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INTEGRATING CANCER INTO A LIFE MOSTLY LIVED

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Abstract

The experience of cancer for the elderly was explored through a cross-sectional interview study. Symptoms are posited to be the core of the cancer experience inasmuch as they are the way in which the cancer itself is perceived by an individual. The study substructure is formed by a review of data-based literature and a theoretical foundation that incorporates symbolic interactionism, Erikson's Life Cycle, the meta-concept of comfort, and cultural histories of aging and of cancer. The analysis was guided by the grounded theory method.

Nineteen participants, recruited from two medical centers, contributed data through single interviews. Ten participants were men and nine were women. The average age was 74 years. Two participants were African American and the remainder were European American.

Constant comparative analysis indicated that the participants made cancer a part of their already well-established lives rather than having the cancer become the center of their lives. "Integrating cancer into a life mostly lived" is the conceptual term used to describe this process. The conditions for the process are old age, having cancer, and receiving Western medical treatment. The process involves five horizontal levels, and four phases within the internal component of the process. The over-riding conceptualization, or core concept, "integrating cancer into a life mostly lived", is supported by nine major concepts.

The five levels on which the process is seen are: the philosophical level of the existential dialectic on living dying and death; the internal level of the dialogue with the self; the behavioral level of "engaged in living a life mostly lived"; and time.

There are four phases of the internal dialogue with the self. "Life before cancer" encompasses the conditions of "life experience" and body knowledge" that are necessary to the remaining phases. The first phase, "coming to bouts with yourself", and its diagnostic co-process begin the process of "integrating". The cancer focus phase, "redefining thresholds of daily living", has to do with managing the disruption of symptoms and unexpected treatment which are the condition "reminders of cancer". Thresholds for acceptable levels of disruption are defined and redefined in conjunction with strategies to manage the disruption. The living focus phase of "living on new terms" re-emphasizes patterns of daily living when disruption exists under thresholds deemed to be currently acceptable and when the condition "reminders of cancer" becomes "symptom and treatment stories" through successful management of disruption. The last two phases are those in which most narrative and chronological time is spent. The behavioral outcome of the process is "remaining engaged in living a life mostly lived". This observable part of the process is the consequence of the existential dialectic and the dialogue with the self in concert with the larger context in which the elderly individual lives. Time forms the processual substrate for the entire process and is seen in the data in both chronological and narrative forms.

The grounded theory of "integrating cancer" suggests an experiential understanding of cancer in old age. "Integrating cancer" suggests the necessity for understanding the elderly who have cancer on their own terms of contextually defined disruption and comfort and for examining current health care approaches to these individuals. Further research in the emergent mode of grounded theory is needed to firmly establish the utility of the theory of "integrating cancer" to the science and practice of nursing.

Margaret J Wallhagen, Ph.D, RN
Chair, Dissertation Committee

For Barbara

"Life is not a having and a getting, but a being and a becoming."

- attributed to Myrna Loy, actress and humanitarian

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CHAPTER I

Introduction

The Significance of Cancer in the Elderly

Cancer in the elderly is a multi-faceted problem of epidemic proportions. It is veiled by myth, misinformation, ageism, and scarce specific knowledge. Cancer is acknowledged to affect the health and function of thousands of elders in ways only sketchily described at organismal and population levels (Ershler, 1993; Miller, 1991; Witten, 1989) and relatively uncharted at an experiential level. The effects are compounded by the manifold nature of cancer in the elderly, as it is not one disease but many. Further, the substantial physical and psychosocial heterogeneity of the elderly themselves adds additional complexity (Rowe & Kahn, 1987).

Old age is widely held to be a great risk factor for many types of cancer (Cohen, 1989; Crawford & Cohen, 1987; Ershler, 1993; Kaesberg & Ershler, 1989; Miller, 1991; Pitot, 1977; Witten, 1989). The American population is, as a whole, becoming older. It will continue to do so, given current growth trends, until in about 60 years the elderly comprise approximately one quarter of the population (Boyle, et al., 1992). More than one in ten now and one in four in 60 years will be at significant risk for cancer just by virtue of age (Boyle, et al., 1992; Ershler, 1993).

Baranovsky and Meyers (1986) show that people aged 65 and older account for more than half of all cancers diagnosed. Yet the age group currently accounts for less than 15% of the entire American population (Baranovsky & Meyers, 1986; Boyle, et al., 1992; Given & Given, 1989). Those over 65 years of age diagnosed with cancer are at greater risk for cancer-related morbidity and mortality (Baranovsky & Meyers, 1986). Cancer-related mortality is often preceded by significant morbidity given the natural history of cancers, the toxicity of current treatments, and the prevalence of co-morbidity in old age (Manton, Wrigley, Cohen, & Woodbury, 1991).

Cancer killed more than 430,000 people aged 55 and over in 1989 (Boring, Squires, & Tong, 1993). This accounts for 87% of all cancer deaths and 20% of all deaths from any cause in that year. These figures are expected to increase in the coming years (Baranovsky & Meyers, 1986; Boring, et al., 1993).

The Physiology of Cancer in the Elderly

Cancer in the elderly has generally been viewed as aging in the context of cancer; that is, cancer is seen as the more prominent issue. However, in the face of myth, misinformation, and limited knowledge of geriatric oncology, there is growing recognition that cancer in the elderly may be unlike cancer in younger adults. It may not be inherently less or more severe but rather more heterogeneous. Some malignancies may have different natural histories in older hosts (Balducci et al., 1988; Balducci, Khansur, Smith, & Hardy, 1989; Benson, Kaplan, & Olson, 1986; DeMaria & Cohen, 1987; Zachariah, Zachariah, Wang, & Balducci, 1992). In addition, co-morbidity common to the elderly may alter that history, complicating interpretation of symptoms and early detection (Leventhal & Prohaska, 1986). And, furthermore, anti-neoplastic treatment may not be more or less well tolerated, but tolerated differentially based on the physiological, psychological, and social characteristics of the elderly individual.

Physiological change with age is increasingly seen to create differential efficacy of therapies, and tolerance of cancer symptoms and of treatment side effects (D'Agostino, Gray, & Scanlon, 1990; Phister, Jue, & Cusack, 1989). Investigators are becoming able to identify which treatments are more effective for particular malignancies common to the elderly. Furthermore, they are identifying how characteristics of symptoms and side effects (e.g. intensity, duration) change with age. Recognition of the heterogeneous nature of cancer in the elderly is leading to re-evaluation of cancer and anti-neoplastic therapies in the context of aging (Bates, Riley, Houghton, Fallowfield, & Baum, 1991; Begg & Carbone, 1988; Falkson, Gelman, & Pretorius, 1986; Gazet et al., 1988; Lu-Yao, McLerran, Wasson, Wennberg, 1993). This is a perspectival shift to seeing cancer in the context of aging. Still, overall, malignancies tend to be inconsistently diagnosed and treated, and haphazardly managed in older adults (Boyle, et al., 1992; Goodwin, Hunt, & Samet, 1991; Miller, 1991).

The Illness Trajectory

Prevention, detection, and treatment of cancer in the elderly has been hampered by exclusion of those individuals from clinical trials, misinformation about the elderly, and ageism (e. g. the elderly are unable to handle the diagnosis of cancer or too frail to withstand its treatment) (Goodwin, Hunt, Humble, Key, & Samet, 1988). These attitudes continue to promote limited emphasis on prevention, poor screening (Bennett et al., 1991), diagnosis at late stages (Grover, Cook, Adam, Coupal, & Goldman, 1989; Niemen & Holmes, 1989; Samet, Hunt, Lerchen, & Goodwin, 1988), and sub-optimal treatment for the elderly population with cancer (Bergman et al., 1991; Goodwin, Hunt, &

Samet, 1993; Greenfield, Bianco, Elashoff, & Ganz, 1987; Guadagnoli, et al, 1990).

The Experience of Cancer for Older Adults

The nature of responses to and experience of cancer for the elderly is currently extrapolated from research on younger individuals, surmised from clinical experience, or simply guessed at on an individual basis (American Nurses Association (ANA), 1980; Boyle, et al., 1992; McMillan, 1989). The experience of cancer, for the purposes of this discussion, is defined to include responses to the process of being diagnosed and living with cancer. Symptoms and side effects are the core of this response. An individual can only perceive cancer bodily through perception of symptoms and side effects. Other information, such as diagnosis itself, is externally obtained. Perception and attribution of symptoms and side effects, within the context of an individual life, creates the experience of cancer for a particular individual.

Symptoms and side effects constitute discomforting disruption in the way human beings experience themselves and their bodies. And, most often in cancer, symptoms and side effects are sustained without distinguishing between attribution to disease or treatment respectively. Symptoms and side effects are thus both included here under the term symptoms. The experience, then, includes the physical and emotional symptoms of cancer and its treatment; the functional ramifications of these symptoms; and issues of daily living, disruption in that living, and managing the disruption.

