffered by an older adult with cancer. Glenda, Jeff, Larry, and Jack all died shortly after being interviewed for this research study. The implications of these losses for social workers working with older adults with cancer will be explored in the next chapter. Other than the theme of loss, all the themes are positive in nature. The theme that seemed to be the most critical was social support.

Chapter 6: Conclusion and Implications

The upbeat and positive attitude of most of the participants of this study was an unexpected surprise. Their resilience in the face of cancer seemed remarkable. In contrast, descriptions of cancer patients in the literature seem full of angry and frightened people (Boer, et al., 1998; Derogatis, et al., 1983; Gear & Haney, 1990; Heim, et al., 1997; Varricchio, et al., 1996). Other than Michael and Larry this is not what I found. Although these two appeared to lack resilience overall, this study has highlighted the resilience of most of the participants in this study. We have seen that cancer did not destroy their spirits.

Participants were asked to describe their response to cancer and its impact on their lives. Analysis of these descriptions yielded the following major themes and sub-themes: 1) social support, 2) spirituality-faith (belief in God, hope, and helping others), 3) a positive attitude (acceptance, lack of fear, gratitude, and keeping a present-focus), 4) positive coping (past coping, assertive behavior, reminiscing, and humor), and 5) loss (loss of weight and appetite, loss of energy and self-care ability, loss of social relationships, loss of activities, and loss of belief in one's competence). While one might expect a fair amount of negativity among those struggling with cancer, these participants were largely positive in their responses. Four of the five major themes were positive.

There appeared to be some overlap among the themes of a positive attitude and spirituality-faith. For example, gratitude and lack of fear seemed to be components of both a positive attitude and spirituality-faith. Depending on a person's philosophical

orientation, acceptance, lack of fear, gratitude, and keeping a present-focus could be considered aspects of having a positive attitude or of spirituality-faith. I chose to assign lack of fear and gratitude as sub-themes of a positive attitude due to the intensity of the participants' statements about these two sub-themes when attitude was discussed. In the following discussion, lack of fear and gratitude will be examined in relation to spirituality-faith and having a positive attitude.

This chapter begins with a literature review of resilience and a pattern analysis of the major themes and sub-themes identified in this study. Analysis continues with an exploration of the major themes and sub-themes and consideration of how they might relate to the construct of resilience and the subjective meaning of the cancer experience. Following this analysis, implications for social work practice are presented. The chapter continues with a discussion of this study's limitations and recommendations, and plans for further research. I conclude with a postscript giving an update of each participant.

My interest in doing this study began with the first phone call from my sister, Julie, in 1996 telling me that she had cancer. From the time of that phone call up until her death, one and half years later, I spoke with her almost daily. I lived in a residential hospice with Julie for five days and it was that experience that moved my research agenda to the psychosocial aspects of cancer. My sister received the kind of care that all those with cancer should receive.

As I progressed through the interviews, I was struck by the resilience of the participants. The image of resilience became even stronger as I pored over the interview

data. The analysis of the data suggested an association between resilience and several of the themes. These relationships are explored below. Even the three participants who knew they would soon die from their cancers were not devastated. My first thoughts on the data were that living with cancer was an ongoing critical incident. "A critical incident is any situation . . . which produces strong emotional responses" (Frolkey, 1996, p. 10) and has the potential to overwhelm the individual's ability to cope (Laws & Hawkins, 1995). Two examples of critical incidents are rape or a robbery. After exploring this further, however, I realized that the physical and emotional responses that often accompany a critical incident were not (other than with Michael and Larry) ongoing with the participants, whereas living with cancer is an ongoing process. The following section presents a literature review on resilience followed by a pattern analysis and a discussion of how the five major themes relate to each other and to the concept of resilience through the theoretical lens of symbolic interactionism.

Resilience

The concept of resilience first appeared in the social science literature in the 1970's (Luthar, Cicchetti, & Becker, 2000; Masten, 2001). The construct emerged with the study of children of schizophrenic mothers and the finding that many of these children thrived despite their high-risk status. Research on resilience then moved to cover multiple adverse conditions. The initial research focused on personal qualities of children and later moved to environmental factors that appeared to increase the chances

of resilient responses. Risk factors for resilience and protective factors of resilience are now the subject of investigation (Luthar et al., 2000).

“Resilience relates to a *dynamic process encompassing positive adaptation within the context of significant adversity*” (italics in the original) (Luthar et al., 2000, p. 543). This construct includes 1) exposure to a severe threat or significant adversity, and 2) positive adaptation despite threats to development (Luthar et al., 2000). Other authors use varying definitions of the same construct. Resilience “. . . conveys the idea that individuals can avoid negative outcomes despite the presence of significant risk factors in their environment. It also includes the idea that individuals can regain normal levels of functioning after developmental setbacks, both with and without the help of external interventions” (Staudinger, Marsiske, & Baltes, 1995, p. 801). To a number of the respondents in this study, returning to a sense of normalcy was important. Bar-Tur and Levy-Shiff (2000) see resilience as the “maintenance, recovery, or improvement in mental and physical health following change . . . Resilience is an outcome of an individual’s resources operating as protective factors at the sociodemographic, psychological, social, and biological levels” (p. 263).

Related to resilience is the concept of risk. One is not seen as resilient unless there is considerable risk involved in his or her developmental processes (Howard & Dryden, 1999). These same authors describe how the research on resilience grew out of research on at-risk children and their consequent psychopathology. Risk represents succumbing to adversity, and resilience represents overcoming adversity (Doll & Lyon,

1998). According to the above definitions, there must be sufficient risk present for resilience to result. An older adult with cancer would appear to be sufficiently at-risk. With “at-risk” being a deficit-based construct and resilience being strength-based, one would expect social workers to focus on resilience when working with clients. This is often not the case (Early & GlenMaye, 2000).

Tiet et al. (1998) found that at-risk children and adolescents who were more resilient than their peers had 1) higher IQ's, 2) better family functioning, 3) closer parental monitoring, 4) more adults in the household, and 5) higher educational aspirations. In a review of studies on risk and resilience, Doll and Lyon (1998) found several individual and contextual characteristics of resilient children and youth. The individual characteristics were:

- 1) good intellectual ability, 2) language competence, 3) positive temperament or easygoing disposition, 4) positive social orientation including close peer friendships, 5) high self-efficacy, self-confidence, and self-esteem, 6) achievement orientation with high expectations, 7) resilient belief system/faith, and 8) higher rate of engagement in productive activities. (p. 358)

Contextual characteristics were:

- 1) family-related support, 2) close, affectionate relationship with at least one parent or care-giver, 3) effective parenting (characterized by warmth, structure, and high expectations), 4) access to warm relationships and guidance from other extended family members, 5) school or community-related support, 6) access to

and relationships with positive adult models in a variety of extra-familial contexts, including schools, 7) connections with at least one or a variety of pro-social organizations, and 8) access to responsive, high quality schools. (p. 359)

The individual characteristics that are consistent with my data on older adults with cancer are: 1) positive temperament or easygoing disposition, 2) positive social orientation including close peer friendships, 3) resilient belief system/faith, and 4) a higher rate of engagement in productive activities. The contextual characteristics that are in harmony with the data are: 1) family-related, and 2) access to warm relationships and guidance from other extended family members. This also fits with the research of Siegel, Raveis, and Karus (1998) who found that older persons with HIV had 1) a self-concept as a wise, resourceful, and insightful person, 2) less a feeling of being cheated than did younger persons with HIV, 3) an appreciation and a valuing of time, 4) greater patience and contentment than younger persons with HIV, and 5) a greater acceptance of physical limitations than younger persons with HIV. The Siegel et al. (1998) study also demonstrated that the older the person with HIV, the less negatively impacted they were. This appeared to be true in this study of older adults with cancer. The two participants who lacked resilience were also among the youngest in this study.

Few published works have focused specifically on older adults and resilience. One article I found is an empirical study (Felten, 2000) and the other is theoretical in nature (Staudinger et al., 1995). According to Felten (2000), resilience may not be the same at different developmental stages across the life course. "Longitudinal studies have

not been done to measure the construct stability of resilience across the life span” (p. 103). Felten (2000) studied resilience among seven community-dwelling women 85 and older. She defined resilience as “the ability to achieve, retain, and/or regain a level of physical and/or emotional health after devastating illness or loss” (p. 104). This is similar to the definitions used in research with children and adolescents. Felten’s (2000) definition of resilience and the ones presented earlier all fit well with the findings of this study.

Felten (2000) developed an interview guide to obtain descriptive qualitative data. The questions were based on theoretical themes found in the literature and the author’s own clinical experience. Some of the questions asked were:

You have lived a very long time, and have experienced so much in your life, what do you think has allowed you to live this long? In your opinion, what has influenced you the most in being able to be so relatively healthy at this age? Have you had any major illnesses or injuries since you retired? How has that influenced your life since that time? Try to remember back to when you were experiencing that illness; how did you make it back this far? You were able to get better after you were so sick; how was it to regain your health after that experience? What does it mean to you to regain your health? (p. 106)

Content analysis of the interview data produced themes and issues related to: 1) frailty, 2) determination to survive, 3) coping skills learned during previous experiences with hardship, 4) knowledge of and access to care, 5) health practices related to one’s culture,

6) family support, 7) self-care activities, 8) providing care for others, and 9) functioning like efficient working machines.

Five of Felten's (2000) nine themes are similar to a number of the themes found in the current study. Determination to survive appears related to having a positive attitude. Coping skills learned during previous experiences with hardship and self-care activities have a resemblance with this study's theme of positive coping, family support can be likened to social support, and providing care for others is comparable to this study's sub-theme of helping others. Table 2 depicts the consistency of the themes found in this study with those of previous studies of older adults.

Table 2: Consistency with Themes Found in Previous Studies of Older Adults

Siegel, Raveis, & Karus (1998) (HIV positive older adults)	Felton (2000) (community-dwelling women, 85+)	Pentz (2002) (older adults with cancer, 65+)
	Family Support	Social Support
Appreciation/valuing life Acceptance Less feeling of being cheated	Determination to survive	Positive attitude <ul style="list-style-type: none"> • Gratitude • Acceptance
Contentment Helping others	Providing care for others	Spirituality-Faith <ul style="list-style-type: none"> • Helping Others
	Coping skills learned during previous hardships Self-care	Positive coping <ul style="list-style-type: none"> • Past coping
	Frailty	Loss

According to the life-span perspective, development happens until death and is multi-directional (Staudinger et al., 1995). In a theoretical book chapter, Staudinger et al., (1995) assert that the multi-directionality of development is characterized by gains, losses, and maintenance of stability across all domains of functioning. Staudinger et al., (1995) view resilience as relating to regaining stability. Reserve capacity is equated with the ability to grow beyond current or normal levels of functioning. These authors argue that the energy for reserve capacity is diminished in older adults. Internal and external resources should be used to avoid negative outcomes and therefore increase resilience. I would counter that with Jack developing his support system after being diagnosed with cancer, he has grown past his prior level of functioning. It appears that these authors contend that older adults have limited resources for continued growth and resilience and should focus their energies on maintaining stability. The data previously presented and the following discussion demonstrate otherwise. Clearly, we need to know more about the association between age and resilience.

Applying the construct of resilience that was developed with children to older adults with cancer could be problematic. We might miss resilient characteristics of one group by using definitions that apply to the other. The resilient characteristics of older adults with cancer may not be the same as for children and adolescents and their environments. As indicated earlier, much of the literature on resilience is about children and adolescents (Cohler, Stott, & Musick, 1995; Doll & Lyon, 1998; Howard & Dryden,

1999; Masten, 2001; Masten & Coatsworth, 1995; Rew, Taylor-Seehafer, Thomas, & Yockey, 2001; Updegraff & Taylor, 2000). Little resilience research has focused on adults of any age (Felten, 2000). Searching "Social Work Abstracts," "Sociofile," "PsychLit," "MedLine," "CancerLit," and "EBSCOhost," I found no studies looking at older adults with cancer and resilience. Before I discuss the relationship between the themes and resilience, a pattern analysis of the possible relationships among the themes is presented.

Pattern Analysis

I found doing a pattern analysis of the themes to be an interesting experience. This study included six participants less than six months since diagnosis and seven participants more than six months since diagnosis. I did not know which group would cope better (those diagnosed less than six months prior to the interview or those diagnosed more than six months), but I did expect to find some differences between the two groups. There did not appear to be any differences in terms of coping or in relation to the themes. The pattern analysis did not break down by time since diagnosis as I anticipated. The major difference seems to be between those still taking chemotherapy and those who are done or never had chemotherapy. The participants still taking chemotherapy are all experiencing extreme fatigue and other physical symptoms like nausea and vomiting. With the exception of those at the end-stage of the disease process, none of the participants not taking chemotherapy reported that they were currently

experiencing extreme fatigue, nausea, or vomiting. Table 3 depicts the patterns among the five key themes.

Table 3: Pattern Analysis Among the Major Themes

		Attitude	
		Positive	Negative
Social Support	Yes	Albert, Bill, David, Glenda, Hubert, Hank, Isaac, Jack, Jeff, Judy, Mildred	
	No		Larry, Michael (low perceived support)
Spirituality-Faith	Yes	Albert, Bill, David, Glenda, Hubert, Hank, Isaac, Jack, Jeff, Judy, Mildred	Michael
	No		Larry
Positive Coping Strategies	Yes	Albert, Bill, David, Glenda, Hubert, Hank, Isaac, Jack, Jeff, Judy, Mildred	Larry, Michael
	No		
Loss	High	Albert, Bill, David, Glenda, Hubert, Hank, Isaac, Jack, Jeff, Judy, Mildred	Larry, Michael
	Low		

Eleven of the thirteen participants exhibited positive attitudes and positive coping strategies related to their illness. Judy was the only participant with a positive attitude whose positive coping strategies did not include lack of fear or acceptance. Judy had been diagnosed for less than six months and stated that in time she hopes to reach acceptance. Larry and Michael were negative and did not, as a rule, exhibit positive

coping strategies. Thus, there were two distinct groups of participants, buoyant (the resilient ones) and rigid (the non-resilient ones).

Eleven of thirteen participants had high social support, a spiritual focus to their lives, and expressed gratitude in their lives. Michael was the only participant without strong social support who spoke of the value of spirituality-faith. Larry was the only one who did not speak of spirituality-faith. Judy has high social support, yet remains fearful and not accepting of her illness. Michael and Larry were mostly negative and most in need of psychosocial support.

As losses multiply, one would expect older adults with cancer to be in psychosocial decline. Other than with Larry and Michael, this did not appear to happen. Most of the older adults with cancer in this study were, for the most part, brimming with spiritual and emotional strength and resilience. One would not necessarily have to have a spirituality-faith focus to have a lack of fear, hope, and the ability to find meaning in helping others, but these factors appear to be connected with spirituality-faith among the participants in this study.

The participants with high social support demonstrated resilience through having a positive attitude and the use of positive coping skills. Research on cancer patients in general shows a relationship between high social support and an increased quality of life (Bloom & Spiegel, 1984; Fobair & Zabora, 1995; Grimby & Svanborg, 1997; Henderson, P., 1997).