Pertinent Literature

Only a handful of recent data-based health care publications that directly address any aspect of the cancer experience for the elderly may be located in comprehensive literature searches. (Baider, Peretz, & De-Nour, 1992; Brown, 1993; Edlund & Sneed, 1989; Goodwin, Hunt, & Samet, 1991; Greenberg, Gray, Mannix, Eisenthal, & Carey, 1993; Heidrich & Ward, 1992; Larson, Lindsey, Dodd, Brecht, & Packer, 1993; McGill & Paul, 1993; McMillan, 1989; Love, Cameron, Connell, & Leventhal, 1991; Nerenz, Love, Leventhal, & Easterling, 1986; Satariano, Ragheb, Branch, & Swanson, 1990). The broad definitions of symptoms and cancer experience are helpful to locate the dozen pertinent research reports. These papers explore physical symptoms, functional status, and issues of disruption and management in daily living.

As a body, the literature is characterized by positivistic perspectives and methods, and inconsistent use of theoretical bases. Most importantly, it is difficult to judge whether the aims of the studies reported are congruent with the concerns of the older individuals who are under study. The theoretical bases employed often do not incorporate recognition of experiential salience. And the paradigm and methods used do not allow for validation from subjects. In a new area of inquiry, such as the experience of cancer for the elderly, which is complex and generally without established theoretical underpinnings, the use of narrow perspectives and theoretical bases is of concern.

However, the increasing frequency with which the reports are appearing indicates growing recognition that the experience of cancer for the elderly is a complex field of study, rich with variation and in need of exploration (Boyle et al., 1992; Heidrich, 1993; Knobf, Fulmer, & Mion, 1993; Liebman, 1993; O'Hare, Malone, Lusk, & McCorkle, 1993). Yet without different perspectives on problems within the area and varied theoretical approaches, the body of knowledge is likely to develop too narrowly to meet the heterogeneous needs of older adults with cancer.

Statement of the Phenomenon and Need for the Study

The experience of and response to cancer and its treatment in the elderly is a significant phenomenon in several respects. Symptoms are discomforting to the individual (Jacox, 1989). Symptoms, attributions attached to them, and the perspective through which they are interpreted may influence adherence to, completion of, and success of cancer therapy (Eisenberg, 1977; Hunt, Jordan, Irwin, & Browner, 1989; Richardson, Marks, & Levine, 1988; Tishelman, Taube, & Sachs, 1991).

Cancer-related decline in physical, cognitive, and psychological function contributes to declining enjoyment of life (Palinkas, Wingard, & Barrett-Connor, 1990; Pearlman & Uhlmann, 1988). Furthermore, decline in one functional domain may have ramifications for other domains, social support, and access to care (Bortz, 1990; Goodwin, et al., 1991; Rowe & Kahn, 1987, Stein, Linn, Stein, & Linn, 1983). And, from the perspective of the elder in terms of both discomfort and function, the experience of cancer often profoundly disrupts patterns of daily living (Hinds, Chaves, & Cypess, 1992; Hunt, Jordan, & Irwin, 1989; Lynam, 1990).

Knowledge of cancer experience in the elderly is limited by the small scope of the data-based literature which utilizes positivist perspectives and methods and is largely atheoretical. Existing literature ignores the elder's perspective on what aspects of the experience are most salient. This information is necessary to targeting purposeful investigations. Furthermore, the literature offers a scattered, piecemeal understanding of the experience.

The positivistic tradition necessitates narrowly focused studies. A larger theoretical grasp of the phenomenon is essential to apprehend salience and build perspicuous programs of study. Theory building research that explores the experience of the elderly with cancer and acknowledges their perspectives is needed to broaden the development of knowledge in this area.

Purpose of the Study

The present project is designed to produce beginning theoretical description of the phenomenon of experience of cancer for the elderly by examining what may be central to that experience. The experience of symptoms for older adults with cancer will be investigated under the assumption that symptoms are at the heart of the experience. The grounded theory method (GT), which exists within the naturalistic paradigm and induces practical theory grounded in the phenomenon under study, is the means by which the purpose of the study is achieved.

The following chapters outline the evolution of the study. The theoretical and scientific foundations of the study are detailed in chapters two and three. A critical synthesis of the small body of data-based literature which specifically addresses the response to and experience of cancer in the elderly is offered. Particular emphasis is placed on the findings of this literature. This places the present study within the context of existing work addressing the same phenomenon. The reader is referred to the author's (Kagan, 1991) earlier manuscript for a more comprehensive critical examination of the body of geriatric oncology literature. A discussion of the theoretical perspective of the method and the study establishes the substructure of the project. Symbolic interactionism (SI), as the primary philosophical and theoretical base for GT, is discussed along with other frameworks which informed the study.

The fourth chapter describes the design and analytic method, and the manner in which the participants were accrued and data collected from them. A brief outline of the specific analytic process of this study is also included. In chapter five, the interactional process discovered through the analysis and the model of that process will be explored in detail. The dissertation concludes with a discussion of the import of the process discovered, the limitations of the design and implementation, alternative explanations for the results, and implications for nursing research and practice.

CHAPTER II

Scientific Foundation

My use of scientific and theoretical literature, as is consistent with the paradigm and method within which the study exists, has been reflexive, dialectic, and paced by the course of the study (Artinian, 1988; Dreyfus, in progress; Glaser, 1978; Sandelowski, 1986, 1993). I approached the present project with a knowledge of the literature and a fund of theoretical and practical knowledge as a person and as a nurse (Strauss & Corbin, 1990; Glaser, 1978). I recognized that, though the aim of GT is to uncover practical theory, it employs existing literature and theory in several ways (Strauss & Corbin, 1990; Dreyfus, in progress; Sandelowski, 1993).

Presenting the content of the scientific and theoretical literature and the manner in which I employed it is a difficult task. I will discuss both bodies of literature in relatively linear fashion for clarity and expediency. The pertinent data based literature is reviewed first. The exposition of the theoretical perspective employed in the project follows in chapter three. But with this mode of presentation, comes the caveat that, in fact, the process was far more circular and interactive than can be justly represented here.

Investigations of the Experience of Cancer for The Elderly

Introduction and Statement of Purpose

A focused, critical literature review was undertaken to place the present project within the body of existing data on the experience of cancer for the elderly. Research reports directly addressing any aspect of the experience were sought in the psychology, sociology, nursing, and medical literatures. The object of the literature review was to assess the nature of direct, substantive knowledge of the phenomenon and identify gaps in that knowledge. That assessment is conveyed here.

Aim of the review. The aim of the review is to highlight the notion that existing literature, despite what it does achieve, still does not allow for an empirical understanding of the experience of cancer for the older adult from the older adult's perspective. To move toward achieving this aim, the literature critique is focused on the areas of scientific paradigm; theoretical frameworks; selected issues of design, sampling, and analysis; and, especially, findings and their implications for future research to establish the paradigm, framework, and design for the present study. The aim of the review is quite broad while the critique that comprises it is highly detailed

Comprehensive electronic and manual searches of the scientific literature reveal a growing, but very limited number of research reports that directly address any aspect of the experience of cancer for the elderly . There are 13 reports that date back to 1985. They vary widely in scientific and clinical utility. This small body of literature is described and critiqued in several ways toward the end of establishing what is known in this area of inquiry and identifying gaps in epistemology and knowledge. The reports are discussed alternately, as a group and individually, to highlight contributions and implications for the current study. Each report is discussed individually in the section where the issues assessed are pertinent to that particular report.

Search Methods

Literature which addresses the experience of cancer for the elderly is generally difficult to locate. This is likely due to a number of factors. Foremost among these is that geriatric oncology is still viewed as a the intersection of two practice areas in health care. Furthermore, investigation of pyschosocial issues in oncology literature has only recently gained equal footing with physiologically oriented studies and clinical treatment trials in medical literature.

The search for pertinent research reports was on-going and occurred at many levels. The definitions of experience and symptoms posited in the introductory chapter were used. I selected all articles on the prominence with which old age and cancer were featured. The title and abstract had to evince commitment to old age and cancer as primary variables in the investigation. Emphasis on conditions associated with old age (e.g. prostate cancer which occurs almost exclusively in old age; being post-menopausal) also garnered entry into the review.

The electronic data bases, Melvyl Medline, Psychlit, and Sociofile, were searched using appropriate key words in many combinations and permutations. These data bases accessed recent (e.g. 1990 to 1993) publications. The search results from the different data bases often overlapped. Often I relied on less formal means of access. Certain journals were reviewed monthly. These are journals, in oncology or gerontology, known to me to publish research reports of interest. Foremost among these is Oncology Nursing Forum which, as the journal of the Oncology Nursing Society, has taken seriously the call for new knowledge in geriatric oncology nursing (Boyle, et al., 1992) and tacitly emphasizes the implication of the Social Policy Statement in its publications (ANA, 1980). Additionally, I reviewed other likely journals, such as Social Science and Medicine, on a quarterly basis because of the general applicability of papers published.

Finally, I relied heavily on review of reference lists from any related articles dealing with aspects of geriatric oncology. This technique was essential to obtaining older papers.

The time of publication was not a factor in selection for the review because the body of literature is so small. Nevertheless, limiting the search to the past five years would omit only two of the 13 papers. This serendipitously reveals the growth spurt in this literature. Half the papers reviewed here were published in 1992 or 1993. The implication of the growth spurt is growing acknowledgement at many societal levels of the significance of investigating the experience of cancer for the elderly.