The theme of a positive attitude and its sub-themes (i.e., acceptance, lack of fear, gratitude, and keeping a present-focus) can all be seen as components of resilience. At least some of the identified positive coping skills (e.g., past coping, assertive behavior, reminiscing, and humor) were used by the 11 resilient participants to some degree.

All four of the positive themes (social support, spirituality-faith, positive attitude, positive coping) appear to moderate the impact of loss. While all the participants experienced losses, only two were not resilient. Loss appeared to have a particular association with spirituality-faith. Interestingly, the participants who appeared to have the most losses spoke the most of spirituality-faith. It is unknown if their spirituality-faith was strong before they experienced the losses or was influenced by their losses. This could be the subject of further investigation. The participants whose losses appeared to negatively impact them the most were Michael and Larry. Larry had low social support and Michael had low perceived social support. Ferring and Filipp (2000) demonstrated how perceived social support was more important than actual social support in determining well-being. Social support also appeared to have a particular association with loss and therefore was a moderator of loss, i.e., high social support appears to decrease the negative impact of loss on older adults with cancer.

Eleven out of thirteen participants appeared to be resilient. They had strong social support and illustrated the importance of positive coping strategies. They talked about the importance of their spirituality-faith, kept a positive attitude, stayed focused on the

present, and stated they were not afraid, were accepting of their illness, and found reasons to be grateful. They seemed to be resistant to the negative consequences of cancer.

With this depiction of the themes, a number of questions and hypotheses come to mind. For example, is having a positive attitude (acceptance, lack of fear, gratitude, and keeping a present-focus) a component of positive coping and/or aspects of spirituality-faith? Is it possible to be resilient and lack social support? Or, are these sub-themes components of resiliency? Is it possible to be resilient and lack spirituality-faith? Do resilient older adults live longer? Do resilient older adults have a higher quality of life? Some possible hypotheses for further research are as follows:

- 1) Cancer patients with strong faith have more positive coping responses. The participants in this study who spoke of a strong faith had positive coping responses.
- 2) Older adults with cancer who have a strong faith are more resilient than those without a strong faith. Participants with strong faith in this study displayed characteristics typical of resilient people described in the literature.
- 3) Older adults with cancer who have strong social supports are more resilient. The only participants of this study without strong social support (Larry and Michael) did not display resilient characteristics.
- 4) Having a positive attitude is a mediator of the impact of having cancer and the impact of cancer treatment. Participants in this study with a positive attitude were less negatively impacted than the participants without a positive attitude.

- 5) Resilience plays a moderating role with loss and fatigue. Resilient participants in this study appeared less impacted by loss and fatigue than their less resilient peers.

The focus of the discussion to follow is on the themes and their relationship to resilience.

Study Themes and Resilience

For the study of older adults and resilience, I recommend the use of Felten's (2000) definition of resilience. It is concise, to the point, and covers all the necessary ground of the definitions detailed earlier (Bar Tur & Levy-Shiff, 2000; Luthar et al., 2000; Staudinger et al., 1995). Felten (2000) defined resilience as "the ability to achieve, retain, and/or regain a level of physical and/or emotional health after devastating illness or loss" (p. 102). Plus, Felten's definition is derived from data collected with older adults. One problem with Felten's definition is it does not include the notion of "growing past" (the reserve capacity depicted by Staudinger, et al., 1995) an older adult's previous level of functioning.

Social Support

One constant in the resilience literature is the importance of social support (Cohler, Stott, & Musick, 1995; Doll & Lyon, 1998; Felten, 2000; Howard & Dryden, 1999; Masten, 2001; Masten & Coatsworth, 1995; Rew, et al., 2001; Updegraff & Taylor, 2000). Felten's (2000) study of community-dwelling women over age 85 demonstrated the importance of social support to older adults' continued well-being. What that encompasses for a child and an older adult with cancer can be similar in some respects

and vastly different in others. Both children and older adults need social support, but that social support takes different forms. For young children social support is mostly family (particularly parents), but for older adults with cancer social support can be family, friends, health care professionals, and others. Social support held much symbolic and literal meaning for the participants. This theme was stressed often by the participants and seemed to be a component of resilience. All but two of the participants had what appeared to be a good support system. Robinson and Garber (1995) have shown how social support can be an important buffer during times of illness.

From the symbolic interaction perspective we find that meanings arise out of interactions with others (Blumer, 1969). According to Charon (1995):

Our acts are often symbols. Whatever we do is often meant to give off some meaning, to communicate with others. We tell one another in what we do, what we think, feel, see; what our intentions are; what is coming next. (p. 43)

A quote from Judy illustrates this point. “. . . I think people just have to be understanding and listen. That’s important, to be a listener.” And in response to being asked who listens to her she stated: “Oh, well, my daughter and my husband and my son. I have a friend I went to high school with, two of them. . . And then I have another friend that we can just say anything to each other, and that’s wonderful.” Mildred and Judy also stated that the support they received in the form of cards, telephone calls, prayers, and the expressed concern of their friends and family has had a great impact on their ability to cope. Mildred saw her cancer bring her family and friends closer together. Jack had more

and closer friends after his cancer diagnosis than before the diagnosis. Jack, Judy and Mildred found symbolic meaning in the behavior (“acts”) of others.

Ferring and Filipp (2000) have developed a model that views coping as “reality construction.” Their model holds that objective reality is moderated through an attentive process into a perceptive reality. This fits with the Robinson and Garber (1995) finding that perceived support is more highly correlated with well-being than actual support. Michael has a ready-made support system in AA, but stated he is not listened to and that he gets all the support he needs from TV. Judy, Mildred, and Jack stated that feeling cared for was supportive. As Jack stated, “If it hadn’t been for this cancer, I wouldn’t have met a lot of people I really love. . . I wouldn’t be living if it wasn’t for them. It’s just fellowship and friends.” Those who had high levels of social support had more positive attitudes toward life and their cancer experience. As Sontag (1990) has shown, meaning is important in an illness experience. For a number of the participants, social support appeared critically important in finding meaning in their illness. With strong social support, Mildred and Jack were able to find meaning in their cancer experience, while Michael and Larry, with little social support, were unable to find meaning in their cancer experience.

According to Blumer (1969), the first premise of symbolic interactionism is that “human beings act toward things on the basis of the meanings that the things have for them” (p.2). Critical events have “strong” personal meaning to the participant (Burns & Harm, 1993) and make a strong impact on a person (McLachlan & McAuliffe, 1993).

The second premise of symbolic interactionism is that “the meaning of such things is derived from, or arises out of the social interaction that one has with one’s fellows” (Blumer, 1969, p.2). Social support is related to resilience and was shown to be an important buffer during times of illness (Robinson & Garber, 1995). The two non-resilient study participants, Larry and Michael, were both remarkable in the lack of social support they had. Larry had no visitors the month he was in the nursing home. Michael stated on numerous occasions “nobody listens to me.” In contrast, Glenda and Judy had high social support and found their cancer experience less troubling than Larry and Michael did. The emotional ups and downs appeared less severe for those with a strong support structure (e.g., Jack, Glenda, Mildred and Bill). All the social workers agreed that meaning for older adults with cancer was found in relationships with family members. When responding to the question “What is it they most want in life at this point?” Susan stated, “To spend time with families. . . I would say almost exclusively over 65, to be with their families, people that they love.” Michael and Larry did not have this same positive experience. Michael often stated that nobody would listen to him. Symbolically, it is as if Larry and Michael had been put out to pasture either by themselves or their families. Thus, resilience appears to be related to the social support received and given by older adults with cancer.

Spirituality-Faith

Spirituality-faith is often cited in the literature as a helpful factor in coping with cancer (Bloom & Spiegel, 1984; Blum & Blum, 1988; Christ & Sormanti; 1999;

Henderson, P., 1997). A belief in God, hope, and helping others were identified factors exhibited by a number of the study participants. Even though gratitude was strongly identified as a sub-theme of having a positive attitude, it will also be discussed in the context of spirituality-faith. While Jeff and Michael spoke of being resigned to their fate, they also talked about their belief in God helping them to manage their emotions. All the participants except for Larry spoke of the importance of their religion, faith, or spirituality. This coincides with Doll and Lyon's (1998) finding that resilient children and youth had more faith than their non-resilient peers.

The one factor that helped in coping that I found surprising was the expression of gratitude and feelings of being blessed. Judy expressed it this way: "I'm so fortunate to have...you know I thank God every day that I've got my family there and that's wonderful, grandchildren...and I think to myself they are healthy and we've really been very, very fortunate." Jeff said he was "grateful to be here," and Albert said he was grateful to be breathing. Gratitude was not a resilience factor in any of the studies found in the literature. Gratitude may be unique to the resilience of older adults. For Judy and Mildred, the kindness of others and the little things they did helped them manage day-to-day. They were grateful for the little things people did for them. Judy said one of the most important factors was the little things like a card or a hug. Jack also found meaning in the kindness of others.

David, Jack, and Jeff often stressed the meaning they found in helping others. Similarly, Felten (2000) identified "helping others" as a characteristic of resilient older

adults. Jack displayed meaning in being able to help others as a hospice volunteer. He said it gave him a reason to live and keep on fighting. He often stressed that “self-pity” was a quick way to death if one had cancer. David helped others with cancer and gave \$25,000 to furnish a local hospice. Jeff struggled at times due to his physical health keeping him from his former activities of helping others through the Masons. While Felten (2000) did not have faith as a resilience factor, Doll and Lyon (1998) did. Twelve of 13 participants in the present study spoke of the importance of their spirituality-faith.

A body of cancer literature stresses the importance of hope to cancer patients (Callan, 1989; McGill & Paul, 1993). While not an overriding theme in this study, it was important to some of the participants and was stressed by the social workers. Jeff, David, Mildred, Judy, Michael, Jack, and Glenda expressed hope as wanting to get better. Glenda hoped to die before her younger brother. A number of participants expressed hope in having quality time with family and friends. Jeff hoped to get to his next birthday, which he did. Judy and a number of others expressed hope in a deepening of their faith and belief in God. David and Michael’s hope was related to having their incontinence stop. Bill hoped to not die in pain. The social workers emphasized the importance of hope, and noted that what cancer patients hope for changed throughout the course of the disease. For example, hope appeared to change from hoping for a cure to hoping to be pain-free or hoping to attend some important event like a grandchild’s wedding or graduation.

A Positive Attitude

While the Doll and Lyon (1998) study focused on at-risk children and adolescents, they found high self-efficacy, self-confidence, and self-esteem to be related to resilience. These factors are likely associated with one's attitude. In this study the participants' resilience was also shown in their attitudes. Some were fighting to stay emotionally positive. Jeff went from a positive attitude to a negative one in a very short period of time. His inability to be physically active appeared to impact his attitude the most. With physical activity being related to mental well-being (Fox, 1999), one could see how Jeff would struggle emotionally.

The participants' attitude, positive or negative, appeared related to their quality of life. A number of authors (Airès, 1974; Hooyman & Kiyak, 1998; Moller, 1990) have demonstrated America's attitude toward a possible terminal illness and death as one of avoidance. Symbolically and literally, we are a youth-loving and aging-hating culture (Hooyman & Kiyak, 1998; Kart, 1997). Older adults with cancer are also susceptible to believing these stereotypes. Still, this quality in our society need not interfere with an older adult's attitude helping in the adaptation to a cancer diagnosis and the subsequent course of the disease.

Mildred stated she would not change anything in her life. When questioned further, she stated that she would not have chosen this cancer, but this is what she has to deal with so be it. She does not dwell on her cancer. Her attitude, which stood out from the other participants due to her exuberance for life, is also shown when she said if she

doesn't "win," she is going to enjoy it to the end without bitterness or self-pity. Jeff displays more of an ambiguous attitude. To quote: "My attitude is hey, it's here. I can't do nothing about it, and I go to get treatments." He said he feels bad physically all of the time. Those with the most positive attitudes were feeling fairly well physically when they were interviewed.

Similar to the notion of having a positive attitude, Felten (2000) found that determination to survive was a major theme relating to the resilience of older adults. Jack stated that having cancer "made me want to live." He also said that having cancer had really enlightened him on many things. The illness experience can be symbolically reinterpreted to restore one's view of the world (Updegraff & Taylor, 2000). This appears to have been Jack's approach.

In his book, *Man's Search for Meaning*, Viktor Frankl (1970) states that a person can have everything taken from them except for the last freedom, the freedom to choose their own attitude. A number of the participants illustrate the importance of their attitudes in their lived experience. Judy struggles with her attitude and not allowing the cancer to overwhelm her life experience. In answer to the question, "so has it overtaken your life?" she said there is not much time that she does not think of her cancer. Michael also struggles with not letting the cancer overtake him. He found himself being "frustrated all of the time" and often not being able to think of anything else.

Bill, Mildred, and Jack had attitudes that were helpful in enhancing their lived experience. Jack made statements that displayed a fighting spirit and his determination to

survive. His oft-repeated statement, "I don't have time to die" illustrates his determination to live as fully as possible until he dies. When talking about his possible death, Bill's attitude came out as hope for more life on the "other side" of this death. His hopeful and positive attitude came in living this life to the fullest and in a belief in a life after this one. Mildred's attitude remained upbeat even when she was sick from chemotherapy and radiation. Being able to find symbolic meaning in their illness experience, these three were able to not only lessen the negative psychological impact, but also appeared to continue developing emotionally because of the cancer. They appeared to have plenty of reserve capacity.

Michael and Larry did not perceive any benefit from their cancer and their attitudes were much more negative than those of Mildred and Jack. They did not see it as a wake-up call to change their lives (McMillen, 1999), but only as a negative that would soon kill them. Less than a month after the interview, Larry passed away, mostly alone, from his cancer. In a number of other studies the physical health of a person appears directly correlated with their attitude and being depressed (Boer, et. al., 1998; McGill & Paul, 1993). Michael was doing poorly physically and he was depressed and largely negative in his attitude. At the last follow-up Michael was still depressed, mostly about his fatigue and his continuing need to wear diapers. While Larry and Michael were doing poorly physically and appeared to be depressed and not enjoying life, most of the participants in this study who were not faring well physically still talked about having a satisfactory quality of life. Albert, David, Glenda, Isaac, Judy, Jeff, and Mildred all

usually did not feel very well, but they found satisfaction in their lives and did not appear depressed.

When asked what keeps him going, Jeff stated: "My attitude. Ain't nothing else but that." He stated this perspective even though he was frustrated by not being able to do what he used to be able to do. Having a positive attitude is one of the protective functions Masten and Coatsworth (1995) reported to be related to resilience. Judy, Jack and Mildred all emphasized the importance of their attitude in helping them deal with cancer. These three, who all had strong support systems that "hear them," have what I would call a positive slant on their cancer. Michael and Jeff have negative attitudes toward their cancer and appear to have less emotional health. Both of these men have a number of people around them, but report that their family members don't listen to them.

A lack of fear seemed to go hand-in-hand with participants' positive attitude. Surprisingly, most of the participants said they were not fearful. As the results showed, David's reaction to his cancer diagnosis was sort of "oh well." He did not experience his diagnosis of cancer as a traumatic event. He related this feeling to his wife's recent death to cancer being harder to take than any threats to his own life. Isaac said that having cancer did not scare him at all, that at 80 years old why should he worry? Bill's resilience was expressed in his confidence in his surgeons. He said everything moved so fast from diagnosis to surgery he did not have time for fear. Bill was also comforted in his spiritual belief in a life after this one. When first told of their diagnoses, Mildred and

Glenda said they felt they could beat cancer. Only three (Judy, Michael, and Larry) displayed some fear. Larry expressed fear in the process of dying, but not of death itself. Michael said he was “thrown for a loop,” and Judy stated she could not understand why cancer was so fearful a thing. Judy was the only one of these three that had an effective support system. Participants who were connected to spirituality-faith tended to be less fearful than those without this component of resilience. Some possible means of helping decrease the fear of older adults with cancer are discussed below.

The participants’ attitude impacted them at every stage of the illness process. Michael was pessimistic at the beginning and has stayed that way. Mildred has kept a positive attitude throughout. Even though he was dying, Jack kept a positive attitude and found meaning in his cancer experience. Thus, despite ageism in our society, and facing a terminal diagnosis like cancer, some older adults nonetheless remain quite resilient.

Positive Coping Strategies

Returning to a sense of normalcy is important to those experiencing a traumatic critical incident (Frolkey, 1996) such as a cancer diagnosis. This requires using coping skills throughout the cancer experience. To deal with the consequences of cancer the participants used the following positive coping strategies: 1) past coping, 2) humor, 3) assertive behavior, and 4) reminiscing. The relationship among these factors is unclear, but in this study they appear to be components of resilience.

Felten (2000) identified previous coping skills learned during previous experiences with hardship as one of the characteristics of resilient older adults. Some of

Mildred's coping strategies come from having beaten cancer previously. She stated that she chooses to not think of cancer running her life and even when it gets bad, she will live as fully as possible. Judy displayed avoidance behaviors in not wanting to read or watch television shows about cancer, dying, or death. This avoidance could be viewed as positive or negative. It could be positive in that she may be lessening the impact of cancer by not letting it permeate every aspect of her life. On the negative side she could be missing information that could increase her life expectancy or quality of life. She could also be making her road to acceptance longer. Humor and reminiscing are elaborated on later in this chapter.

In summary of the first four themes, they are positive in nature. The resilient older adults with cancer in this study all exhibited strong social support, spirituality-faith, a positive attitude, and positive coping strategies. The relationship among the themes and sub-themes and between these themes and resilience is conceptually unclear. These conceptual relationships will be further explored below.

Loss and Fatigue

While an important issue, extreme fatigue did not break out as a major theme, but is encompassed in the theme of loss. Extreme fatigue was characterized by participants no longer playing a part in most, if not all, of the prior activities in which they used to find meaning. The participants attributed this extreme fatigue to their cancer or cancer treatment. With the exception of Albert, participants with extreme fatigue were all taking chemotherapy or were in the last stages of their disease just prior to death. Albert had

multiple health problems. Table 4 displays the apparent association between extreme fatigue and the effects of chemotherapy, the physical response to end-stage of disease, and participants' attitude.

Table 4: Pattern Analysis of Extreme Fatigue

Extreme Fatigue			
		Yes	No
Chemo-Therapy	YES	Jeff, Judy, Michael, Mildred	Bill
	NO	Albert, Glenda, Jack, Larry	David, Hank, Hubert, Isaac
End Stage of Disease	YES	Glenda, Jack, Jeff, Larry	
	NO	Albert (multiple health problems), Judy, Michael, Mildred	Bill, David, Hank, Hubert, Isaac
Positive Attitude	YES	Albert, Glenda, Jack, Jeff, Judy, Mildred	Bill, David, Hank, Hubert, Isaac
	NO	Larry, Michael	

This study is consistent with a number of studies that show a relationship between extreme fatigue and chemotherapy and between extreme fatigue and the end-stage of cancer (Derogatis et al., 1983; Ferring & Filipp, 2000; Henderson, P., 1997). Eight of the

13 participants experienced extreme fatigue. Four of the five participants that were taking chemotherapy were experiencing extreme fatigue. Amazingly, extreme fatigue did not appear to decrease most of the participants' positive attitudes. The only participants who did not display a positive attitude (Larry and Michael) were two with extreme fatigue. Interestingly, these are also the two with low levels of perceived or actual social support. From Table 4 we can see that the end-stage of cancer and taking chemotherapy are probably associated with extreme fatigue. Importantly, we can also see that experiencing extreme fatigue need not deplete a person's positive attitude toward life. The possible implications of fatigue and social work interventions and research are explored below.

Loss and fatigue were a factor in the cancer experience of all the participants. Loss and fatigue are probable triggers for a resilient response. Through an interpretive process (Blumer, 1969), the event of loss and/or fatigue is cognitively restructured so as to not devastate the lives of some of the participants.

The definitions of resilience presented earlier included significant adversity or a severe threat as a precursor to resilience. The losses experienced by the older adult participants as a result of their cancer represent significant adversity. The terminal diagnosis experienced by some of the participants could be seen as a severe threat. The participants experienced many consequences of cancer. After symptoms emerged, all the participants had to cope with tests, waiting for test results, and then being told of a cancer diagnosis. After being told of the diagnosis, the participants had their feelings to deal

with as well as informing family and friends. After the initial shock came treatment discussions and the effects of treatment. All of these stressors produced responses similar to those of persons who have experienced a critical incident (Laws & Hawkins, 1995). Many experienced heightened awareness of vulnerability of self as well as frustration with the effects of treatment.

Bill had one lung removed and part of the other. He had to learn to breathe again and then take chemotherapy and radiation. After their surgeries, David and Michael have had to cope with wearing diapers and having no bladder control. Symbolically, they both took this as a blow to their masculinity and humanity. They have not been able to reach the normalization that many seek after a critical incident (Laws & Hawkins, 1995). At the last interview, a number of months after the initial one, David and Michael were still struggling with having to wear diapers. David expressed it this way, "Yeah. I have some days, I get pretty frustrated." As shown in Table 4, Albert, Glenda, Judy, Jeff, Mildred, Michael, Larry and Jack all had to cope with extreme fatigue brought on by the cancer and treatment. Other than Mildred, the other five appear to be suffering role loss and having to cope with not being able to do as much as before.

Cancer treatment often brought on nausea, vomiting, and extreme fatigue. The data suggested that fatigue was a physical response to cancer treatment. Jeff needed to take a break from treatment due to the chemotherapy "killing" too many of his white blood cells. Jeff stated he could no longer do gardening or yard work due to fatigue. He also expressed anger and frustration at the loss of enjoyment of food, even though his

wife was a “damn good cook.” Judy, Glenda, and Mildred also expressed frustration with loss of enjoyment of food. Glenda viewed it as losing herself and withering away. All of the participants who lost their appetites expressed sadness at the loss of this enjoyment.

Judy expressed feelings of loss of a sense of her own competence as a result of fatigue limiting her activities. She is no longer able to do things with her friends and family. She is a grandmother who used to be active in her grandchildren’s activities. Now she doesn’t always feel like going to their activities because she is fatigued and sometimes nauseated.

Only three participants had to deal with the cessation of treatment because it was believed there was nothing more medical interventions could do against their cancer. Stopping treatment is often a quality of life issue due to harmful effects of treatment (Byock, 1997; Heim, et al., 1997). Glenda and Jack were in hospice when interviewed. Besides fatigue, they had to cope with end-of-life issues and knowing they were going to soon die. They had to cope with the imminent loss of everything, including their life.

McMillen (1999) shows how survivors of traumatic events re-interpret events to find meaning. According to Janoff-Bulman (1989), people involved in traumatic events “cognitively restructure” their thinking about the event to maintain or return to previous levels of functioning. Most of the participants appear to have structured their cancer experience in such a way for it to not be traumatic. Mildred appears to have restructured her cancer experience in relation to her previous experience with cancer to maintain

equilibrium. Other than Michael and Larry, the participants did not seem to be negatively impacted by loss. Increasing losses may be associated with an increased yearning for spirituality-faith. Bill stated that since his cancer diagnosis, his spirituality has deepened. Jack said he would “not make it” without his faith. With most of the participants this cognitive restructuring seemed to be an ongoing process throughout their cancer experience.

To sum up, loss did not necessarily lead to desolation, but instead may serve to increase resilient responses such as positive coping, acceptance and gratitude, and keeping a present-focus. The likelihood of such resilient responses seemed to be greater in the presence of strong social support and spirituality-faith.

Grounded Theory

For resilience to become operative a person must perceive a threat (Feltan, 2000; Staudinger et al., 1995). Figure 1 presents a proposed conceptual model based on the data from this study.

Figure 1
Grounded Theory of A Cancer Diagnosis/Treatment, Resilience and the Subjective Meaning
of the Cancer Experience of Older Adults

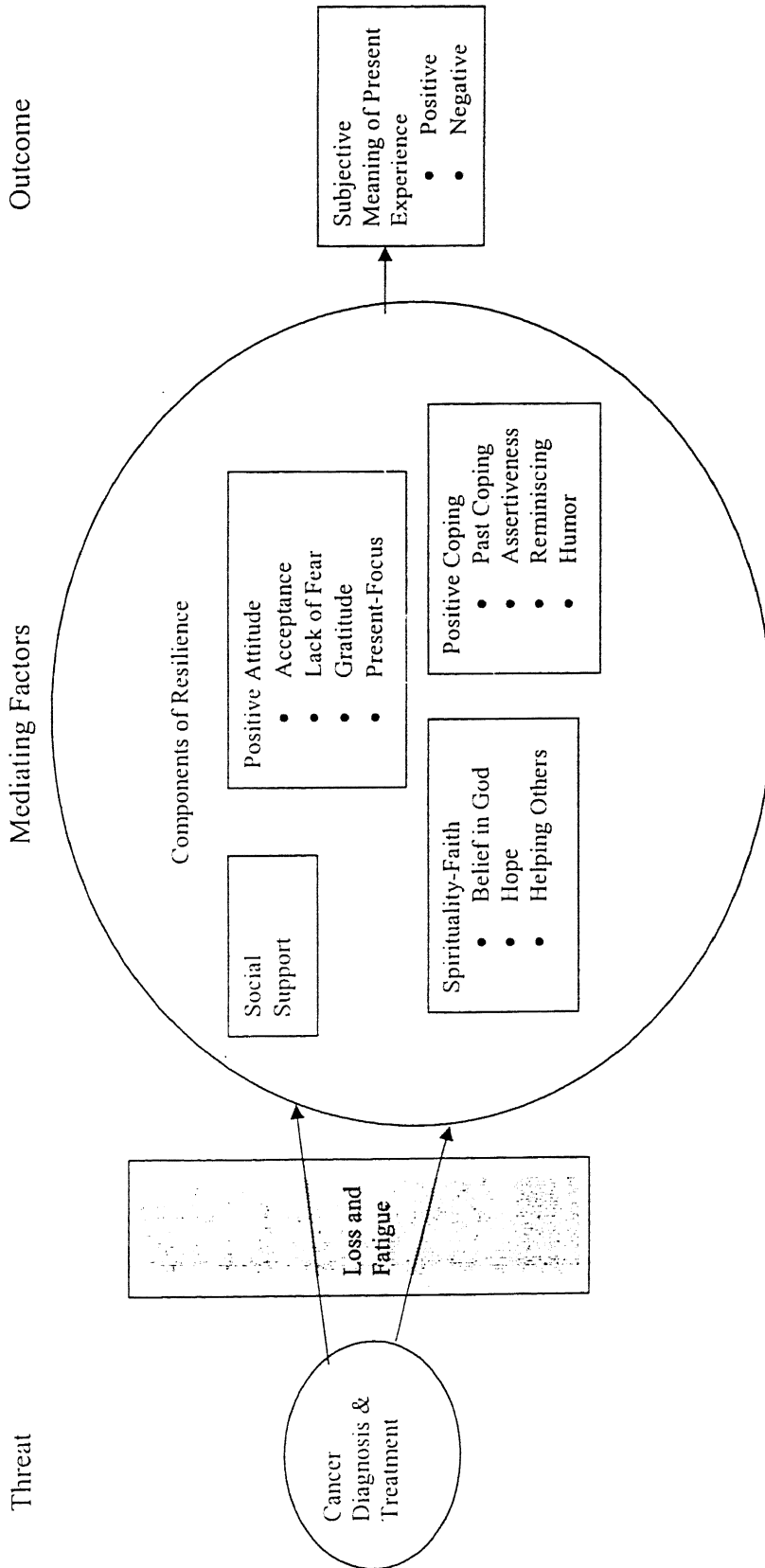


Figure 1 depicts the initial cancer diagnosis and treatment as a threat, the identified components of resilience (themes and sub-themes) as mediating factors, and the subjective meaning of the present experience of older adults as an outcome. In this study, high social support and spirituality-faith appeared to moderate the impact of a cancer diagnosis and cancer treatment. A positive subjective meaning of the cancer experience is heuristically suggested if the components of resilience are present. For the most part, the participants with high social support and spirituality-faith responded to their cancer diagnosis and treatment with a positive attitude (mental constructs), positive coping strategies (action), and a lack of fear. These two factors (social support and spirituality-faith) appear to work in concert to increase the chances of a positive subjective experience. A hypothesis for future testing with a larger sample could be: The components of resilience increase the chances of a positive subjective experience in older adults with cancer.

The two participants (i.e., Michael and Larry) that appeared lacking in the components of resilience displayed a negative attitude, negative coping strategies, the presence of fear, and appeared depressed or in emotional decline. Of these two, only Michael expressed any belief in spirituality-faith and his did not appear to help him a great deal. In keeping with numerous other studies (Bar-Tur & Levy-Shiff, 2000; Bloom & Spiegel, 1984; Christ & Sormanti, 1999; Fobair & Zabora, 1995), it would appear that social support is a critical factor in the response to cancer and in the psychosocial outcomes of older adults. It is not clear from this study what impact loss and fatigue have

on the psychosocial outcome of a cancer diagnosis, but those with a more positive outlook did not appear to be overly impacted, in a psychosocial sense, by loss and fatigue.

From this study it appears that social support, spirituality-faith, a positive attitude, and positive coping all support having a positive subjective experience. Spirituality-faith seems to be associated with this subjective experience in the meaning some people find in their belief system. The more positive participants appear to find spiritual meaning on the basis of what having cancer means to them (Blumer, 1969). The second premise of symbolic interaction is that meanings arise out of social interactions (Blumer, 1969). David and Jack were able to have a more positive experience due to being able to help others.

Social support appears to enhance the subjective meaning of the cancer experience through the people available with which to talk out one's feelings and the opportunity to shift focus away from one's cancer to the happenings in significant others' lives. The strength and nature of the links among the themes and between the themes and the resulting subjective experience need further investigation. A path analysis of the relationship between the themes and having a positive or negative subjective experience could prove to be useful in clarifying the nature of these associations. With an improved understanding of these linkages, social workers would then be better equipped to promote the factors that are helpful to older adults with cancer and prevent the occurrence of those that are not.

The third premise of symbolic interaction holds that meanings are constructed out of an interpretive process (Blumer, 1969). Having a positive attitude that encompassed acceptance, gratitude, and keeping a present-focus all can be seen as arising out of an interpretive process. The first premise of symbolic interaction is that one acts on an event based on the meaning placed on the event (Blumer, 1969). If after a diagnosis of cancer one could see a possibility of an acceptable quality of life, positive coping skills would likely be used more often than if an acceptable quality of life is not expected. An older adult with cancer who sees no quality of life benefit in using past coping skills, being assertive, reminiscing, and finding humor in their situation is unlikely to use these positive coping skills.