The Body of Literature

The Positivistic Paradigm

The research reports (Baider, Peretz, & De-Nour, 1992; Brown, 1993; Edlund & Sneed, 1989; Goodwin, Hunt, & Samet, 1991; Greenberg, Gray, Mannix, Eisenthal, & Carey, 1993; Larson, Lindsey, Dodd, Brecht, & Packer, 1993; McGill & Paul, 1993; McMillan, 1989; Heidrich & Ward, 1992; Love, Cameron, Connell, & Leventhal, 1991; Nerenz, Love, Leventhal, & Easterling, 1986; Satariano, Ragheb, Branch, & Swanson, 1990) reviewed here are linked by several common features. Most importantly, they all exist within the positivistic tradition, or paradigm of conducting science (Denzin, 1989; Lincoln & Guba, 1985).

The positivist tradition emphasizes deductive investigation of hypotheses (Lincoln & Guba, 1985). Investigators must chose how to prioritize the variables they believe to be important within the phenomenon under study prior to beginning the investigation. A priori theory provides the rationale for those choices. The prioritization leads to operational definition of variables and then to operationalization through instrumentation. Instruments generally translate variables into quantitative results. The results must then be translated back into words and linked with the original scheme of priority. This is the traditional model of conducting science (Denzin, 1989).

In several of the recent nursing publications (Brown, 1993; Heidrich & Ward, 1992; Larson, et al., 1993; McGill & Paul, 1993), the rationale for the relative priority and relationships of variables is supported and made explicit through use of a conceptual or theoretical model. This is the strongest means by which to implement the positivistic paradigm (Dulock & Holzemer, 1991). However, the use of a framework has its own limitations which will be discussed later. More often, and especially in the medical literature, a conceptual or theoretical model is implied and the review of literature places the study in the larger context of existing, pertinent knowledge. This method, while not as sound as use of an explicit framework, is generally acceptable if the research is within a well established area of investigation. The authors may then draw upon acknowledged scientific substructure present in reviewed research reports addressing the same phenomenon.

Authors investigating aspects of the experience of cancer for the elderly have no established substructure from which to work given that there are fewer than 15 reports of such research published in the past decade. The research reports that do not include rationale for the variables and their relationships under study rely on assumption and extrapolation from investigations of similar phenomena in different groups without acknowledging the inherent limitations of such an approach (Baider, Peretz, & De-Nour, 1992; Edlund & Sneed, 1989; Goodwin, Hunt, & Samet, 1991; Greenberg, Gray, Mannix, Eisenthal, & Carey, 1993; Love, Cameron, Connell, & Leventhal, 1991; Nerenz, Love, Leventhal, & Easterling, 1986; Satariano, Ragheb, Branch, & Swanson, 1990).

Ganz, et al. (1985), Greenberg, et al. (1993) and Love, et al.(1991), rely largely on oncology literature, extrapolate from research done in younger samples, and use instruments intended for use with younger individuals without establishing their utility for the elderly. This structure does not acknowledge the possibility that the elderly are physically and psychosocially different from younger adults.

Conversely, several authors incorporate the notion of change associated with aging thereby adding to the internal validity of the investigations. McMillan (1989) acknowledges the implications of the biology of aging for the physical experience of cancer symptoms. Such an approach lends credence to her investigation of the relationship between age and cancer symptom intensity. Baider, et al. (1992), Edlund & Sneed (1989), Goodwin, et al. (1991), Nerenz, et al. (1986), and Satariano et al (1990) incorporate psychological or social gerontology literature in framing their studies. In doing so, the authors enhance the likelihood of uncovering characteristics of the phenomenon under study unique to or different in the elderly.

In a larger sense, the authors of these 13 papers do not clearly state that the phenomena they are investigating are essentially unexplored in the elderly population. The logical extension of such a statement is to recognize that frameworks appropriate to the area of inquiry are unknown in a practical sense. Failure to acknowledge this key aspect closes off the opportunity to grapple with whether the positivistic paradigm is appropriate to pioneer this area of investigation.

Use of the naturalistic paradigm (also known as the qualitative paradigm) would, in fact, be better suited to this area of inquiry in several ways (Denzin, 1989; Lincoln & Guba, 1985). First, it allows for flexible use of theory. Investigation can be deductive or inductive. Theory can be used to inform or guide inquiry within the paradigm and need not be the foundation of investigation (Sandelowski, 1993).

Second, particular inductive methods (e.g. grounded theory) within the naturalistic paradigm are designed to build theory and abstract unexplored phenomena to a conceptual or theoretical level (Glaser & Strauss, 1967; Strauss & Corbin, 1990). This is in contrast to the positivistic paradigm in which even exploratory studies are strengthened through incorporation of an a priori model of the phenomenon and a deductive approach (Dulock & Holzemer, 1991). Considering the two approaches, the naturalistic paradigm is deemed more appropriate for the conduct of the current project given the scant volume of knowledge of the experience of cancer for the elderly.

Theoretical Frameworks

Examination of theoretical frameworks currently in use offers guidance in setting up the current project. Brown (1993), Heidrich & Ward (1992), Larson, et al. (1993) and McGill & Paul (1993) use explicit theoretical frameworks to support their investigations. Brown (1993) and Larson et al. (1993) appropriately employ essentially physiological frameworks that also include certain behaviors (e.g. tobacco use) and particular physical symptoms (e.g. fatigue) as intervening variables on functional outcomes for individuals with lung cancer. Social (Larson et al., 1993) and spiritual (Brown, 1993) variables were also included in the frameworks but tended to be measured through a mono-method bias or lost in the discussion of findings.

Each author also identifies age as a primary variable eventually affecting functional status. Larson et al. (1993) feature age more prominently. They successfully use a brief review of literature to support investigation of unknown age effects in lung cancer. However, the critical theoretical link between old age and functional status is not clearly identified. It is then not possible to grapple with the theoretical implications for using 65 years of age as the definition of old age. This operational definition is grounded more in the social construction of old age than in the biology of aging (Blesch, 1988; Cole, 1992; Rebenson-Piano, 1989).

Brown (1993) identifies age, gender, usual weight, and tobacco use as pre-cancer factors influencing weight loss and, ultimately, functional status in individuals with lung cancer. Again, a brief review of literature supports the investigation of age effects. However, Brown (1993) does not achieve theoretical synthesis of age and the other pre-cancer variables in her discussion. The definition of age is handled more successfully than by Larson, et al. (1993). Age is represented as a continuous variable in regression analyses. In all, however, the theoretical models used by Larson, et al. (1993) and Brown (1993) strengthen the substructure and the internal validity of each report.

Heidrich and Ward (1992) and McGill and Paul (1993) report psychosocial investigations. They explore, respectively, the roles of self in adjustment to cancer in old age and of hope and functional status in the elderly who have cancer. Heidrich and Ward (1992) opt to synthesize two models of the self, borrowed from psychology (viz. Taylor, and Rosenberg cited in Heidrich and Ward, 1992) into a conceptual framework. Heidrich and Ward (1992) note that the work of Taylor stems from investigation of self esteem and control in individuals with cancer and that Rosenberg's work deals with conception of the self. Neither model that Heidrich and Ward (1992) employ contributes information about what they conceive as differentiating the elderly, and elderly women as their identified sample, from younger individuals adjusting to cancer. The reader is left to wonder if a comparison with young women who have cancer would have produced different results from the comparison with older women who did not have cancer utilized by the authors.

McGill and Paul (1993) use Roy's Adaptation Model of Nursing to guide their investigation of hope and function. Roy's (cited in McGill & Paul, 1993) work is supportive of the variables and relationships explored. However, the authors do not clearly state how this model allows for differentiating the issue of age. Rather, an elderly sample is employed and instruments often used in gerontological research operationalize the variables. The substructure of the study is threatened by the omission of the critical linkage from theory to operational definitions of age, hope, and functional status.

Clearly, investigators must more consistently use theoretical models in investigating the experience of cancer for the elderly. But, further, they must also be aware of the ramifications of particular frameworks for implementation of a study. Use of varied conceptual and theoretical models to inform naturalistic inquiries that utilize interview guides, and thereby overcome lags in development of instruments specific for and sensitive to this population, is a means to stronger substructure. Instrument development, through rigorous psychometric work done prior to the types of clinical investigations reviewed here, is another.

Issues of Design, Sampling, and Analysis

Descriptive design. The 13 papers at hand begin to diverge along lines of design and sampling. Four are descriptive (Brown, 1993; Goodwin et al., 1991; Greenberg et al., 1993; McMillan, 1989). Brown (1993), Greenberg et al. (1993) and McMillan (1989) investigate symptom issues. Goodwin et al. (1991).explore psychosocial issues.

Brown (1993) studied the relationship of age, as a pre-cancer variable, on weight loss in persons with non-small cell lung cancer. The descriptive design is appropriate to the question posed. However, the study would be strengthened through clearer discussion of the rationale for a two group convenience sample and use of a power analysis to support the sample N. The second half of the sample was studied only through medical record review and the threats to both reliability and validity of such data are not discussed.

Greenberg et al. (1993) examine the relationship of fatigue and serum interleukin-1 (IL-1) levels in men receiving radiation therapy for prostate cancer. While the design supports investigation of the question, the sampling criteria do not. Men older than 80 years were excluded despite the knowledge that incidence of prostate cancer increases linearly with advancing age (Balducci, et al., 1989). Only 14 men were accrued to the study, lending inadequate statistical power to support the analysis of variance. The authors do, however, acknowledge the preliminary character of the findings.