McMillen (1999) suggests that some people benefit from adversity. In line with symbolic interactionism, and possibly other theoretical constructs like attribution theory or cognitive dissonance reduction, McMillen (1999) found that a perceived benefit appeared to moderate any negative psychological impact of the stressful event. Attribution theory states that “. . . behavior is not influenced as much by what happens as it is by the meaning that we attach to what happens” (Reinertsen, 1999, p. 54). The theoretical construct of cognitive dissonance reduction holds that many individuals have feelings of discontent that are like hurts deep in the unconscious. “Typically, such discontent derives from personal needs of individuals that are not being gratified in the home and family and other areas of life” (Cassel, Chow, DeMoulin, & Reiger, 2001, p. 450). Both attribution theory and the theoretical construct of cognitive dissonance reduction stress how people internally examine events in their lives (Reinertsen, 1999;

Cassel, et al., 2001). According to Blumer (1969) and Charon (1995), symbolic interactionism examines the internal and external worlds and attempts to explain the relationship between the two. For this study, symbolic interactionism speaks clearly to the social work concept of the person-in-environment. Cohler et al., (1995) found that overcoming an illness early in life increased resilience later in life. Mildred growing through her previous cancer experience helped her to cope with the recent diagnosis.

Fear is a possible subjective experience to having cancer. Only three of the participants expressed fear of death. A number of them expressed the thought that at their age they would die of something so why not cancer. Death did not appear imminent to any of them so stating they had no fear could have been denial. Jack stated that he did not at that time fear death, but he thought he would go kicking and screaming when the time came. Thus, an interpretive process was used by the participants to deal with and/or find meaning in their thoughts about death.

In summary, Figure 1 is a grounded theory of the subjective or lived experience of older adults with cancer. Contextual and individual characteristics are often the focus of study with children and resilience (Doll & Lyon, 1998). These characteristics have some similarities with the proposed theoretical perspective concerning older adults with cancer and older adults in general. Differing aspects would include, but not be limited to, 1) reliance on past coping. Older adults will probably have coped through a number of crises throughout their lives. 2) children are often studied in the spheres of education, emotions, and behaviors; an older adult model would likely exclude the education sphere and include emotions and behaviors; 3) spirituality-faith needs to be a focus of research

on older adults and resilience; 4) there appears to be a strong potential for a positive subjective meaning assigned to the lived experience of cancer among older adults, and 5) the absence of fear appears to be part of the lived experience among older adults with cancer. Next, I will examine how the proposed theoretical framework can be helpful to social workers that work with older adults with cancer and suggest some possible social work interventions.

Relevance for Social Work Practice and Interventions

A number of social work interventions logically follow from the discussion of the relationship among the identified themes as components of resilience. Although these interventions could help many, we need to remember that the older adult with cancer is in charge of his or her treatment or whether he or she even receives treatment. The social work value of self-determination needs to be in the forefront of all interventions. The data from this study suggest that there may be at least two distinct groups of older adults with cancer who seem to have different interventive needs. There are those who are resilient and may not need social work intervention or who could offer support to others. Then, there are those like Michael and Larry who have a very different set of needs.

A number of the participants in this study were recipients of social work interventions. Albert, David, Glenda, Hubert, Hank, Isaac, Jack, and Larry all had some assistance from social workers. David is the only one who spoke negatively of this intervention. He said he was being pushed to deal with issues, such as his wife's impending death, that he was not ready to deal with and he asked the hospice social worker not to return. Jack and Glenda had high praise for their hospice social workers.

Jack credited them with keeping him alive. Some of the other participants may have benefited from a social work intervention, but did not receive one. Judy, Michael, and Jeff stated that they did not know social work interventions were available.

In this study the participants that had strong social support and strong coping mechanisms did not appear to need social work interventions. They also appeared highly resilient. Still, those who do not currently need help, might need help in the future if their disease gets progressively worse or their life situation alters in a negative fashion. Possible social work interventions for older adults with cancer are described below.

Spiritual eldering. Spirituality-faith was an important factor for most of the participants. One striking feature of these participants was their general lack of fear. Perhaps a life well-lived and the qualities related to one's faith bring a certain peace at life's end even in the face of cancer. It appears that most of the participants have surmounted Erikson's last psychosocial crisis, integrity versus despair, and have come through with integrity. "Integrity refers to an ability to accept the facts of one's life and to face death without great fear. . . . Despair is characterized by a feeling of regret about one's past and includes a continuous nagging desire to have done things differently" (Zastrow & Kirst-Ashman, 1997, p. 595). Most of the participants appear to have reached the point of integrity with their life. They may be able to help younger adults with cancer to cope with their disease process.

The theoretical textbooks of which I am aware paint a picture of aging as largely a time of illness, deterioration, and despair (Hooyman & Kiyak, 1998; Kart, 1997; Newman & Newman, 1995; Zastrow & Kirst-Ashman, 1997). These texts spend very

little time on the strengths of older adults, with the vast majority of the text focused on what can go wrong as one ages and the problems of aging. The most recent issues of *Research on Aging* had no articles on the positive aspects of aging. Of the articles reviewed for this dissertation, all seemed to use a pathology model of aging as their starting point. In contrast, the data from this study indicate that many older adults with cancer have much to give. Spiritual eldering is a practice in a number of cultures (Schachter-Shalomi & Miller, 1995) and may be a means of benefiting from the wisdom of older adults with cancer and honoring them at the same time. According to Schachter-Shalomi and Miller (1995), spiritual eldering “helps us consciously transform the downward arc of aging into the upward arc of expanded consciousness that crowns an elder’s life with meaning and purpose. . . It envisions the elder as an agent of evolution, attracted as much by the future of humanity’s expanded brain-mind potential as by the wisdom of the past” (pp. 5-9).

To view older adults with cancer as a resource, social workers will need to face their own reluctance of broaching spiritual concepts with their clients (Bullis, 1996; Canda, 1988). The importance of faith in the lives of older adults with cancer needs to be explored by social work practitioners and researchers. Spirituality is a source of comfort to many (Canda, 1988) and in particular to those facing a diagnosis of cancer. Those who could be spiritual elders and those who are in despair can be helped to complete Erickson's cycle of growth and achieve ego integrity rather than despair at the end of life (Newman & Newman, 1995; Zastrow & Kirst-Ashman, 1997). In the face of an illness that can be terrifying, these older adults with cancer were amazingly resilient.

Although many social workers choose not to address spirituality-faith with their clients (Canda, 1988), social workers should recognize the importance of addressing this topic with older adults with cancer. One might suspect that lack of fear is closely tied to spirituality-faith. Exploring what meaning, if any, older adults with cancer ascribe to spirituality-faith would appear to be an obvious intervention. If this is important to them they need to be encouraged to explore and deepen this aspect of their lives.

It might be possible to pair spiritually-comfortable older adults with cancer with those spirituality-minded, but struggling with their faith. Like Jack, these older adults with cancer could be encouraged to volunteer for hospice or in other settings. Crist-Houran (1996) has shown that volunteering increases one's sense of purpose in life and decreases boredom. This same author demonstrated that those who volunteered were twice as likely to report being happy with themselves as non-volunteers. Encouraging spiritual eldering may have the added effect of decreasing ageist stereotypes in our society. David, Bill, Jack, and Jeff all found increased meaning in life through volunteering their time, talents, and money. David, Bill, and Jeff all volunteered their time prior to being diagnosed with cancer, and continued to do so after diagnosis. For Jack this was a new experience. Seeing older adults with cancer as spiritual elders could legitimize their experiences and increase the quality of life for themselves as well as others.

Family and relationship counseling. Family and relationship counseling is another intervention that could increase the quality of life of older adults with cancer. The Larrys and Michaels of the world would probably benefit from this type of

intervention, but others could benefit as well depending on the state of their disease and shifts in their social support system. Social work practice models encompass a number of theoretical perspectives. Cognitive/behavioral social work examines thinking and behavioral processes that may lead to negative outcomes for clients (Dulmus & Wodarski, 1998). Task-centered social work practice is similar to cognitive/behavioral, but is focused on completing tasks related to the target of intervention (Zastrow, 1999). Structural family therapy deals with understanding and changing the structures inherent in dysfunctional family systems (Aponte, 1992). All of these models encompass the healing power of human relationships. While healing in the realm of cancer may mean curing the disease to some, it can be so much more. Healing can be the coming together of estranged relationships, the forgiveness of past hurts, or the letting go of regrets (Byock, 1997).

It can be argued that all the problems social workers deal with stem from unhealthy relationships. Relationships with animals and children have been shown to decrease depression and increase quality of life of nursing home residents and homebound older adults (Kart, 1997; Matcha, 1997). One would think that improving relationships of all types could increase the quality of life of older adults with cancer as well.

While many of the participants' relationships became closer as a result of their cancer diagnosis, some grew more distant. There is a plethora of research that documents the benefits of family and relationship counseling for those with relationship difficulties (Coletti, 1994; Dattilio, 2001). Life-threatening illnesses have been shown to stress even

the best relationships (Boer, et al., 1998; Christ & Sormanti, 1999; Winscot, 1993). Social work interventions may need to be aimed at the relationships of older adults with cancer. Betty, the older adult with cancer in the vignette on page one, benefited from social work family therapy. One social worker in this study said older adult women with cancer often find their families are not emotionally ready to hear what they need to say. This was not borne out by most of the participants, but needs to be examined by social work practitioners and researchers.

Adults like Michael could possibly benefit from relationship counseling. They could be assisted in using the social support that appears available to them, but is not being effectively used. Family counseling might help older adults like Jeff feel listened to. The transition from first symptoms to diagnosis and then to treatment is often difficult to manage. When a cancer patient is experiencing the nausea, vomiting and fatigue brought on by chemotherapy (Judy, Mildred and Jack, for example), our interventions can be aimed at the cancer patient and family members and friends. Research has shown that cancer patients' best sources of support are family and friends, but they often are overwhelmed with the amount of care needed (Fobair & Zabora, 1995; Henderson, P., 1997; Postone, 1998; Tope, et al., 1993). Helping family and friends to cope would probably increase their effectiveness in supporting the cancer patient. Interventions could include counseling and arranging respite care and other home-based services that are currently available, but inadequate to meet the need (Borgenicht, Carty, & Feigenbaum, 1997).

Older adults with a terminal diagnosis and their families are often navigating uncharted waters. They may need help with the “five things of relationship completion” (Byock, 1997, p. 140). These five things are saying, “I forgive you;” “Forgive me;” “Thank you;” “I love you;” and “Goodbye” (p. 140). Michael and Larry appeared to need help with the “five things of relationship completion.” There are times a social worker may need to lead a family in a decision-making process or basic family therapy. Adults like Michael and Jeff could use some help enlisting their families to be more supportive.

Reminiscing. Reminiscent therapy could be used in any type of counseling setting with older adults with cancer. Most of the interview with Glenda and large sections of the interviews with Jeff, Judy, Isaac, and Mildred were spent with them reminiscing about their lives and the people in their lives. From my experience as a clinical social worker in nursing homes, I knew that reminiscing has great potential for therapeutic effect. Life review has long been known to have therapeutic value for older adults (Butler, 1963): Life review and reminiscence therapy are often and effectively used in nursing homes to decrease depressive symptoms and social isolation (Burnside & Haight, 1994; Haight & Michel, 1998). These two therapeutic techniques have also been shown to ease the transitions faced by dying older adults (Brady, 1999). These methods could not only be used to help older adults with cancer, but could also be a means of transmitting the life lessons of older adults with cancer to other generations. The oncology social workers interviewed stated that when the older adults with cancer in their groups talk of times past, the social workers often try to steer them to the present. Instead

of bypassing a major coping strategy of older adults with cancer, social workers should encourage the therapeutic use of reminiscing.

With gratitude being expressed and being helpful to a number of participants, perhaps this could be a focus for interventions. Writing gratitude lists is a strategy used to decrease relapse for those recovering from substance abuse problems (Gerwe, 2000; Walton, Reischl, & Ramanathan, 1995). Older adults with cancer could be encouraged to do this as well -- either independently or as part of a strategy on reminiscing. The participants who were listened to as well as the ones who were not, expressed the need to be listened to and heard. Reminiscing could be used to bring an older adult with cancer and the people in their support system closer together as well as to help older adults who need it to achieve ego integrity (Zastrow & Kirst-Ashman, 1997).

Building a support system. Those less resilient older adults in this study, Michael and Larry, appear to need help obtaining what the other 11 participants already have. Social work has a long history of working with populations-at-risk (Zastrow & Kirst-Ashman, 1997). Not being listened to, not having their needs acknowledged, not being valued for themselves, and the physical and mental consequences of cancer puts some older adults with cancer at-risk. As we have seen, they struggle with emotional ups and downs, experience problems with treatment, need a support system, and have a host of other issues. One social worker spoke of his frustration with some older adults with cancer viewing group sessions as a social event rather than as therapy. Instead of being frustrated, social workers could use this apparent need for a social outlet to facilitate

relationship building among older adults with cancer. Interventions could encourage and empower older adults with cancer to remain socially engaged.

The participants with strong social support viewed this support as a blessing. Some older adults with cancer may need help building a support system. Home visits by social workers could increase an older adults' support system. Those like Michael would benefit by learning to utilize the social supports available to them, but not effectively used. Glenda taught us that if concrete help with daily needs is given, the family can focus on the social and emotional support that is often needed. There appears to be a relationship between social support and resilience. Social workers could increase resilience by helping older adults with cancer strengthen their formal and informal supports. Reminiscing, building a support system, and other strategies could be potential interventions in concert with individual and/or group counseling.

Individual and group counseling. The goals of those in individual or group counseling are often the same (Gambrill, 1997; Hepworth & Larsen, 1997; Zastrow, 1999). Goals and issues that can be dealt with in both types of counseling include, but are not limited to: 1) acceptance of their current life status, 2) finding aspects of their lives to be grateful for, 3) keeping a present-focus, 4) building or strengthening a support system, 5) grief work, 6) stress reduction, 7) facing fear, 8) keeping a positive attitude, and 9) strengthening or finding spirituality-faith.

Two participants--Jeff and Bill--displayed assertive behaviors in relation to their cancer and treatments. The social workers commented on the lack of assertive behaviors of older adults with cancer. The social workers viewed this as a cohort effect, i.e., being

trained to defer to authority. Assertiveness training appears to be needed by some older adults with cancer and could be accomplished through individual or group therapy.

Promoting the resilience of older adults with cancer in all the roles social workers play is critical in improving their lives. Acceptance was spoken of often by many of the participants. Helping older adults with cancer reach acceptance could promote resilience. There appears to be a disconnect between some social work interventions and the needs of older adults with cancer to reminisce, be listened to, have a support system, and reach acceptance. Future research could help develop social work best practices in using reminiscing, listening to what older adults are saying, building support systems, and reaching acceptance of one's illness.

An older adult with cancer has both situational and transitional stress. The stress is situational in that each stage of the illness experience presents different dilemmas. The onset of symptoms produces a search for a cause. In the case of Judy and Mildred, the search was prolonged. Once a diagnosis and course of treatment is decided upon, a social worker can help the older adult with cancer deal with the emotions brought on by a cancer diagnosis. Michael and Jack both experienced anger and fear. Judy, Bill and Larry all shared about their fear. Talk therapy research has shown that the act of sharing these feelings often brings about their reduction (O'Hanlon & Martin, 1992). Accumulating losses is another stressful area for older adults with cancer. Frankl (1970) shows us how one can find meaning in multiple losses. Facilitating an older adult's search for meaning can be a social work intervention.

Grief counseling has been demonstrated to decrease despair in older adults who are dealing with loss (Hancock, 1990). Moving from symptoms to diagnosis, to various forms of treatment and remission, being told that there is no more that can medically be done, and active dying are all periods of transitional stress. Social work interventions may be different at each transition point or process. Many may need grief counseling, relationship counseling, or counseling to deal with a multitude of issues.

Older adults with a terminal diagnosis (e.g., Glenda, Larry and Jack) may require a different style of social work. Authors on hospice care discuss the need for those working with terminal patients to be comfortable with their own mortality (Byock, 1997). Death and dying can be messy, traumatic and painful for all involved (Moller, 1990). Social workers working with a terminal population require special training (Callan, 1989). We learned from Jack that terminal patients, as well as all social work clients, need to be treated with respect and not patronized. Glenda and Jack had effective social work support. Larry's needs were too great to be met by the one social worker available.

Cognitive/behavioral social work interventions appear ideally suited to increasing the positive coping of older adults with cancer and thereby increasing their resilience. Through these interventions it might be possible to tap into older adults' reserve capacity (Staudinger, et al., 1995). Accumulated losses did not appear to negatively impact most of the participants of this study. It may be that social support, spirituality-faith, having a positive attitude, keeping a present-focus, gratitude, and acceptance diminish the psychosocial impact of accumulated loss. This is another reason that social workers could intervene to enhance these factors. Two other factors that can be addressed in

individual and group therapy are hope and helping the older adult with cancer to return to a sense of normalcy, even with a possibly reduced capacity.

Volunteerism. Helping others was important to several participants (Bill, David, Jack, Jeff, Mildred, and Judy). Jack taught us that those with a terminal diagnosis can reach out and help others as well as, if not better, than trained professionals. Social workers need to recognize the skills and experiences of older adults with cancer. Tapping into the talents and wisdom of older adults with cancer could be accomplished through paid work or volunteering. Volunteering, of course, should be dependent on older adults' willingness and physical and emotional stamina. It is clear that many older adults with cancer have much to contribute.

Case management. Norlin and Chess (1997) define case management as a "method of professional practice conducted by a specific individual or team characterized by an ongoing responsibility to help functionally impaired clients" (p. 23). Case management skills are needed to help some older adults with cancer access resources, such as hospice, home health care, and durable medical goods like wheelchairs.

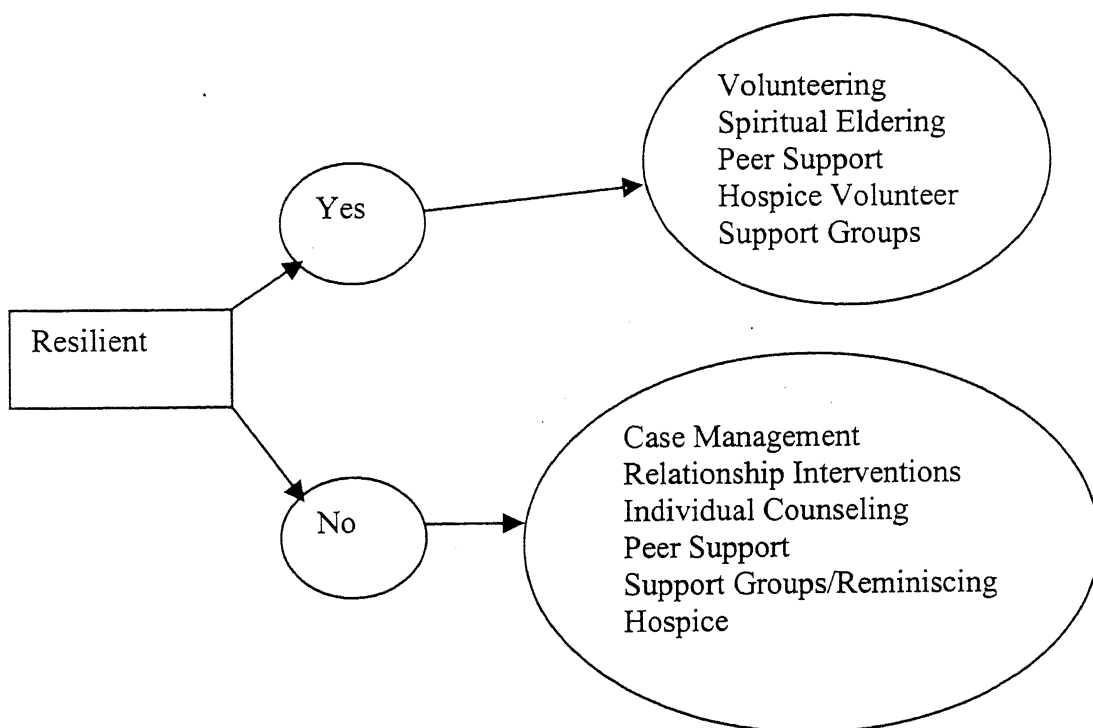
While most of the participants do not need an advocate, they may if their functioning decreases. Others like Larry, Michael, and Jack could benefit from the services of an advocate. Advocacy is an important aspect of case management. Low-income older adults with cancer, or those with inadequate health insurance, often need an advocate. The advocate role for a social worker involves stepping forward and speaking on behalf of the client system (Zastrow & Kirst-Ashman, 1997, p. 45). Other than Larry and Jack, all the participants in this study appeared to have adequate resources to get their

needs met. Jack developed hospice as an effective advocate, and therefore his needs were eventually met. Larry did not have an advocate, and although all his basic physical needs were met, his needs for psychosocial support were not. He had nobody but the interviewer and the nursing home social worker with whom to discuss his fears about dying. The nursing home social worker was responsible for over 100 patients. One of the participants, David, said that older men who live alone seem to struggle more emotionally and are more isolated than older women who live alone. Larry taught us that those in nursing homes may need visiting companions to take the place of non-existent or uninvolved family members.

Summary of Interventions

Figure 2 depicts some social work interventions for resilient and non-resilient older adults with cancer.

Figure 2: Interventions for Older Adults with Cancer



A number of resilient older adults with cancer might want to help other less resilient people with cancer. For these resilient older adults with cancer, being called on to volunteer, be spiritual elders, provide peer support, and work with those in hospice might help them to find meaning in their illness experience. Peer support might also be beneficial to those less resilient older adults with cancer. While hospice has grown in recent years, it is still used by only a small percentage of those who could benefit from its philosophy of palliative care (Byock, 1997). Many resilient older adults with cancer may want to and could benefit from participation in cancer support groups. Social workers need to take care that those who choose not to help others are not shamed in any way.

To efficiently use this model of resilient older adults with cancer, social workers might use a quick screening tool to determine which older adults with cancer are resilient and which are not. This tool would look for evidence or the lack of social support, a positive attitude, a present-focus, positive or negative coping strategies, effective spirituality-faith, level of fear, acceptance of their illness, and the ability to find gratitude in their lives. Such a tool could also serve the purpose of sensitizing social workers to the potential for positive aspects of living with cancer.

Christ and Sormanti (1999) found that social work practitioners felt unprepared to deal with end-of-life care issues and issues of an older population in general. The social workers surveyed cited their education as being lacking in preparation to work with an aging population. The three social work practice texts reviewed emphasized the problems of older adults and said little if anything about resilience and adaptive ability (Gambrill, 1997; Hepworth & Larsen, 1997; Zastrow, 1999). Even the American Cancer

Society's clinical guide for oncology social work stressed pathology rather than strengths (Stearns, Lauria, Hermann, & Fogelberg, 1993). Most of the older adults in this study were resilient and adapted their functioning to regain a sense of normalcy in an abnormal situation. One would think that with the social work emphasis on the strengths perspective we would capitalize on the resilience of a population, rather than stress pathology. One implication for social work practice, and society at large for that matter, is that we are missing a tremendous resource by relegating older adults to the scrap heap. As social workers we need to utilize the strengths of older adults, even those with cancer, to help themselves and others. In many ways, older adults, including those with cancer, are an unredeemed resource. Older adults with cancer who want to be a resource should be encouraged to do so. They could be a resource for hospice care, cancer support groups, as spiritual elders, and other such activities.

There are many resources for social workers to draw from when working with older adults with cancer. The Council on Social Work Education (CSWE), the accrediting body for schools of social work, has launched "Strengthening Aging and Gerontology Education for Social Work" (SAGE-SW). SAGE-SW provides opportunities for faculty development in gerontology and provides other resources for faculty, students, and practitioners. SAGE-SW is dedicated to preparing ALL social workers to meet the needs of a growing aging population (CSWE, 2000). Social workers can draw from the "Project on Death in America"

(<http://www.soros.org/death/index.htm>) and a host of other resources for working with the older person with cancer. Besides developing curricula on death and dying for social

workers, the “Project on Death in America” provides research and other funding to enhance the quality of life of those actively dying and their caregivers. The Cancer Survivors Toolkit is available at the Project on Death in America website as well as links to many other resources for cancer patients and others with terminal illnesses.

In summary, this study has shown the resilience and resources of many older adults with cancer and some of the needs of others. Given the findings, social workers need to assess for resilience and provide interventions if needed and wanted. Volunteering and spiritual eldering appear to be areas that could be greatly enhanced. Peer support and relationship interventions are also infrequently used resources with older adults (Butler, Lewis, & Sunderland, 1998). If an older adult with cancer does not have adequate social support, they may need help in building a support system or in some cases providing them with one. With positive coping being a main theme in this study, social workers need to stress the strengths perspective and minimize a pathology model of assessment and treatment.

Limitations, Recommendations, and Plans for Future Research

Given that older adults are the fastest growing segment of our population (U.S. Bureau of the Census, 2000), there is much more that social work as a profession needs to do on behalf of or in partnership with older adults. The estimated number of social workers needed to serve our aging population far outstrips the current numbers of the gerontologically trained students being graduated from schools of social work (Scharlach, Damron-Rogriquez, Robinson, & Feldman, 2000). Only 3% (1,071) of the 34,480 master’s level social workers graduating in 1996 selected aging or gerontological social

work as their area of concentration. Stereotypes against aging were cited as the most common reason for not choosing to work with older adults (Scharlach et al., 2000). It is clear from the increasing number of older adults possibly needing services that many more social workers need a basic competence in working with older adults.

From this exploratory investigation one could easily see the beginnings of a larger study on resilience and older adults with cancer. One limitation of this study is the lack of cultural diversity. With only one person of color we do not get a clear picture of this population and their needs in the face of cancer. Research on cultural dynamics and their impact on resilience and coping with cancer would help social work practitioners implement effective interventions with older adults with cancer. Another limitation is the homogeneity of the participants with respect to economic status. Does resilience hold up when there are limited resources? The one participant with limited resources did not appear to be resilient, although I did not interview him until he was near death. He may have been very resilient prior to entering the nursing home. Another possible limitation is that those who volunteered to participate might have a more positive attitude than those who did not choose to participate. One individual initially agreed to participate and then changed her mind.

Larry and Michael were the participants displaying the greatest needs. We need to investigate the prevalence of older adults with cancer like Larry and Michael. Also, different types of cancer could lead to different results than were found with this study. A study with more participants with different types of cancer could be beneficial. Longitudinal research on the stability of the construct of resilience across developmental

stages suggested by Felten (2000) has not been completed. Longitudinal research on older adults with cancer could examine ongoing needs and whether resilience holds up as their cancer progresses.

It is clear from the data that these participants were an amazingly resilient group of people. As social workers we need to acknowledge and highlight such resilience. We need research specific to older adults with cancer focusing on the concepts of resilience and reserve capacity. We need to investigate further the pathways to resilience and how this can be facilitated by gerontological social workers. This resilience could also be used to combat the myths of aging and therefore attract more social workers to gerontological social work. The conceptual links between lack of fear, acceptance, positive attitude, gratitude, and spirituality-faith also need to be explored. The explanatory role of symbolic interactionism in response to and coping with cancer in various stages should be investigated as well. Research on the apparent relationship among the themes identified in this study and between the themes and resilience could help many older adults with cancer. Research on the association between resilience and positive coping strategies could lead to more effective social work interventions for older adults with cancer.

An inquiry into possible gender differences in the needs of older adults with cancer is needed. Social work practitioners and researchers could learn many valuable lessons by examining the different interventive needs of older adult women and men with cancer. Research could be done using social workers that work with older adults in a variety of settings (e.g., nursing homes, senior centers, assisted living facilities,

counseling centers, etc.). When his or her client is diagnosed with cancer, how does the social worker react to this change in circumstances? We need to see how social workers handle the issues brought on by a cancer diagnosis.

Research centered on the specific meanings and metaphors older adults use with cancer would probably be helpful in working with this population, similar to Sontag's (1990) work on illness and AIDS as metaphor. Are there age differences in resilience and coping? Is there a correlation between the identified themes of this study and between the themes and time since diagnosis and age? This could possibly lead to interventions that would be beneficial for older adults at different stages of cancer. We need to explore the possible connection between increasing losses and the thirst for a comforting spirituality-faith. Studying the cohort group influences on older adults with cancer could also be helpful. We could look at questions such as how older adults' common life experiences have impacted their resilience in the face of a cancer diagnosis. The next study I would recommend with older adults with cancer would take a three-pronged approach. We need a quantitative study examining the themes with a representative group of older adults with cancer across racial, ethnic, socioeconomic, and gender lines. I also recommend a longitudinal examination of the themes as the cancer progresses and a qualitative exploration at the very end of life for this population.

One surprising aspect of learning from this study was the difficulty I had switching from clinical interviewing to interviewing for research purposes. The purpose of clinical interviewing is to arrive at solutions to problems with a planned course of action as one outcome. Thus, clinical interviewing tends to be problem-focused.

Research interviews, particularly qualitative in-depth interviews, are designed to elicit information without a planned therapeutic goal (Esterberg, 2002). I wanted answers, but not solutions to individual problems. Initially, I found it challenging to not act as a clinical social worker. I would recommend other clinically trained researchers be mentored in the interviewing process by an experienced researcher. They could process tapes of interviews together and adjust interviewing techniques as needed. While I recommend suppressing aspects of clinical interviewing in research, the skills of clinicians in putting others at ease is a tremendous benefit in research interviews. All of my active listening skills were helpful in eliciting information from the participants.

Conclusion

Old age is often seen as a time of inevitable decline with a diminished quality of life (Kart, 1997). A person with cancer is usually viewed as having nothing left to contribute to life (Henderson, 1997). Older adults are also frequently seen as having little to contribute to their own lives or the lives of others (Kart, 1997). With this picture one would think that older adults with cancer would experience double jeopardy.