McMillan (1989) investigates the relationship between age and intensity of nausea, vomiting, and pain. She acknowledges the limitations of the secondary data analysis performed and limits the analysis to correlations. Two convenience samples were used in the original study, one to study nausea and vomiting, the other to examine pain in adults with cancer. McMillan (1989) admits the two samples employed are not comparable and are from different primary studies, but does not adequately support sample and analysis decisions, such as different age limits for defining 'younger' and 'older' in each sample, that are essential to investigation of aging effects and solid research report.

Goodwin et al. (1991) examine the influence of age on social support for elderly individuals with newly diagnosed cancer. The survey design and logistic regression analysis are well supported by the population-based sample from the New Mexico Tumor Registry. Sampling criteria are clearly specified and include no capricious judgements around age. However, the exclusion of Native Americans is not supported and the requirement of physician consent likely excludes individuals without a primary physician.

Comparative descriptive design. Many of the reviewed papers employ comparative descriptive design. Comparison groups are used to describe difference either on the basis of age or incident cancer. Such designs are especially useful in this unexplored area as two of the most salient issues are: a) Does the experience of older individuals with cancer differ from that of younger individuals with cancer? and b) Does the experience of elderly individuals with cancer differ from that of elderly individuals who do not have cancer? Ganz et al. (1985), Edlund and Sneed (1989), Larson et al. (1993), Nerenz et al. (1986), and Satariano et al. (1990) all employ age comparisons. Nerenz et al. (1986) study the impact of age on symptoms. Larson et al. (1993) study the influence of age on symptoms and functional status for individuals with lung cancer. Ganz et al. (1985) explore the relationship between age and psychosocial disruption. Satariano et al. (1990) study age and functional status in women with breast cancer. And Edlund and Sneed (1989) compare emotional responses to cancer on the basis of age. The designs and analyses used in this group of studies, while not without threats to validity, are generally suited to the questions involved. Sampling issues present far more problems for internal validity.

None of the authors, despite the prominence of age in the designs, adequately deals with the way in which old age is quantified. Ganz et al. (1985) and Larson et al. (1993) make age dichotomous and identify 65 years of age as the marker. The decision is presented, in both cases, without adequate attention to physiological and social antecedents of 65 years of age as the marker of old age (Cole, 1992; Cremin, 1992; Rebenson-Piano, 1989). The strength of any findings related to age is jeopardized by inadequate operationalization. Edlund and Sneed (1989), Nerenz et al. (1986) and Satariano et al. (1990) achieve more successful comparisons. They create age categories that are loosely labeled in relation to one another, rather than in relation to an absolute.

Heidrich and Ward (1992) and McGill and Paul (1993) use cancer as the comparative variable in their respective investigations of adjustment to cancer for elderly women and functional status in elderly people with common solid tumors. The group without cancer, in both studies, was composed of randomly selected elderly individuals who were not matched to the group with cancer on any variables. Again, old age is defined as older than 65 years. In this case the distinction was less problematic as age was not the comparison variable.

Heidrich and Ward (1992), like McMillan (1989), report a secondary data analysis. They represent the design as theory testing despite that only a synthesized conceptual model is described. While the intent is clear, it is not supported by a substructure. McGill and Paul (1993) have the distinction of presenting a well substructed research report. Variables are well operationalized and clearly linked to instruments. The authors also specify a power analysis and pre-set alpha level. Such substructure lends substantial confidence to their findings.

Baider et al. (1992) report an investigation of the effect of surviving a concentration camp during World War II has on coping with cancer in later life. They are the first authors to operationalize the recognition of historical cohort effects on the experience of cancer (Cole, 1992; Cremin, 1992; Patterson, 1987). The holocaust survivor and non-holocaust survivor groups were matched for age and time since diagnosis but not for diagnosis itself. The design, sampling technique, and analysis were adequately linked. The substructure was supported by a purposeful literature review. Further benefit would have been gained, in this case, by an historically oriented conceptual model given the obvious links to ethnicity, culture, and religion.

Experimental design. The remaining study in this group is experimental in design. Love et al. (1991) report a study of post-menopausal women receiving tamoxifen for breast cancer. It had great appeal as a seemingly carefully constructed, much needed study. The report of this randomized, double-blind, placebo-controlled clinical trial reveals, however,.that "Volunteer subjects were required to be *younger than 65 years*, diagnosed with axillary node negative breast cancer up to ten years previously, and clinically post-menopausal." (Love et al., 1991, p. 1842; emphasis added).

While this sample inclusion criterion is perhaps defensible in light of the purpose of the study as written, it replicates the exclusion of elderly individuals from clinical cancer trials that is now widely acknowledged to have limited growth of knowledge and practice in this field (Begg & Carbone, 1983; Goodwin et al., 1988). This limits the relevance of the findings for the purposes of this review, and for understanding tamoxifen side effects in *elderly* women with breast cancer.

Findings and Implications for Future Research

The research reports reviewed here, despite concerns about paradigm, theory, design, sample, and analysis, imply much for future research through the trial, error, and success they represent. I will first summarize what substantive knowledge of cancer experience for the elderly can be gleaned from the studies. I will then highlight the directions for future research suggested by the limitations and gaps I have previously discussed. The discussion will cover the following areas: validating symptom experience, dispelling myths, and the importance of context. Summary of findings and gaps in the literature precedes discussion of the implications for the present study.

Validating symptom experience. Greenberg, et al. (1993) and Love, et al. (1991) serve to validate the subjective physical experience of cancer symptoms common to the elderly being treated for prostate and breast cancers. Greenberg, et al's (1993) preliminary attempt to illuminate the relationship between the experience of fatigue and the biomarker, interleukin-1, reinforces the need for further investigation of it and similar relationships between other symptoms and biomarkers.

The authors found fatigue peaks at the end of therapy while interleukin-1 peaks about midway through the course. Nonetheless, the discovery of a pattern of association is confirming in itself as fatigue is difficult symptom to observe. This characteristic may contribute to discounting fatigue and the disruptive effect it has on daily living. Hence, associating fatigue with a measurable biomarker may lessen the degree to which it is discounted.

Love, et al. (1991) achieve similar success in validating the experience of women on tamoxifen therapy. While this study only included women younger than 65 years, the clinical trial reveals significantly greater vasomotor and gynecologic symptoms in women taking tamoxifen versus those taking a placebo. Persistent symptoms were reported by 60.6% of the women taking tamoxifen versus 33.3% of those taking the placebo at 12 months ($p < .001$). The trial needs to be replicated with women over 65 years of age, but the magnitude of the difference between groups lends credence to the experience of women who clinically complain of the side effects caused by what is generally viewed as a benign treatment.

Dispelling myths. Brown (1993), Edlund and Sneed (1989), Larson et al. (1993), and Nerenz et al. (1986) support the notion that elderly individuals are not inherently more fragile or predisposed to a more arduous experience of cancer because of age. All of these reports found no significant differences attributable to age in the symptom distress and functional status experienced by the samples employed.

The idea that the elderly do experience cancer in a physically different, but not necessarily more difficult, way from younger individuals is underscored by the trend in findings from McMillan (1989) and Satariano (1990). McMillan's (1989) results suggest that the intensity of pain, nausea, and vomiting may decline with age. She is careful to point out, however, that these findings may also stem instrumentation issues, particularly under-reporting as a cohort effect among the elderly (McMillan, 1989).

Satariano et al. (1990) conclude that upper body physical function problems after mastectomy are more prominent among the young elderly (65 to 74 years) than among middle-aged and old elderly women. The authors posit that the lessening of functional status problems for the old elderly may be an issue of increased chronic illness in this group (Satariano, et al., 1990). The old elderly may report fewer functional problems because they are accustomed to less functional ability from chronic problems that pre-date cancer. This is the idea that cancer is experienced by the elderly in the complicated context of normal and pathological aging changes.

The importance of context. The direct implication of the issue of context is that cancer is one of many disruptive problems for the elderly, rather than being the central problem it is for younger individuals, and hence competes for prominence in the global experience of illness. Contextual complexity is an essential issue for study of the experience of cancer for the elderly. It is underscored by the approaches and findings reported by Baider, et al. (1992), Edlund and Sneed (1989), Ganz et al., (1985); Goodwin, et al. (1991), Heidrich and Ward (1992), and McGill and Paul (1993) in dramatically different ways.

Baider, et al. (1992) explore the effect of the holocaust on group characteristics of cancer experience. They find that such a traumatic life experience significantly alters the experience of cancer. Holocaust survivors tended to be more fearful and rigid in their responses to cancer than did the comparison group. The crucial contribution of the study is then the idea that prominent life experience, which tends to be broader and deeper in old age, may profoundly influence the experience of cancer.

Edlund and Sneed (1989) found that, in their sample, those over 70 years of age may experience less distress at the diagnosis of cancer but only before treatment is begun. Ongoing treatment, as a variable, diffused the correlation between age and distress. The authors astutely point out that the elderly cancer patient may be influenced, once therapy is initiated, by what they perceive to be the expected response to cancer. This suggests that the on-going experience of cancer shapes itself, to a certain degree, through personal and social interpretation of what it means to be old and to have cancer.