In remission or not, most of the older adults with cancer in this study were able to regain a sense of normalcy, maintain some quality of life, contribute to their own life and those around them, and for some to grow past where they were before they were diagnosed with cancer. Eleven of the 13 participants remained highly engaged in their lives. While there were some things many could no longer do, most appeared to live a life steeped in gratitude. Living past 65 does not mean the end of a meaningful life and

having cancer does not have to end one's satisfaction with life. These participants have shown that life can be good no matter what curves we are thrown.

As mentioned earlier, older adults with cancer are usually studied from a medical model stressing pathology (Varricchio, et al., 1996). They are seldom the focus of research; they are usually part of a larger study. There is much we can learn about resilience from these older adults with cancer. This study has shown they can continue to function and even thrive in the face of cancer. These older adults with cancer have confirmed Frankl's (1970) statement that the last freedom is the freedom to choose one's own attitude in the face of any circumstance. This freedom cannot be taken from us.

This study of older adults with cancer has been an amazingly rewarding experience. These thirteen older adults let me into their hearts and minds. Surprisingly, there was a positive face to living with cancer. None of the participants wanted cancer, but most of them made the best of a tough situation. I have learned from them the importance of social support, positive coping skills, having a positive attitude, keeping a present-focus, finding things to be grateful for, reaching acceptance with their disease, and spirituality-faith. They have also taught me that multiple losses do not have to devastate a person and that it is possible to have cancer and not be wracked with fear. In not acknowledging the resilience shown by these participants, we may be missing a tremendous resource that could be used to help others become resilient. Their lack of fear and resilient personalities were affirming of their value as individuals. It is time we social workers learned from them and listened to them to help create a more just and wise

society. It is time we listened, honored, and learned from older adults with cancer. They can be our spiritual elders again.

Postscript

Status of the participants as of May 2001:

Albert - Condition has improved since interview and he continues to live in assisted living.

Bill: Has no sign of cancer and continues to manage an AA clubhouse.

David: No sign of cancer, but continues to struggle with having to wear diapers. He spends most of his time helping other people.

Glenda: Passed away on December 4, 2000, surrounded by her family.

Hubert: Health is improving and remains in assisted living.

Hank: No change since interview, doing well.

Isaac: Health is declining, but is not related to his cancer. He remains alert and is now in a long-term care facility.

Judy: She remains in fairly good spirits, but her cancer is growing. She will be taking 37 radiation treatments over the next few months.

Jack: Passed away on December 1, 2000, surrounded by friends.

Jeff: Passed away on May 2, 2001. He reached his goal of living to his 73rd birthday.

Larry: Passed away on December 1, 2000.

Mildred: Continues to look for blessings. She has been newly diagnosed with hepatitis C. She is not being treated for this due to possible interactions with her cancer drugs.

Michael: His fatigue is increasing, but he is still able to play golf. His legs are giving out with no medical diagnosis yet. He said he falls a lot.

References

- Aponte, H. J. (1992). The black sheep of family therapy: A structural approach to brief therapy. In S. Budman, M. Hoyt, & S. Friedman, (Eds.), *The first session of brief therapy: A book of cases* (pp. 324-342). New York: Guilford.
- Ariès, P. (1974). *Western attitudes toward death: From the middle ages to the present*. Baltimore: Johns Hopkins University Press.
- Bar-Tur, L. & Levy-Shiff, R. (2000). Coping with losses and past trauma in old age: The separation-individuation perspective. *Journal of Personal & Interpersonal Losses*, 5 (2/3), 263-282.
- Beck, A. T. (1967). *Depression: Cause and treatment*. Philadelphia: University of Pennsylvania Press.
- Bloom, J. R. & Spiegel, D. (1984). The relationship of two dimensions of social support to the psychological well-being and social functioning of women with advanced breast cancer. *Social Science and Medicine*, 19 (8), 831-837.
- Blum, R. H. & Blum, D. S. (1988). Psychosocial care of the cancer patient: Guidelines for the physician. *Journal of Psychosocial Oncology*, 6 (½), 119-135.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Boer, H., Elving, W. J. L., & Seydel, E. R. (1998). Psychosocial factors and mental health in cancer patients: Opportunities for health promotion. *Psychology, Health, and Medicine*, 3 (1), 71-80.
- Bordieri, J. E. & Solodky, M. (1992). Congruity of perceived psychosocial needs of individuals with cancer. *Rehabilitation Counseling Bulletin*, 36 (2), 120-126.
- Borgenicht, K., Carty, E., & Feigenbaum, L. Z. (1997). Community resources for frail older patients. *Western Journal of Medicine*, 167 (4), 291-294.

- Brady, E. M. (1999). Stories at the hour of death. *Home Health Nursing*, 17 (3), 176-180.
- Bullis, R. K. (1996). *Spirituality in social work practice*. Washington, D.C.: Taylor & Francis.
- Burns, C. & Harm, N. J. (1993). Emergency nurses' perceptions of critical incidents and stress debriefing. *Journal of Emergency Nursing*, 19 (5), 431-436.
- Burnside, I. & Haight, B. (1994). Reminiscence and life review. Therapeutic interventions for older people. *Nursing Practice*, 19 (4), 55-61.
- Butler, R. (1963). The life review: An interpretation of reminiscence in the aged. *Psychiatry* 26, 65-76.
- Butler, R. N., Lewis, M. I., & Sunderland, T. (1998). *Aging and mental health: Positive psychosocial and biomedical approaches* (5th ed.). Boston: Allyn and Bacon.
- Byock, I. (1997). *Dying well: Peace and possibilities at the end of life*. New York: Riverhead Books.
- Callan, D. B. (1989). Hope as a clinical issue in oncology social work. *Journal of Psychosocial Oncology*, 7 (3), 31-47.
- Canda, E. (1988). Spirituality, religious diversity, and social work practice. *Social Casework*, 69 (4), 238-247.
- Cassel, R., Chow, P., DeMoulin, D. E., & Reiger, R. C. (2001). Comparing the cognitive dissonance of 116 juvenile delinquent boys with that of 215 typical high school students. *Education*, 121 (3), 449-455.
- Charmaz, K. (1994). The grounded theory method: An explication and interpretation. In B. G. Glaser (Ed.), *More grounded theory methodology: A reader* (pp. 95-115). Mill Valley, CA: Sociology Press.

- Charon, J. M. (1995). *Symbolic interactionism: An introduction, an interpretation, an integration* (5th ed.). Englewood Cliffs, NJ: Prentice Hall.
- Christ, G. H. & Sormanti, M. (1999). Advancing social work practice in end-of-life care. *Social Work in Health Care*, 30 (2), 81-99.
- Cohler, B. J., Stott, F. M., & Musick, J. S. (1995). Adversity, vulnerability, and resilience: Cultural and developmental perspectives. In D. Cicchetti & D. J. Cohen (Eds.), *Developmental psychopathology: Risk, disorder, and adaptation* (volume 2) (pp. 753-800). New York: John Wiley & Sons.
- Coletti, M. (1994). Family therapy with drug addicts' families. *Journal of Drug Issues*, 24, (4), 623-639.
- Council on Social Work Education. (2000). *Strengthening aging and gerontology education for social workers*. [Http://www.cswe.org/sage-sw/index.htm](http://www.cswe.org/sage-sw/index.htm)
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Crist-Houran, M. (1996). Efficacy of volunteerism. *Psychological Reports*, 79, 736-742.
- Dattilio, F. M. (2001). Cognitive-behavior family therapy: Contemporary myths and misconceptions. *Contemporary Family Therapy*, 23 (1), 3-18.
- Denzin, N. (1978). *The research act: A theoretical introduction to sociological methods*, (2nd ed.). New York: McGraw-Hill.
- Denzin, N. (1989). *Interpretive interactionism*. Newbury Park, CA: Sage.
- Derogatis, L. R., Morrow, G. R., & Ferring, J. (1983). The prevalence of psychiatric disorders among cancer patients. *Journal of the American Medical Association*, 249, 751-757.

Doll, B. & Lyon, M. A. (1998). Risk and resilience: Implications for the delivery of educational and mental health services in schools. *School Psychology Review*, 27 (3), 348-364.

Dulmus, C. N. & Wodarski, J. S. (1998). Major depressive disorder and dysthymic disorder. In B. Thyer & J. Wodarski (Eds.), *Handbook of empirical social work practice: Mental disorder* (pp. 273-286). New York: John Wiley & Sons.

Early, T. J. & GlenMaye, L. F. (2000). Valuing families: Social work practice with families from a strengths perspective. *Social Work*, 45 (2), 118-131.

Esterberg, K. G. (2002). *Qualitative methods in social research*. Boston: McGraw Hill.

Fackelman, K. A. (1993). Cancer treatment: Does age bias interfere? *Science News*, 144 (15), 229-230.

Felten, B. S. (2000). Resilience in a multicultural sample of community-dwelling women older than age 85. *Clinical Nursing Research*, 9 (2), 102-124.

Ferring, D. & Filipp, S. H. (2000). Coping as a "reality construction": On the role of attentive, comparative, and interpretative processes in coping with cancer. In J. H. Harvey & E. D. Miller, (Eds.), *Loss and trauma: General and close relationship perspectives* (pp. 146-165). Routledge, NY: Brunner-Routledge.

Fobair, P. A. & Zabora, J. R. (1995). Family functioning as a resource variable in psychosocial cancer research: Issues and measures. *Journal of Psychosocial Oncology*, 13 (½), 97-114.

Folstein, M. (1998). Mini-mental and son. *International Journal of Geriatric Psychiatry*, 13 (5), 290-294.

Fox, K. R. (1999). The influence of physical activity on mental well-being. *Public Health Nutrition*, 2 (2A), 411-418.

Frankl, V. E. (1970). *Man's search for meaning: An introduction to logotherapy*. Boston: Beacon Press.

Franklin, C. (1998). Distinctions between social constructionism and cognitive constructivism: Practice applications. In C. Franklin & P. Nurius (Eds.), *Constructivism in practice: Methods and challenges*, (pp. 57-96). Milwaukee: Families International Inc.

Frolkey, C. (1996). Trauma in the workplace. *Personnel Journal*, 75 (11), 10-14.

Gambrill, E. (1997). *Social work practice: A critical thinkers guide*. New York: Oxford University Press.

Gear, E. & Haney, L. A. (1990). The cancer patient after diagnosis: Hospitalization and treatment. In E. J. Clark, J. M. Fritz, & P. P. Rieker (Eds.), *Clinical sociological perspectives on illness and loss: The linkage of theory and practice* (pp. 274-288). Philadelphia: Charles Press.

Glaser, B. G. (1994). The constant comparative method of qualitative analysis. In B. G. Glaser (Ed.), *More grounded theory methodology: A reader* (pp. 182-196). Mill Valley, CA: Sociology Press.

Glaser, B. & Strauss, A. (1965). *Awareness of dying*. Chicago: Aldine.

Glaser, B. & Strauss, A. (1968). *The discovery of grounded theory*. New York: Aldine.

Goldstein, E. G. (1995). Psychosocial approach. In R. L. Edwards (Ed.), *Encyclopedia of social work* (19th ed., Vol.3, pp. 1948-1954). Washington, DC: NASW.

Gerwe, C. F. (2000). Chronic addiction relapse treatment: A study of the effectiveness of the high-risk identification and prediction treatment model. Part I. *Journal of Substance Abuse Treatment*, 19 (4), 415-427.

Grimby, A. & Svanborg, (1997). Morbidity and health-related quality of life among ambulant elderly citizens. *Aging*, 9 (5), 356-364.

Haight, B. K. & Michel, Y. (1998). Life review: Preventing despair in newly relocated nursing home residents short and long-term. *International Journal of Aging & Human Development*, 47 (2), 119-153.

Hancock, B. L. (1990). *Social work with older people* (2nd ed.). Englewood Cliffs, NJ: Prentice-Hall.

Harpham, W. S. (1995). Psychosocial oncology: A view from the other side of the stethoscope. *Journal of Psychosocial Oncology*, 13 (3), 89-105.

Heim, E., Valach, L., & Schaffner, L. (1997). Coping and psychosocial adaptation: Longitudinal effects over time and stages in breast cancer. *Psychosomatic Medicine*, 59, 408-418.

Henderson, A. (1995). Psychosocial—personal aspects of cancer. *Women's Health Weekly*, N, 16-21.

Henderson, P. (1997). Psychosocial adjustment of adult cancer survivors: Their needs and counselor interventions. *Journal of Counseling and Development*, 75 (3), 188-195.

Hepworth, D. H. & Larsen, J. A. (1997). *Direct social work practice: Theory and Skills* (4th ed.). Pacific Grove, CA: Brooks/Cole.

Hequembourg, A. L. & Farrell, M. P. (1999). Lesbian motherhood. *Gender & Society*, 13 (4), 540-553.

Hooyman, N. & Kiyak, H. A. (1998). *Social gerontology: A multi-disciplinary perspective* (4th ed.). Boston: Allyn & Bacon.

Hoshmand, L. L. S. T. (1989). Alternative research paradigms: A review and teaching proposal. *The Counseling Psychologist*, 17 (1), 3-19.

- Houldin, A. D. & Wasserbauer, N. (1996). Psychosocial needs of older cancer patients: A pilot study abstract. *MEDSURG Nursing*, 5 (4), 253-256.
- Howard, S. & Dryden, J. (1999). Childhood resilience: Review and critique of literature. *Oxford Review of Education*, 25 (3), 307-324.
- Janoff-Bulman, R. (1989). Assumptive worlds and the stress of traumatic events: Applications of the schema construct. *Social Cognition*, 7, 113-136.
- Kart, C. S. (1997). *The realities of aging: An introduction to gerontology*, (5th ed.). Boston: Allyn & Bacon.
- Katovich, M. A. & Reese, W. A. (1993). Postmodern thought in symbolic interaction: Reconstructing social inquiry in light of late-modern concerns. *Sociological Quarterly*, 34 (3), 391-412.
- Krause, K. (1993). Coping with cancer. *Western Journal of Nursing Research*, 15, (1), 31-43.
- Lal, B. B. (1995). Symbolic interaction theories. *American Behavioral Scientist*, 38 (3), 421-442.
- Laws, T. & Hawkins, C. (1995). Critical incident stress: A normal response to an abnormal situation. *Australian Nursing Journal*, 2 (7), 32-37.
- Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw Hill.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, 71 (3), 543-562.
- Madan, A. K., Aliabadi-Wahle, S., & Beech, D. J. (2001). Age bias: a cause of underutilization of breast conservation treatment. *Journal of Cancer Education*, 16 (1), 29-32.

- Marshall, C. & Rossman, G. B. (1995). *Designing qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.
- Masten, A. S. (2001). Ordinary magic: Resilience processes in development. *American Psychologist*, 56 (3), 227-238.
- Masten, A. S. & Coatsworth, J. D. (1995). Competence, resilience, and psychopathology. In D. Cicchetti & D. J. Cohen (Eds.), *Developmental psychopathology: Risk, disorder, and adaptation (volume 2)* (pp. 715-752). New York: John Wiley & Sons.
- Matcha, D. A. (1997). *The sociology of aging: A social problems perspective*. Boston: Allyn & Bacon.
- McGill J. S. & Paul, P. B. (1993). Functional status and hope in older adult people with and without cancer. *Oncology Nursing Forum*, 20 (8), 1207-1211.
- McKenna, R. J. (1994). Clinical aspects of cancer in the elderly. *Cancer*, 74, 2107-2117.
- McLachlan, M. & McAuliffe, E. (1993). Critical incident counseling for psychology students in a refugee camp: Implications for counseling. *Counseling Psychology Quarterly*, 6 (1), 27-35.
- McMillen, J. C. (1999). Better for it: How people benefit from adversity. *Social Work*, 44, (5), 455-469.
- Moller, D. W. (1990). *On death without dignity: The human impact of technological dying*. Amityville, NY: Baywood Publishing.
- Monfardini, S., & Yanick, R. (1993). Cancer in the elderly: Meeting the challenge of an aging population. *Journal of the National Cancer Institute*, 85, 532-538.
- National Association of Social Workers. (1996). *Code of ethics*. Washington, DC: Author.