Ganz, et al. (1985), in the oldest report, paradoxically highlight the role of life experience through issues that arise in relation to sampling and instrumentation. They exclude all women from the final sample because the sites for data collection failed to produce sufficient numbers and employ the Cancer Inventory for Problem Situations (CIPS), an instrument designed for use with younger individuals. The results suggest that the younger group experiences greater problems than the older group, especially with regard to work situations. While this conclusion may be valid to a certain degree, Ganz, et al. (1985) fail to explore alternative explanations.

The most obvious explanation is that the CIPS may not measure issues salient to the elderly. This general problem arose in many of the studies reviewed here, and most authors did not adequately explore the need for instrument development. In addition, the elderly subjects may respond differently to various instruments as McMillan (1989) points out. Elderly adults may respond out of cohort effects around expressing health problems or they may experience problems in contexts which alter their perception of them (Cremin, 1992).

Goodwin, et al. (1991) approach the issue of immediate context through an exploration of functional status and social support networks in the elderly newly diagnosed with cancer. They found a substantial degree of partial dependence and declining social support associated with advancing age, all ethnicities studied except Hispanics, being female or poor, and recent relocation (Goodwin, et al., 1991). The authors suggest that it is these contextual factors, and not the traditional misconception of physical frailty, which put the elderly at risk for limited access to care and consequent substandard cancer treatment.

Heidrich and Ward (1992) explore the psychological context of self in relation to adjustment to cancer for elderly women. They found the group with cancer had adjusted their ideal selves, that conception of self that motivates aspects of development, to reduce the dissonance between that self and their actual, 'day-to-day' selves. Heidrich and Ward (1992) place the findings within existing literature through a parallel with Taylor, Lichtman, and Wood's (1984) idea of downward social comparison. Downward social comparison is the evaluation of one's situation in relation to others like you whom you perceive to have worse situations. The general effect is a boost in self-esteem. The implication is that elderly women may better adjust to cancer with use of cognitive strategies like downward social comparison.

McGill and Paul (1993) bridge psychological and physical context with an investigation of hope and functional status in the elderly with and without cancer as an issue of adaptation. Physical health was found to have a significant positive relationship to hope as it was measured by the Miller Hope Scale. The overall relationship of function to hope was assessed in a regression model. The functional domains measured explained only nine per cent of the variance in hope and group membership explained less than one per cent of the variance. While McGill and Paul (1993) offer a well-written discussion of the findings, they do not address the larger issue of investigative paradigm. Representation of the relationship of functional status to hope as linear and unidirectional is, perhaps, oversimplified given the complexity of the concepts. Yet the idea that functional domains did influence hope in this well substructed but philosophically arguable model highlights the role of the contextual levels of experience addressed.

Summary of findings. The research reports reviewed here suggest several characteristics of the experience for the elderly with cancer. First, they suggest that the physical experience of cancer , its symptoms and treatment side effects which are often indistinguishable, is likely different from that of younger adults. This may be due, in part, to changes with age and co-morbidity. Second, they underscore the fact that old age does not predispose the elderly to worse physical and psychosocial experiences of cancer. And third, they make an embryonic argument that context may truly shape the experience of cancer for the elderly. Levels of context, or environment within the nursing paradigm (Fawcett, 1978), from the psychological to the social were among the most intriguing and useful variables in several of these studies.

Summary of gaps. Conversely, important elements are not found in this body of literature. These deficits contribute to limited knowledge development in the experience of cancer for older adults. First, there is paradigm bias toward positivistic and, hence, quantitative, deductive investigation. The bias is limiting given the need for exploration of the phenomena in the area, the lack of apparently useful theory, and the complex and the subjective nature of the many aspects of the experience phenomenon in need of exploration. Second, there is a widespread failure to place the existing studies either within appropriate theoretical or conceptual frames, or alternatively, to acknowledge the paucity of applicable theory and to engage in theory-building research.

Implications for the Present Study

The present study is shaped by recognition of the strengths and weaknesses of the data-based literature that precedes it. I have placed it within the naturalistic paradigm and selected grounded theory, an inductive theory generating methodology, to supply both theoretical perspective and method. Grounded theory also avoids some of the instrumentation problems discussed earlier. It does so through reliance on an iterative, emergent interview technique, constant comparative analysis, and data collection parameters guided by the emerging analysis. Grounded theory concomitantly demands rigorous attention to the qualities the interviewer, as investigator, brings to the study as the primary data collection tool. Among those qualities is the theoretical information the interviewer-investigator uses to shape and color the investigation. In the next section, I will discuss symbolic interaction (SI), the theoretical underpinning supplied by GT, and the blend of theoretical perspectives which I use to augment SI and therefore to inform the project.

CHAPTER III

Informing the Present Study

Introduction

I used existing theory and concepts in two ways to inform this project. First, I was committed to two specific theoretical ideas as they form the basis of my world view, through which I locate nursing and the experience of cancer for the elderly (Charmaz, 1990; Sandelowski, 1993). The first theoretical perspective, symbolic interactionism (SI), is a branch of sociological theory arising out of American Pragmatism. It forms the theoretical foundation of GT. The second perspective is cultural history, the study of the evolution of phenomena within a culture. Both are intrinsic to my world view as it bears upon the present study. The experience of cancer is one that necessarily reshapes the elder's self and therefore changes interaction with others. The reshaping is partly contingent on the cultural constructions of what it means to be old and to have cancer in our society and personal interpretations of those meanings (Charmaz, 1990).

Second, I was informed by particular grand and middle range theory which was resonant with the study problem (Dreyfus, in progress; Sandelowski, 1993). Erikson's Life Cycle, particularly the eighth stage of integrity versus despair, and the nursing meta-concept of comfort are essential to placing the study problem within my world view. In his explication of the eighth stage, Erikson (1982) completes the Life Cycle and clarifies inter-generational continuity. He posits that wisdom and faith motivate interaction from older to younger generations as a means to communicate life experience and meaning. Comfort, and its negative state of discomfort, are necessary to understand how elders experience themselves and their bodies differently with diagnosis and treatment of cancer.

Purpose and Method of Discussion

In this chapter, I will explicate the aspects of SI, comfort, the Life Cycle, and the cultural histories of aging and of cancer that form the theoretical and epistemological foundations of the present study. They influence how and what I think, but do not proscribe content, in relation to the phenomenon under study. I will treat each respectively. The discussion is critical but is not intended to be comprehensive. The reader is referred to the original sources for that level of discussion. I will explicate the utility of each model after discussing the structure and content pertinent to the study. The chapter will conclude with a summary of theoretical information.

Theoretical Perspective

Symbolic interaction handles certain aspects of individual behavior and human interaction with less specificity than it does other aspects. The mind which generates and constantly shapes the self and the interaction through which meaning is attached and interpreted are solidly delineated in SI. Issues of the physical body, generations, and social and historical transmission of meaning are supported less well by SI.

As a consequence of the strengths and weaknesses of SI, my world view and the perspective through which I study the elderly with cancer is informed by the meta-concept of comfort (Jacox, 1989), Erikson's (1982; Erikson, Erikson, & Kivnick, 1986) Life Cycle, and cultural histories of aging and of cancer (Cole, 1992; Patterson, 1986). These models of thought address the issues of body, generations, and historically-based meaning that are important to the phenomenon of experience of cancer for the elderly that are not well supported by SI.

Symbolic Interaction

History

Symbolic Interaction arose in the mid-19th century from several schools of American and European thought. Mead (1962; Turner, 1986) synthesized the primary trends in American social thought while at the University of Chicago. Influenced by the pragmatic philosophy of Dewey and others, he developed the concepts of mind, self, and society. The central assumption from which these concepts spring is the understanding that human beings create and use symbols to communicate and form societies through interaction with others (Mead, 1962).

Blumer (1969) came to the University of Chicago at the end of Mead's tenure (Turner, 1986). He established what is now recognized as SI. Symbolic interaction became a prominent social psychological model through which to understand, interpret, and abstract the processes of human interaction. Blumer (1969) left the University of Chicago and went on to influence a number of important sociologists. Their manifestations of SI are identified as the Chicago School. Blumer (1969) is the major theoretical proponent of SI as the inductive, interpretive means to building theory around human interaction. The Chicago School is the realization of Blumer's (1969) theoretical stance.

Among the sociologists influenced by Blumer and Mead is Strauss, who with Glaser, originated GT (1967). I acknowledge the substantial influence Glaser's positivistic, quantitative training at Columbia University had on GT, especially the analytic techniques. However, the theoretical contribution is made by SI in the iteration of the method used in this project as presented by Strauss and Corbin (1990). Therefore I treat SI as the primary theoretical background of GT.

Grounded Theory is a scientific method of interpreting social phenomena and abstracting practical theories of them (Blumer, 1969; Dreyfus, in progress; Glaser, 1978; Sandelowski, 1993; Strauss & Corbin, 1990). The method and associated techniques arise from the Chicago School of SI (Blumer, 1969; Turner, 1986). Using GT as the means to investigate the study problem was to acknowledge that I saw the experience of cancer for the elderly largely through the assumptions, concepts, and propositions of SI.

Structure

The assumptions and concepts of SI are congruent with the experience of cancer for the elderly. It is an experience of the self which shapes and is shaped by meaning and interaction around cancer and being old in daily living. Human beings are capable of representing themselves and their environments as objects, or symbols (Blumer, 1969; Mead, 1962). This is the mind, and the capacity to objectify oneself creates the abstraction called the self. Symbolic representations allow for communication and hence interaction. It is through interaction on many levels that society is created and evolves. Symbolic interaction tends to focus on the interaction of a few rather than the larger society connoted by the common use of the term (u. e. community).