Nee, L. E. (1995). Effects of psychosocial interactions at a cellular level. *Social Work, 40* (2), 259-262.

Newman, B. M. & Newman, P. R. (1995). *Development through life: A psychosocial approach* (6th ed.). Pacific Grove, CA: Brooks/Cole.

Norlin, J. M. & Chess, W. A. (1997). *Human behavior and the social environment: Social systems theory* (3rd ed.). Boston: Allyn & Bacon.

Novotny, E. S., Hyland, J. M., Coyne, L., Travis, J. W., & Pruyser, H. (1984). Factors affecting adjustment to cancer. *Bulletin of the Menninger Clinic, 48* (4), 318-328.

O'Hanlon, W. H. & Martin, M. (1992). *Solution-oriented hypnosis: An Ericksonian approach*. New York: W. W. Norton.

Polkinghorne, D. E. (1989). Phenomenological research methods. In R. S. Valle & S. Halling (Eds.), *Existential-phenomenological perspectives in psychology* (pp. 41-61). New York: Plenum.

Popenoe, D. (1995). *Sociology* (10th ed.). Englewood Cliffs, NJ: Prentice Hall.

Postone, N. (1998). Psychotherapy with cancer patients. *American Journal of Psychotherapy, 52* (4), 412-425.

Project on Death in America: Transforming the culture of dying. (2001). <http://www.soros.org/death/index.htm>

Reason, P. (1994). Three approaches to participative inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 324-339). Thousand Oaks, CA: Sage.

Reinertsen, K. D. (1999). What does it all mean. *Electronic Design, 47* (26), 54-58.

- Rew, L., Taylor-Seehafer, M., Thomas, N. Y., & Yockey, R. D. (2001). Correlates of resilience in homeless adolescents. *Journal of Nursing Scholarship*, 33 (1), 33-40.
- Robinson, N. S. & Garber, J. (1995). Social support and psychopathology across the life span. In D. Cicchetti & D. J. Cohen (Eds.), *Developmental psychopathology: Risk, disorder, and adaptation* (volume 2) (pp. 162-212). New York: John Wiley & Sons.
- Rowland, J. (1994). Psychosocial counseling in cancer: In pursuit of the perfect paradigm. *Advances: The Journal of Mind-Body Health*, 10 (2), 19-29.
- Rubin, A. (1985). Practice effectiveness: More grounds for optimism. *Social Work*, 30, 469-476.
- Schachter-Shalomi, Z. & Miller, R. S. (1995). *From age-ing to sage-ing: A profound new vision of growing older*. New York: Warner Books.
- Scharlach, A., Damron-Rogriquez, J., Robinson, B., & Feldman, R. (2000). Educating social workers for an aging society: A vision for the 21st century. *Journal of Social Work Education*, 36 (3), 521-539.
- Shaker, L. A. (1992). *The psychosocial impact of a cancer diagnosis on an elderly cohort*. Ann Arbor, MI: UMI Dissertation Services.
- Siegel, K., Raveis, V., & Karus, D. (1998). Perceived advantages and disadvantages of age among older HIV-infected adults. *Research on Aging*, 20 (6), 686-712.
- Singer, B. A. (1983). Psychosocial trauma, defense strategies and treatment considerations in cancer patients and their families. *The American Journal of Family Therapy*, 11 (3), 15-21.

Skvoretz, J. & Fararo, T. J. (1996). Generating symbolic interaction. *Sociological Methods and Research*, 25 (1), 60-103.

Sontag, S. (1990). *Illness as metaphor*. New York: Anchor Books.

Staudinger, U. M., Marsiske, M., & Baltes, P. B. (1995). Resilience and reserve capacity in later adulthood: Potentials and limits of development across the life span. In D. Cicchetti & D. J. Cohen (Eds.), *Developmental psychopathology: Risk, disorder, and adaptation* (volume 2) (pp. 801-848). New York: John Wiley & Sons.

Stearns, N. M., Laurie, M. M., Hermann, J. F., & Fogelberg, P. R. (1993). *Oncology social work: A clinician's guide*. Atlanta: American Cancer Society.

Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Strauss, A. & Corbin, J. (1994). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 273-285). Thousand Oaks, CA: Sage.

Strauss, A. & Corbin, J. (Eds.). (1997). *Grounded theory in practice*. Thousand Oaks, CA: Sage.

Thomlison, R. J. (1984). Something works: Evidence from practice effectiveness studies. *Social Work*, 29, 51-56.

Tiet, Q. Q., Bird, H. R., Davies, M., Hoven, C., Cohen, P., Jensen, P. S., & Goodman, S. (1998). Adverse life events and resilience. *Journal of the American Academy of Child and Adolescent Psychiatry*, 37 (11), 1191-1200.

Tishelman, C. (1993). Who cares? Patients' descriptions of age-related aspects of cancer and care in Stockholm. *Cancer Nursing*, 16 (4), 270-282.

Tope, D. M., Ahles, T. A., & Silberfarb, P. M. (1993). Psycho-oncology: Psychological well-being as one component of quality of life. *Psychotherapy Psychosomatics*, 60, 129-147.

Updegraff, J. A., & Taylor, S. E. (2000). From vulnerability to growth: Positive and negative effects of stressful life events. In J. H. Harvey & E. D. Miller (Eds.), *Loss and trauma: General and close relationship perspectives* (pp. 3-28). Philadelphia: Brunner-Routledge.

U. S. Bureau of the Census. (1992). Population projections of the United States by age, sex, race and Hispanic origin: 1992-2050. *Current population reports*, series P-25, No. 1092. Washington, D.C.: U.S. Government Printing Office.

U.S. Bureau of the Census. (2000). *USA statistics in brief-population and vital statistics*. <http://www.census.gov/statab/www/part1.html>.

U. S. Department of Health and Human Services. (1996). *Cancer rates and risks*. NIH Publication No. 96-691. Washington, D.C.: National Cancer Institute.

Varricchio, M., Gambardella, A., Balbi, V., Amato, L., Tortoriello, R., Ammendola, S., Tagliamonte, M. R., & Paolisso, G. (1996). The oncological therapy in the older adult. *Archives of Gerontology and Geriatrics, suppl. 5*, 593-598.

Walton, M. A., Reischl, T. M., & Ramanathan, C. S. (1995). Social settings and addiction relapse. *Journal of Substance Abuse*, 7 (2), 223-231.

Winscot, C. P. (1993). Psychosocial needs of cancer patients and their spouses. Ann Arbor, MI: UMI Dissertation Services.

World Book Multimedia Encyclopedia. (1999). San Diego, CA: IVID Communications, Inc.

Zastrow, C. H. (1999). *The practice of social work* (6th ed.). Pacific Grove, CA: Brooks/Cole.

Zastrow, C. & Kirst-Ashman, K. K. (1997). *Understanding human behavior and the social environment* (4th ed.). Chicago: Nelson-Hall.

Appendix A:

Interview Guide for Older Adults with Cancer

1. How has having cancer changed your life?
2. What are the most difficult things about living with cancer?
3. What needs do you have?
4. Are your physicians, social workers, nurses, and family members meeting those needs?
5. Who can you count on for support when you need it? (family, friends, - minister, lawyer, neighbors, support group)
6. What could someone else learn from your experience?

Appendix B:

Interview Guide for Focus Group of Social Workers

1. Introduce yourself and describe your experience with cancer patients.
2. What would you say is the most important thing that keeps cancer patients going?
3. What coping strategies do you observe them using to function day to day? (time with family and friends, religious or spiritual pursuits, sleeping, etc.)
4. What were your observations when they were first told of the diagnosis?
5. Tell me about your observations of their relationships (family, friends, medical personnel) and what, if any, impact they have had on their ability to function.
6. How has having cancer changed their life?
7. What is it that they most want from life at this point?
8. What are their needs?
9. Are their physicians, social workers, nurses, and family members meeting those needs?
10. Who can they count on for support when they need it? (family, friends, minister, lawyer, neighbors, support group)
11. What else would you like to tell me about your experience as an oncology social worker?
12. What could someone else learn from your experience?

Appendix C

IUPUI AND CLARIAN INFORMED CONSENT STATEMENT

for

Project Title: Cancer: The Lived Experience of Older Adults (Older Adults)

Study Purpose: This research is to gain an understanding of the lived experience of older adults with a cancer diagnosis.

Number of People Taking Part in the Study: You are invited to participate in a research study. If you agree to participate, you will be one of 6-10 subjects who will be interviewed.

Procedure for the Study: If you agree to be in the study, you will do the following things: you will be interviewed about your social, spiritual, and psychological experience with cancer. If a follow-up interview is needed it will be conducted by telephone unless you request an in-person interview. In most cases one interview will be sufficient. You will be given the opportunity to review what the investigator has written. Upon your request, a summary of the results will be mailed or brought to a place of your choosing. It is anticipated that a summary of the results will be available for your review within several weeks after the interview. You will have the opportunity to offer additional comments or corrections if there is anything you disagree with. You may convey them in writing or orally to the investigator and your comments will be incorporated into the final document. The interviews will be audio-taped and Marty Pentz, the interviewer, will be doing the transcription. You may choose not to have the interview recorded. You may choose where the interview will be conducted (private home, office, etc.). Each interview will take approximately one to two hours. If you choose to participate, a mini-mental status exam will be conducted

to determine your appropriateness for the study. This exam is a brief set of questions used to examine your psychological and emotional functioning.

Risks of Taking Part in the Study: During the study, the risks are in the area of openly talking about your experience with cancer. This study may involve currently unforeseeable risks to you. Even though you will know prior to the interview that we will be talking about your personal life and feelings about living with cancer, it could still be an emotionally painful experience. You may choose not to answer a question or stop the interview at any time. If, as a result of the interview(s), you feel you need counseling, a referral will be provided.

Benefits of Taking Part in the Study: You may benefit from talking about your experience. Social workers and others may benefit from a better understanding of your needs and of what is important to you. Another possible benefit is knowing that your participation may be helping other older adults with a cancer diagnosis by obtaining knowledge which will help social workers address their needs.

Alternatives to Taking Part in the Study: Instead of being in the study, you have the option of talking to your physician, social worker, nurses, and other health care workers taking part in your care to ask that your needs be met.

Date of Current Informed Consent Statement _____ Participant Initials _____

Confidentiality: Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. You will never be identified in any report or publication. The tape recordings will be locked in a filing cabinet until January of 2002, and will then be shredded.

Costs/Compensation: You will not be paid for participating in this study.

In the event of injury resulting from your participation in this research, necessary medical treatment will be provided to you and billed as part of your medical expenses. Costs not covered by your health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled.

Contact for Questions or Problems: If you have any question regarding this study and the procedures used you can reach the principal researcher Dr. Margaret Adamek at (317) 274-6730. Martin J. K. Pentz, doctoral student and interviewer, can be reached at (h) (317) 823-8384, (w) (317) 506-4886. The phone number for Area 9 is (765) 973-8301 and the Wellness Community is (317) 257-1505.

Voluntary Nature of the Study: Taking part in this study is voluntary: You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled.

Subjects Consent: My signature below means that I have freely agreed to participate in this study and that all provisions have been explained to me.

I acknowledge receipt of a copy of this informed consent statement.

Signature of Subject: _____ Date: _____

Signature of Witness: _____ Date: _____

Appendix D

IUPUI AND CLARIAN INFORMED CONSENT STATEMENT

for

Project Title: Cancer: The Lived Experience of Older Adults (Social Workers)

Study Purpose: This research is to gain an understanding of the lived experience of older adults with cancer.

Number of People Taking Part in the Study: You are invited to participate in a focus group. If you agree to participate, you will be one of 6-10 social workers who will be participating in this research.

Procedure for the Study: If you agree to be in the study, you will do the following things: you will be part of a 2 hour focus group that will examine your perceptions of the lived experience of older adults (65 and over) with cancer. The focus group will be audio taped and will be held at Area 9 in Richmond, IN. It will be conducted approximately four months into the study.

Risks of Taking Part in the Study: The risks of participating in this study appear to be minimal. Each member signing an informed consent acknowledging that only the researcher will report what is shared in the group outside of the group will maintain confidentiality in the focus group. The importance of confidentiality will be emphasized to focus group participants.

Date of Current Informed Consent Statement_____Participant Initials_____

Benefits of Taking Part in the Study: The benefits to participation are discussing information which may benefit cancer patients in the future.

Alternatives to Taking Part in the Study: You are not required to take part in this study as part of your job.

Confidentiality: Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. You will never be identified in any report or publication. The tape recordings will be locked in a filing cabinet until January of 2002, and will then be destroyed by fire.

Costs/Compensation: You will not be paid for taking part in this study. In the event of injury resulting from your participation in this research, necessary medical treatment will be provided to you and billed as part of your medical expenses. Costs not covered by your health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled.

Contact for Questions or Problems: If you have any questions regarding this study and the procedures used you can reach the principal researcher, Dr. Margaret Adamek at (317) 274-6730, and the co-investigator, Martin J. K. Pentz at (h) (317) 823-8384, (w) (317) 506-4886.

Voluntary Nature of the Study: Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled.

Date of Current Informed Consent Statement _____ Participant Initials _____

Subject's Consent: By signing this consent I agree to participate in this study and to be interviewed about my experience as a social worker of older adults with a cancer diagnosis. I may refuse to answer any question I am uncomfortable with and can remain a participant. I may drop out or be withdrawn from the study without any adverse impact. My signature below means that I have freely agreed to participate in this study and that all provisions have been explained to me. I acknowledge receipt of a copy of this informed consent statement.

Signature of Subject: _____ Date: _____

Signature of Witness: _____ Date: _____

Appendix E (Open Codes Second Iteration)

Accept – 6	Activity - 62	Alone - 5
Anger – 10	Appetite - 9	Assertive - 2
Attitude – 21	Avoided - 3	Awareness - 2
Bad – 3	Be Heard - 4	Be Nice - 2
Blessed – 3	Breathe - 3	Cancer Easy - 2
Cared For - 16	Cause - 3	Consequences of Can - 137
Chemo - 9	Confidence - 3	Coping - 16
Cure - 2	Daughter Hears - 3	Death - 8
Denial - 8	Destroy - 2	Determined - 6
Diapers - 6	Difficult - 2	Dr. Do Not Know - 2
Dying - 8	Emotions - 27	Empathy - 27
Enlightened - 4	Evolution of Hope - 3	Exercise - 6
Expensive - 2	Experimented On - 3	Expert - 2
Family Illness - 3	Family Denial - 3	Family Important - 9
Fatigue - 39	Fear - 24	Feel Different - 11
Focus Away - 9	Free of Cancer - 3	Friends Important - 9
Frustrated - 19	Gratitude - 11	Grief - 12
Health - 2	Heard - 8	Help Others - 33
Hope - 9	Humor - 8	In Life - 4
Incontinent - 3	Isolation - 6	Joy in Life - 2
Kindness of Others - 9	Knowledge - 37	Little Things - 13
Loneliness - 3	Loss - 13	Loss of Self - 7
Meaning - 18	Memories - 3	Miss Life - 2
Nausea - 15	Needs Help - 3	No Fear - 5
No Change - 5	No Sharing - 2	Non Normative Event - 50

Not Heard - 25	Not Dying - 2	Numb - 12
ODAT - 10	Ongoing - 77	Others Care - 14
Others Cancer - 12	Overwhelmed - 8	Oxygen - 2
Pain - 25	Patronized - 6	Peace - 2
Pride - 3	Private - 2	Problems - 2
Progression - 2	Prompt Care - 2	Resigned - 5
Self Care - 13	Sharing - 12	Short Time - 2
Sick - 29	Spiritual - 20	Stress - 2
Sudden - 2	Support - 73	Support From TV - 1
Surgery - 3	Time - 2	Touch - 5
Trust Dr. - 5	Understanding Needed - 5	Why Alive - 4

These numbers represent the number of times each of these topics was found in the data.

Appendix F (Open Codes Third Iteration)

Acceptance - 6	Activity important - 62	Anger - 10
Being Patronized Sucks - 6	Being Thought Of - 14	Cancer is Ongoing - 77
Chemotherapy - 9	Confidence - 3	Consequences of Cancer - 137
Coping - 16	Death - 8	Denial - 8
Determined - 6	Dr. Not Knowing - 2	Dying Hard to Do - 8
Emotional Support - 73	Emotions - 54	Exercise Important - 6
Family is Critical - 9	Fatigue - 39	Fear/Anxiety - 24
Feeling Numb - 12	Feeling Cared For - 15	Feeling Alone - 3
Feels Different - 11	Feels Avoided - 3	Focus Away Cancer - 9
Friends are Critical - 9	Frustration - 19	Frustration Diapers - 6
Grateful for Life - 11	Helping Others - 33	Hope - 9
Humor - 8	Importance of Attitude - 21	Incontinence - 3
Isolation - 6	Joy in Life - 2	Knowing others Care - 14
Knowledge - 37	Loneliness - 3	Loss of Appetite - 9
Many Losses - 13	Memories Important - 3	Nausea From TX - 15
Need Understanding - 5	Needing Help Sucks - 3	Non Normative Event - 50
Not Living - 2	Not Being Heard - 25	Numb - 12
Often Feels Sick - 29	One Day at a Time - 10	Others to Talk Normally - 6
Overwhelmed - 8	Pain - 25	Physical Touch - 5
Resignation - 5	Seeking Meaning - 18	Self Care Important - 16
Sharing Important - 12	Small Things Important - 13	Spiritual/Faith - 20
Thrown for a Loop - 5	Wants to Be Heard - 5	Why Alive - 4

Appendix G (Axial Codes)

Axial Codes

1. Social Support
2. A Positive Attitude (acceptance, gratitude, keeping a present-focus)
3. Spirituality/Faith (belief in God, hope, and helping others)
4. Positive Coping (past coping, assertive behavior, reminiscing, and humor)
5. Loss (loss of weight and appetite, loss of energy and self-care ability, loss of social relationships, loss of activities, and loss of belief in one's competence)

Appendix H

MARTY J. K. PENTZ, Ph.D., ACSW, CCSW

10568 Courageous Dr.	Indiana University East
Indianapolis, IN 46236	2325 Chester Blvd.
H (317) 823-8384	Richmond, IN 47374
W (765) 973-8512	
E-mail: mpentz@indiana.edu	

EDUCATION:

Ph.D. Indiana University

Master of Social Work (MSW), University of Oklahoma - 5/91

BA Religion Studies/Psychology Minor - The University of Tulsa - 12/88

Associates in Arts, Psychology, Tulsa Jr. College - 12/86

CREDENTIALS:

ACSW-Academy of Certified Social Workers; LCSW-Indiana Licensed Clinical Social Worker; NBCCH-National Board of Certified Clinical Hypnotherapists

EXPERIENCE:

8/97-present Full-time social work faculty at Indiana University East Richmond (IUE). Teaching research methods for social work, practice evaluation, gerontology courses, substance abuse counseling, human behavior and the social environment, community and organizational practice, and mental health and aging policy. I have taught in both the BSW and MSW programs at Indiana University School of Social Work at IUPUI and in the BSW program at IUE.

4/93-present Therapist in private practice working with individuals, couples, families, and the elderly. Specializing in work with **addictions, eating disorders, phobia relief, anxiety, depression, recovery from sexual and other forms of abuse, marital disharmony, and others.**

8/89-present Workshop presenter on **childhood abuse and other childhood issues, addictions, stress reduction** and other topics.

8/95-8/97 Teaching **Human Behavior and the Social Environment, Social Policy for Mental Health, and Research on Interpersonal Practice** at Indiana University School of Social Work, Faculty Liaison for field placement.

8/93-8/97 Teaching **theory and practice of group counseling, psychology, sociology, addictions counseling skills, pharmacology of drugs of abuse, concepts of wellness and statistics** at Indiana Wesleyan University.

4/92-4/93 (Relocated to Indiana 4/92) Therapist, PITS (Prevention, Intervention, Treatment Services)/Mirage Retreat. Individual, group, and family counseling with adolescent and adult chemical dependency.

12/91-4/92 Therapist, Tulsa Regional Medical Center. Individual, group, and family therapy on an adolescent dual diagnosis unit. Case management, discharge plans, public speaking.

3/89-12/91 Counselor, St. John Med. Ctr., Tulsa, OK. Individual, group, family, and marital counseling for outpatient mental health, and chemical dependency program for adolescents and adults.

3/90-8/90 Social Work Practicum, St. John Medical Center, Tulsa, OK. Mental Health Social Services. Discharge planning, social histories, group and individual counseling.

6/78-3/89 Machinist - Hilti Industries, Tulsa, OK.

PROFESSIONAL SERVICE:

Member of the NASW (National Association of Social Workers) legal regulations committee.

Serve on the addictions section of the NASW.

On the BSW committee of the Indiana University School of Social Work.

On the board of the Indiana Association of Social Work Educators (IASWE).

Chair Person of the 2000 IASWE Annual Conference

Treasurer of the NASW-Indiana Chapter

Serve on the 2002 Midwest Social Work Educators Conference Committee

UNIVERSITY SERVICE

Current

BSW Committee

BSW Sub-Committee on Technology

IUE Faculty Senate

IUSSW Faculty Senate

Coordinator of the Gerontology Certificate Programs

Faculty advisor to the Student Social Work Association, 1997-present (SSWA)

United Way Campaign Co-Chair

IUE Faculty Affairs Committee

Indiana University Faculty Governance Committee

Chair: IUE Research and Grants Committee

IUE Multi-Cultural Affairs Committee

Chair: BSS Policy Manual Committee

Past

BSW Committee

BSW Sub-Committee on Technology

IUE Research and Grants Committee

Chancellor Review Committee

Social Work Task Force of IUE

BSS Division Meetings

BSS Division Long Range Planning Committee Chair

IUE Faculty Senate

IUSSW Faculty Senate

Chair of IUE Social Work Search Committee

AAA (Admissions and Academic Affairs Committee, 1998-2000

Produced statement on the role of AAA, 1998-1999

IUE Technology Committee/Printer Committee

IUE's Social Work Student Review Committee

Coordinator of the Gerontology Certificate Programs

Faculty advisor to the Student Social Work Association, 1997-present (SSWA)

Chair of the first social work gerontology conference, Spring, 1998

Presented a first year experience seminar on social work opportunities, Spring 1998

Created the Social Work/Human Services web page, Spring 1999

Created Gerontology Minor - Spring, 1999

Presented benefits of a social work degree at Connersville HS career day - April 15, 1999

Spoke with minority students at Richmond HS about benefits of college and choices in social work - April 25, 1999

COMMUNITY SERVICE:

Present	Active in my fourth grade daughter's school. United Way of Wayne County Disbursement Committee, Hospice of Dark County, Ohio Area-9 Agency on Aging, Loan to Work Program in Marion County
1/83-4/84	Volunteer group facilitator for the St. John Medical Center Aftercare & Program of their Chemical Dependency unit.
2/85-3/86	
9/91-4/92	Volunteer chair of parent/student forum on drug and alcohol prevention in my children's school system.

VETERAN STATUS: Honorably discharged from the U.S. Army on September 26, 1977.

HONORS: Fellowship for \$12,000 per Year for Two Years at Indiana University School of Social Work for Doctoral Course Work
Three Academic Scholarships at the University of Tulsa (1989-1990)
President's Honor Roll at the University of Tulsa (1990) and The University of Oklahoma (1991-1992).
Rosenthal Prize for Academic Excellence in Scholastic Study of Religion at the University of Tulsa (1990).
Fellowship for the Ph.D. Program at Indiana University (1995-1997).
TERRA Grant for increasing the use of technology in the classroom 1999

PUBLICATIONS: "Heuristic and Ethnographic Study of the New Warrior: A Mature Masculinity or A Re-Packaging of Dominant Patriarchy" in E. Barton (Ed.) (1999). Therapeutic Mythopoetic Men's Work. Greenwood Press: Boston.

PRESENTATIONS: (Invited)

"Counseling the Recovering Male Who was Molested as a Child"
Presented at the Institute for Alcohol and Drug Studies, Evansville, Indiana on May 16, 2000.

"Assessment and Treatment of Sexual Assault Victims" Presented at the IUE Workshop entitled "Sexual Assault 101" on October 13, 2000.

"Counseling the Recovering Male Who was Molested as a Child"
Presented at the Institute for Alcohol and Drug Studies, Evansville, Indiana on May 15, 2001.

PRESENTATIONS: (Peer Reviewed)

"Treatment and Social Work Direct Practice with Adult Males Sexually Abused as Children and Other Male Victims of Trauma" (Midwest Conference on Social Work Education, April 24, 1998). (2 1/2 hrs.)

"Heuristic Study of the New Warrior Experience: Rite of Passage into a Mature Masculinity," (American Men's Studies Association, 7th annual conference, March, 19-21, 1999).

"Cancer: The Psychosocial Experience of Older Adults," (Midwest Conference on Social Work Education, April 6, 2000).

"Cancer: The Lived Experience of Older Adults," (17th Congress of the International Association of Gerontology in Vancouver, Canada, July 3, 2001).

PRESENTATIONS: "Sibling Abuse" NASW-Indiana Chapter State Conference (1995)
(2 ½ hrs.)
"Stress Management" Several nursing homes in Indiana (1994-1996). (1 hr. Ea.)
Several topics related to "Addictions" St. John Medical Center, Tulsa, OK (3/89-12/91). (1 hr. Ea.)

Ph.D. program presentations at Indiana University (1995-1997)

"Sibling Abuse: Prevalence and Impact" (1 hr.)

"Interventions with Adult Males Molested as Children" (1 hr.)

"Heuristic Research" (1 hr.)

"Chaos Theory and Social Work Practice" (1 hr.)

"Social Work Practice and the Social Learning Theory" (1 hr.)

"The Men's Movement and Social Work" (1 hr.)

"Heuristic Study of the 'New Warrior' Experience" (1 hr.)

"Men Molested as Children and the Social Policy Response" (1 hr.)

"The Effect of Bureaucracy on the Treatment Experience of Men Molested as Children" (1 hr.)

Other Presentations

Indiana University Field Instructor Appreciation Day (May 14, 1997), "The Benefits of Computers and the Internet to the Social Work Practitioner" (1 hr.)

First Annual Ph.D. Program Research Symposium (June 4, 1997), "Men Molested as Children: Prevalence, Impact, and Social Work Interventions" (1 hr.)

Presented a colloqui on "Social Work Practice Evaluation" at Indiana University East (June 5, 1997). (1 hr.)

"The social work licensure bill" Presented at Dunn Mental Health Center, Richmond, IN (September, 10, 1998). (1 hr.)

"Sexually Abused Males" presented at Ohio State University (November, 6, 1997. (1 1/2 hrs.)

"Social Work Opportunities" Presented as a seminar for the first year experience at Indiana University East (February, 26, 1998). (1 hr.)

"Hospice and the Continuum of Care" Presentation for the Union County Council on Aging (March, 17, 1998). (1 hr.)

"Communication with the Sensory Impaired Elderly" Presented at the first annual IUE Gerontology Conference (March, 27, 1998). (2 hrs.)

"Pharmacology of the Ten Most Used Drugs by the Elderly" Presented at the first annual IUE Gerontology Conference (March, 27, 1998). (3 hrs.)

"Counseling the Recovering Male Who was Molested as a Child" Presented at the Institute for Alcohol and Drug Studies, Evansville, Indiana (May 20, 1998). (2 1/2 hrs.)

"Social Work Practice with Adult Males Molested as Children" NASW-Indiana chapter workshop (June 19, 1998). (7 hrs.)

"Male Rape: The Molestation of Male Children" Presented at the 9th annual Indiana Coalition Against Sexual Assault (INCASA) September 17, 1998 (1 1/2 hrs.)

"Evaluation of Mental Health Web Sites," Presented at the IASWE Conference on October 2, 1998.

"Hope and Cancer," Presented at Lawrence United Methodist Church, January 20, 1999.

Third annual Ph.D. Program Research Symposium (April 16, 1999) "The Formation and Evolution of Hope and the Older Adult Cancer Patient: Implications for Social Work."

Workshop entitled "Multicultural Course Design and Teaching" October 19, 1999 at Indiana University East.

Ph.D. Doctoral Student Panel Discussion "Doing Social Work Research: The Experience of Doctoral Education," (My Topic was: Cancer: The Psychosocial Experience of Older Adults), June 2, 2000.

POSTER PRESENTATIONS (PEER REVIEWED):

"Ethnographic Study of the New Warrior Training Adventure: A Vision of a Mature Masculinity or a Re-packaging of a Dominant Patriarchy," Presented at the 3rd Annual Society for Social Work and Research Conference, January 22-23, 1999.

"Heuristic Study of the New Warriors Experience: A Rite of Passage Into a New Masculinity," Presented at the 3rd Annual Society for Social Work and Research Conference, January 22-23, 1999.

"Cancer: The Psychosocial Experience of Older Adults," Presented at the American Society on Aging International Conference, December 3, 1999.

CONTINUING EDUCATION:

Treating the Heroin Addict 6 hrs.	Treating PTSD Clients 6 hrs.
Family Therapy 14 hrs.	Hypnosis & Brief Therapy 60 hrs.
Treating Sexual Trauma 6.5 hrs.	Treating Sexual Compulsion 6.5 hrs.
Treating Sexual Addiction 6 hrs.	Addictions Certification 280 hrs.
Brief Solution-Oriented Therapy 12 hrs.	

PROFESSIONAL MEMBERSHIPS:

National Association of Social Workers (NASW)
Council on Social Work Education (CSWE)
Indiana Association of Social Work Educators (IASWE)
National Board of Clinical Hypno-Therapists (NBCCH)