Blumer (1969) extends the original structure of SI to clarify the role of meaning in interaction. He posited that humans act toward others and things in their environments because of the meaning these objects have for them. Meaning, according to Blumer (1969), arises out of the interaction with the generalized other. Therefore, meaning is also a fluid entity as is the self. Interaction is a constant, dynamic human process. Meaning is itself shaped by the interpretive process of interactive encounters with others and one's environment (Blumer, 1969).

Utility

The propositional logic of interplay among the self, meaning, and interaction suits the current project. The experience of cancer for the elderly involves the self and interpretation and incorporation of meaning attached to being old, having cancer, and sustaining symptoms. The experience of cancer implies interaction around cancer in addition to established patterns of interaction in daily living. Furthermore, the elderly are likely to have evolved many levels of meaning attached to interaction by virtue of the length of their lives and interactional experience.

Symbolic interaction offers considerable insight into the aspects of the experience of cancer for the elderly that involve the self and interaction with others. However, SI is less helpful when considering bodily aspects of the experience and the interplay between mind and body. The meta-concept of comfort, and the research around comfort for the elderly, is useful for exploring the bodily aspects of the experience of cancer for the elderly.

The Meta-Concept of Comfort

Comfort is at the heart of my nursing practice with the elderly, and indeed anyone, who has cancer. Concern for human comfort is central to my individual and the collective understandings of nursing (ANA, 1980, 1987; Jacox, 1989; Nightingale, 1969). The responses to cancer that I diagnose and treat in elderly individuals have most often to do with discomfort and regaining comfort.

Symptoms are perceived by individuals, most broadly, as discomfort that disrupts usual patterns of daily living. Discomfort of nausea, for example, often prevents individuals of any age from eating and socializing as they are accustomed. The discomforts of cancer are often exacerbated by or confused with old age (Tishelman, et al., 1990). Discomfort and, consequently, the search for comfort along with the accompanying disruption in daily living are viewed as a central aspect of the experience of cancer for the elderly. Symptoms are the core of that experience. Conceptually, comfort bridges the physiological manifestation of cancer and treatment seen in symptoms with the experience of cancer in daily living.

Definition

Comfort is a multi-dimensional concept of complex inter-relationships between individual human experience and relief from symptoms common to human beings (e.g. pain, fatigue, nausea, dyspnea, anxiety) (Jacox, 1989). Hence, it is truly a meta-concept. This distinguishes comfort from the many symptom concepts attached and inversely related to it. Comfort is experienced subjectively. Discomfort is the experience we seek to avoid. The referents, what makes an individual express comfort or discomfort, may change over time. The state of comfort can only be inferred from description of the experience and observation of non-verbal behavior (Jacox, 1989; Kolcaba, 1992). Kolcaba (1992) defines comfort as the experience in which the basic human needs of ease, relief, and transcendence have been met.

Research

Hamilton (1989a, b) expands the definition offered by Kolcaba (1992) through her research with chronically ill, hospitalized elderly. The study findings suggest that comfort is experienced within the self through interplay among self esteem, disease processes, positioning of the body, and the approach and attitudes of others (n.b. especially those delivering care to the elderly). The negative dimensions of these factors (e.g more symptomatic disease or rough, unpleasant care givers) contribute to discomfort and must be altered to restore comfort. Hamilton's (1989a, 1989b) expansion of the definition of comfort beyond the self and incorporation of interaction and environment is highly congruent with SI.

Utility

The addition of comfort to the perspectival foundation of the current study secures the importance of the inner experience and the significance of the study for nursing. Symbolic interactionism emphasizes the mind as the innate human capacity which creates the self (Blumer, 1969). The physical body is implied but receives no exposition. Comfort addresses the intertwined relationship of mind and body. The perception of comfort is subjective and includes physical, emotional, cognitive, social, and spiritual factors. Therefore, comfort is perceived with the mind and the body through meaning attached to comfort and the attributed cause of discomfort by way of the self and interaction.

The concept of comfort and SI, taken together, illuminate a good part of the experience of cancer for the elderly. Neither however shed light on the generational and developmental aspects of the experience of cancer. These issues may differentiate the experience of cancer for the elderly from that for younger individuals. Erikson's (1982; Erikson, et al., 1986) Life Cycle specifically addresses issues of life stage and generations. Hence, it is a useful addition when approaching study of the experience of cancer for the elderly.

Erikson's Life Cycle

Erikson (1982; Erikson, et al., 1986) theorizes about human psychological development through a cyclical, stage model. Of late, Erikson's (Erikson, et al., 1986) places emphasis on the importance of the eighth and final stage as that which achieves continuity of the psychological life cycle. Part of the attraction care of the elderly holds is a realized, personal sense of continuity through the stories of life experience shared from patient to nurse (Rorro, 1993). Interaction between the oldest generation and a younger one completes part of the life cycle through transmission of meaning and life experience.

Erikson's Eighth Stage

The eighth stage is characterized by the psychosocial crisis of integrity versus despair. Wisdom is the strength evolving out of the crisis. It is the ability to integrate, abstract, and articulate life experience for the benefit of other. Wisdom is, by nature, altruistic and exists well within the relational sphere of 'mankind-mykind'. The dystonic outcome of the crisis is despair. It is focused on the self and cannot see 'mankind-mykind'.

As the balance of the last psychological crisis of life tends toward wisdom, postulates Erikson (1982), comes a mature transmutation of hope, the first strength of the life span, into faith. Faith is essential to revising one's view of life from one's own life into the cycle of life. It is the capacity to imagine a world without yourself. Imagining a world without yourself involves recognizing the greater importance of the continuity of generations and of society. Faith also allows for acceptance of a personal mortality (Erikson, et al., 1986). Faith and wisdom motivate completion of the life cycle within the relational sphere of 'mankind-my kind' (Erikson, 1986). The life cycle is completed as elders are 'grand-generative'. They share the knowledge of a life time with younger generations.

Utility

Erikson (1982; Erikson, et al., 1986) offers, through the structure of his theory and exposition of the traits of the final stage, a means to understand the perpetuation of society and the transfer of life knowledge from one individual to another. The stereotypical story-telling and life review of old age are imbued with validity and greater purpose given this understanding (Haight, 1992). Erikson (1982) overcomes the lack of specificity with which SI handles perpetuation and evolution of society from generation to generation. In this way, the Life Cycle augments the theoretical foundation of the present study.

Serendipitiously, wisdom, faith, and completion of the life cycle suggest that qualitative research methods that use interview data may appeal to elders (Souder, 1992). Interviews, recording of shared information, and dissemination of findings allow an opportunity for concrete communication of life experience. This may approximate some of the benefits of structured life review (Haight, 1992).

Together, SI, comfort, and the Life Cycle provide a fairly sound basis for approaching the study of the experience of cancer for the elderly. None can address issues of particular culture and history inasmuch as each arises out of the disciplines of sociology, nursing, and psychology respectively. History is not the primary concern of these disciplines. Only cultural history can trace social and cultural constructions of old age and cancer in our society. The prominent cultural histories offered by Cole (1992) and Patterson (1987) address the popular constructions of old age and cancer, respectively, in modern American society.

Cultural Histories of Aging and of Cancer

Abstract theory cannot fully explicate the social construction of what it means to be old and to have cancer in our present American society. The history of social meaning attached to the states of being old and having cancer are necessary to a full understanding of the phenomenon under study . Only cultural histories of aging and of cancer trace actual evolving meaning and interaction around these complex constructs over time.

Fortunately, two powerfully written, highly credible secondary historical sources are available. I make no pretense of using primary historical sources. Cole (1992) and Patterson (1987) offer enthralling, informative distillations of cultural histories of aging and of cancer, respectively. These histories complemented and, in some cases, contrasted with the work of others. I rely also on Donow's (1992) essay on Shakespearean aging and on studies of meaning and experience in old age (Cremin, 1992; Dittman-Kohli, 1990) to augment the picture created by Cole (1992). Good, Good, Schaffer, and Lind (1990); Pinnell & Brossat (1988); Saillant (1990); and Gordon (1990) supply invaluable information on the American discourse on cancer and on European cultural comparisons to that discourse.

The Journey of Life: A Cultural History of Aging in America (Cole, 1992)

Cole (1992) exposes the mainstream construction of aging in our society as a moral dichotomy of good and bad that stems from European Protestantism and has been scientified by gerontology into an issue of success and failure (Rowe & Kahn, 1987). The exposition makes clear the roots of the dissonance between actual experience and social conceptions revealed by studies of the experience of being old in modern society (Cremin, 1992; Dittman-Kohli, 1990).

Cole (1992) begins with the position that the conception of the ages of life, with roots in antiquity and many cultures the world over, offers an understanding of a unified lifetime. The unification encompasses the process of life and aging, with its biological basis, and the experience of growing up and growing old. A unified view of life also implies recognition of inevitable death.

The influence of religion. The journey is a prominent metaphor of the ages of life from antiquity through the 18th century (Cole, 1992). It enters our cultural understanding through the influence of judeo-christian religion, and is exemplified in Protestant thought. The idea of life as a journey offers the comfort of a knowable end and the possibility of longevity, but not immortality, through achieving favor from God. The journey of life is represented in countless ways. Homer wrote of Odysseus. The Bible has the story of Job. Cole (1992) skillfully integrates the many threads from myth, religion, and art to reveal a foundational fabric of our modern construction of aging.

Longevity became paramount as the influence of Protestantism, and particularly Calvinism, grew in early American Society (Cole, 1992). There was a collective search for explaining why some people were more comfortable in old age and lived longer than others. Emphasis moved away from the journey itself to the end. Calvinism valued health and activity and, at the same time, accepted frailty and death as the final judgement in one's relationship with God. Individual interests began to stand out against those of the family and veneration of old age. This is different from earlier dialogue in which one's life and one's relationship with God were proscribed to a far greater degree. The moral implications of the quality of old age came to be a salient issue.

The late Calvinist idea of man's evil nature, activity for repentance, and ultimate dependence on God from birth to death was transformed, with the notion of free will, into the early 19th century understanding of the dualism of aging (Cole, 1992). The notion itself was not new. Donow (1992) studies Shakespeare's elderly characters. He reveals a dualism of the elder counselor and the comic oldster. For antebellum protestants, the role of individual character began to overshadow the Calvinist notion of inherently depraved human nature. Aging then became an issue of moral character as much as one of proscribed relationship with God. The length and quality of one's life was dependent on moral rectitude. Hence, health was also seen as dependent on one's moral character.

Religion and health merged to an even greater degree in the popular evangelical health reform movement of the mid-19th century (Cole, 1992). Graham (of graham flour and graham cracker fame), Kellogg (of cereal fame), and others were proponents of health reform (Cole, 1992). The canonization of hygiene lent scientific legitimation to the pursuit of longevity. Death, symbolized by declining health and feared as the ultimate moral failure, could be held at bay. Or so 19th century American society hoped.

At about the same time that the health reform movement was popular, Romantic religion and popular Victorian art created a resurgence of interest in the journey of life. Thomas Cole exemplifies this era in the spiritually ideal series of paintings, "The Voyage of Life". The four paintings, "Childhood", "Youth", "Manhood", and "Old Age", now hang in the National Gallery. They are one of the best known symbols of our historical ideal of aging. Here death, the conclusion of the journey and therefore natural and accepted as Thomas Cole painted it, competed with death, as the feared and aversive moral failure of 19th century Protestantism.

Nevertheless, as science rose to prominence in the late 19th century, various dualistic conceptions of aging competed in American thought and outweighed the image of the journey (Cole, 1992). Among the most prominent versions of dualism, civilized old age and self-help were promulgated largely by a group of independent women. Self-help hinged on activity and altruism until death. The influence of self-help is pervasive even today (Cole, 1992). It is seen in our current adulation of self-improvement.

The most prominent and pervasive dualism, however, is rooted in modern, Western medicine. The turn of the century saw physicians take the lead in the dialogue around aging (Cole, 1992). Experiments were devised to end the controversy around a fixed life span versus prolongevity. The end of that controversy is not yet in sight. Nonetheless, these experiments were harbingers of the evolution of gerontology and the scientification of old age (Cole, 1992). With science came the concept of normal and it's converse, abnormal. Modern gerontology, and consequently the current popular view of a society that reveres science, views aging as a process of the normal and the abnormal. The current emphasis on carefully controlled lifestyles to avoid environmental (read: abnormal) aging is evidence of this influence.

Rowe and Kahn (1987) articulate the unconscious, modern interpretation of aging as a moral dualism that has become shrouded in science. They rename the dichotomy usual and successful aging. Cole's (1992) greatest intellectual contribution is the exposition of current gerontological thought as deeply rooted in religion and history. The ideal of successful aging is not free of moral overtones, as its proponents might think, but is deeply anchored in our cultural history.

The admirable intent of Rowe and Kahn's (1987) paper is to highlight heterogeneity in the elderly population. (I use the word heterogeneity, throughout this research report, to encompass the great diversity of physiological, psychological, and social patterns among the elderly). The goal espouse by Rowe and Kahn (1987) is to steer gerontological research away from investigation of loss and toward broader studies that focus on function and positive capacity. Rowe and Kahn (1987) attempt to achieve the goal by framing the discussion with the Cartesian mind-body dualism. This is seen in their review of physical aging and psychosocial issues associated with the elderly by system and content area. The conceptual understanding Rowe and Kahn (1987) introduce to address heterogeneity is that of usual and successful aging .

Successful aging is intended to encompass the healthy elderly who have escaped functional loss from common problems like osteoporosis.

Unfortunately, usual and successful aging is a dichotomy, burdened by the social connotations of success and failure. The use of a dichotomy is logically incompatible with the continuous range suggested by heterogeneity. Despite the intent, Rowe and Kahn (1987) are unable to escape the narrow social construction that emphasizes the framework of loss in aging they seek to avoid.

Cremin (1992) offers a particularly insightful illustration of dualistic aging and the dissonant experience it creates. Her qualitative investigation of the congruence between the experience of old age for five people and the perception of old age by their adult children revealed that the elderly distinguished between being old and feeling old. The children did not, and identified their parents as old when they lost the central characteristics of the children's experiences of them as parents (Cremin, 1992). The ramifications of such findings are that physical frailty and dependence, as socially constructed usual aging, constrain the interaction and experience of old age. Roles, as one ages, are viewed externally as exclusive and dependent on physical and cognitive capacity. There is no place in our society to view social roles as evolving and changing with advancing age.

Utility. Cole's (1992) cultural history, along with other authors who illuminate aging, provides an explanation of the historical forces at work in the current experience of old age. He supplies larger cultural meanings with which every older American deals in some fashion. The individual meaning and experience are, of course, shaped by particular ethnicity, religion, and life experience. But cultural forces, through overt or covert means, are at play for all members of our society. So to are they at work in the experience of cancer for the elderly.

The Dread Disease: Cancer and Modern American Culture (Patterson, 1987)

Patterson (1987) links the cultural history of cancer with American social and political history in an intimate manner. He begins with the illness of U.S. Grant. Grant achieved immense, but turbulent stature during the Civil War. His presidency was troubled and he was financially ruined in subsequent years. Grant became the object of a national obsession when he was diagnosed with throat cancer in 1884. Rumors were thick until the disease was publicly confirmed in 1885. Grant and his cancer were then featured daily in newspaper headlines. Grant's imminent death from cancer provoked constant, macabre reports of his status and symptoms to his very last moments. Nineteenth century cancer phobia was promoted and focused through the public illness and death of U.S. Grant (Patterson, 1987).

Little was known of cancer in the late 19th century (Patterson, 1987). Attitudes were still rooted in antiquity. Cancer was a mysterious, evil crab. Misinformation abounded. Cancer was widely believed to be contagious. Surgery was gaining recognition as treatment, but the risk of surgery itself was often enough to drive patients away. Sham cures began to spring up (Cassileth, et al., 1991). Sham cures were those purveyed by people seeking to profit from the distress of individuals with cancer rather than aiding them. Traditional medical treatments, from Eastern medicine for example, are not sham cures and very often are highly useful in treating cancer. Proponents of such sham cures even presented themselves at Grant's doorstep (Patterson, 1987).

Cancer benefited from physicians' rise to power at about the same time physicians began to make aging an issue of science(Cole, 1992; Patterson, 1987). At the turn of the century, a group of socially progressive physicians overcame fear and avoidance to campaign against cancer. The campaign profited from new knowledge of contagion and the discovery of X-rays. Cancer research was born. In 1913, the American Society for the Control of Cancer (the predecessor of the American Cancer Society [ACS]) was formed in New York. People suffering from cancer began to be seen as being in need of charitable assistance rather than as afflicted, contaminated individuals who should be shunned (Patterson, 1987).

Progress away from cruel and fearful attitudes was slow. The first third of the 20th century was characterized by struggle. Progressive attitudes and the rise of science battled backward, counter-phobic attitudes often displayed by prominent popular and political figures (Patterson, 1987). Finally in 1937, a group of physicians gained the support of the Federal Government. The National Cancer Institute (NCI) was founded and funding was made available for research. The enlistment of the government within that historical climate laid the foundation for the most pervasive metaphor for cancer: the War (Good, et al., 1990; Patterson, 1987).

The War on Cancer was waged on many fronts. Sham cures still competed with an enlarging arsenal of well researched, but toxic treatments. Cancer deaths increased proportionately as infectious disease was conquered. Cancer in public figures focused attention, anxiety, and progress (Patterson, 1987). Gradually, cancer became something that could be talked about when necessary. Science merged with religion. A large part of the War became rhetoric around hope.

Hope grew as research in the field exploded (Good, et al., 1990).. Knowledge of the cell and the causes and natural history of cancer, coupled with the growing power of the NCI, led to enhanced detection and new treatments. Concurrently, the American Cancer Society stepped up its emphasis on prevention. In 1971, Richard Nixon overtly placed the War on Cancer on the national agenda during his State of the Union address. Funding to the NCI was increased and prominent figures in the War began to speak of conquering cancer. The social institution of the Cancer Establishment and its message of hope were clearly key elements of the meaning our society attached to having cancer .

But hope and the rate at which cancer research progressed were incompatible for the many people who were diagnosed with cancer. The Cancer Establishment was periodically besieged by the popularity of sham cures (e.g. laetrile) and the hope that they offered (Cassileth, et al., 1991; Patterson, 1987). The War was not being won quickly enough. Everyone knew of someone who had suffered greatly in cancer treatment. The treatment was often perceived as worse than the disease. This would have been acceptable if treatment had supported the War metaphor with clear, consistent success. Of course, it did not. Then, as now, cancer treatment achieved only partial control of most malignancies. Patterson (1987) describes this period in the 1970s and 80s as a period of siege for the Cancer Establishment.

Much has happened since the publication of Patterson's (1987) history within the Cancer Establishment that he describes (Good, et al., 1990). The highly touted immunologic therapy with which he concludes his history has evolved greatly over the past six years. Immunologic therapy is not the magic bullet the public perceived it to be through media pronouncements. But immunologic therapy has offered considerable promise for certain malignancies. Currently, gene therapy is anticipated to create dramatic new directions for the "War".

<u>Omitting the history of cancer in old age</u>. Patterson (1987) does not include the connection between aging and cancer in his history. This is probably because it is a history of social discrimination and disavowal. Cole (1992) reinforces the reality of this by revealing the conflicted place aging holds within our culture. Illness in the elderly elicits the connotations of failure and fear attached to old age. Only since 1982 have individuals over 65 years of age been included in federally funded cancer treatment trials (Goodwin, et al., 1988). There is no secure place in the War for the elderly.

Even now, there is scant public attention paid to cancer in elderly compared with that paid to cancer in younger individuals. Media prominently feature the breast cancer movement and triumphant stories of young celebrities winning their personal wars with cancer. Public avoidance of cancer in the elderly continues despite a burgeoning professional interest in geriatric oncology and demographics that make cancer essentially a disease of the elderly. This conflict of social attitudes appears paradoxical at first.

Consider, however, that the metaphor of War is inappropriate to the experience of cancer for the elderly. The elderly are close to the end of their lives and therefore to death. The object of war is to conquer by killing. To fail is to die. The elderly will die shortly even if the battle with cancer is won. Despite winning, the elderly lose by dying anyway. They thereby invalidate the metaphor our society uses to make sense of cancer. And the dualistic understanding of aging made clear by Cole (1992) only compounds the loss by viewing aging and death in terms of lack of success, or failure (Rowe & Kahn, 1987). Perhaps knowledge of cancer and the experience of it in the elderly lags because we have no positive metaphors to shape our social understanding of it.

Summary

For the purposes of the current study, SI offers the mechanism of connecting self and society through symbolic communication and evolution of meaning for individuals (Blumer, 1969; Mead, 1962). The concept of comfort illuminates the role symptoms play in the experience of cancer through discomfort they create and the human need to regain comfort (Jacox, 1989). Erikson (1982) provides for perpetuation of the life cycle and development of meaning and interaction for generations. Cole (1992) and Patterson (1987) posit particular historical metaphors for aging and for cancer that influence the meaning attached to these experiences. Together the models discussed here form the theoretical substrate to support initial discovery of a practical theory of the experience of cancer for the elderly through exploration of symptoms that is the aim of the present project (Dreyfus, in progress; Sandelowski, 1993; Strauss & Corbin, 1990).

The research question. The initial question used to enter the discovery project was: "What symptoms are important and how are they perceived by older adults with cancer"? This question aimed at symptoms, the speculated core of the experience of cancer as the way in which humans perceive the discomfort, change, and loss of cancer in physical, psychological, and social capacities. It was developed as a starting point with the understanding that it would be appropriately shaped by the iterative, dialectical nature of doing GT.

CHAPTER IV

Method, Design, and Research Process

Grounded theory method (GT), as it shapes the current project, is part of a rich, lively methodological tradition in nursing. Grounded theory, as a way of doing qualitative research from inception to publication, has evolved from Glaser and Strauss' (1967) conception. The iteration of GT used here is closest to that discussed by Strauss and Corbin (1990). The techniques of the method evolve out of the interaction between data and analysis and between investigator and participant. Nurses have been intimately involved with the originators of the method and with its application (Chenitz & Swanson, 1987; May, 1991; Stern, Allen, & Moxley, 1984; Strauss & Corbin, 1990). Nurse grounded theorists have helped to refine GT while retaining the original threads.

Purpose of the Discussion

The purpose of the following discussion of method and analysis is two fold. First, the design and analysis which produced the findings are revealed. This is done in a manner that alternates between the chronological and the substantive. Second, my method is discussed for explication and auditability. Both purposes are interwoven in the text. And each is part of the necessary framework for evaluating the credibility and fittingness of the findings against the accepted criteria outlined for qualitative research (Beck, 1993; Becker, 1993b; Burns, 1989; Kahn, 1993; Sandelowski, 1988).

Overview of Grounded Theory

Grounded Theory Design and Analysis

Grounded Theory outlines, rather than specifies research design (Strauss & Corbin, 1990). In order to ground, or anchor, theory in social interaction, diverse sources of information are required to open a phenomenon up for analysis (Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1990). Analysis is concurrent with data collection. Grounded theory relies on the constant comparative techniques, in which the data and analysis are constantly scrutinized in relation to each other over time, to shape and guide further data collection and analysis (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990).

Generally, a research design requires an investigator, a site where the phenomenon of interest may be accessed, sources of information, and means of collecting that information. In GT, the most common sources of data are interviews, documents, and participant observation (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Sources of information are somewhat dependent on whether the mode of investigation is discovery or emergent (Artinian, 1986, 1988; Glaser & Strauss, 1967). Additionally,sources of data may change as the analysis emerges and the theoretical needs of the research change (Strauss & Corbin, 1990). The targeting of sources for the purposes of expanding and deepening the analysis is known as theoretical sampling (Artinian, 1988; Chenitz & Swanson, 1986; Strauss & Corbin, 1990).

Constant comparative analysis is GTs distinctive mode of analysis. It is the technique of continually comparing new data with previous data and existing analytic product to highlight similarity and difference and to elevate common features to abstract representation (Glaser, 1978; Strauss & Corbin, 1990). Furthermore, the emerging analysis is compared with outside or informal sources for verification and refinement of percolating theoretical ideas (Burns, 1989; Swanson, 1986b). The use of GT is one of growth and development, in a very human sense. The process is one in which all aspects of an investigation are inter-connected and the investigator is constantly reflexive.

Coding data. The evolutional structure through which one utilizes constant comparative analysis to reveal the grounded theory is well described by Strauss and Corbin (1990). They outline a coding structure of identification, refinement, and confirmation. Open coding explodes the data and, given adequate attention to theoretical sensitivity, yields myriad initial categories (Glaser, 1978). Axial coding reassembles the data through connections made between categories. Selective coding identifies the core category of the story within the data. This is followed by locating the grounded theory within its conditional matrix through specifying and validating relationships among core and supporting categories, and their properties, dimensions, and conditions (Corbin, 1986; Strauss & Corbin, 1990).

All analysis is recorded and managed through generation of memos. Memos are written to make observations from the descriptive to the theoretical (Strauss & Corbin, 1990). Memos are then sorted to achieve integration of the analysis into a grounded theory (Corbin, 1986; Charmaz, 1990; Strauss & Corbin, 1990)

Data analysis groups. Doing GT is, for the investigator, an uneven and complex process. Its dimensions are manifold. Knowledge of many pertinent academic and professional issues, intellectual rigor, and reflexivity are all important components of the methodological process (Field, 1991; Kahn, 1993; Lipson, 1986; Stern, et al., 1984; Wasserfall, 1993). At times, the investigator must cogitate alone; at others, she must seek out well-informed assistance, input, and mentoring (Glaser, 1978; Kahn, 1993; Stern, et al., 1984; Strauss & Corbin, 1990).

My implementation of GT followed these lines. I performed all data collection and the bulk of the analysis. I also consistently shared and discussed data and analytic results with my dissertation chair and with my committee members. The chair received copies of all transcribed data to review independently. This was a safe guard against missteps in analysis. My dissertation committee, particularly my chair, were primary resources at all points in the study.

In addition, I was a member of two on-going GT data analysis groups. The first was a seminar led by Juliet Corbin and Anselm Strauss. The second was a group of four doctoral student, all doing GT. It was to these two groups, especially my student group as we met weekly, that I went for methodological advice, analytic guidance, and response to various levels of analytic product. I also relied upon Juliet Corbin, as the methodologist on my committee, for specific counsel at difficult points in data collection and analysis. Final responsibility and accountability for the grounded theory, however, is mine alone.

Design of the Project

The original study design (see Appendix 1) was conceived directly after my qualifying examination for candidacy. In that exam, it was suggested that I had been immersed too heavily in the positivist paradigm and had focused too much and too quickly for the phenomenon I had argued needed investigation (Kagan, 1991). The narrowness the immersion created is evident in the design and original inclusion criteria. I projected, in part for funding criteria, the full number of participants and their diagnoses. I neglected to explicate the implications of working in the discovery mode of GT and the influence that would have on the evolution of details beyond the basic design I set out.

The discovery mode of GT was mandated by the unexplored character of the phenomenon. The project is cross sectional in design. The sole formal procedure involving participants is a single interview (see Appendix 2). Each interview was accompanied by notes on observation of context, content, and process. The location of the interview was to be convenient to the participant and usually took place in their homes. Interviews were tape recorded if permission was granted. Interviews were recorded, professionally transcribed, corrected, and coded.

The cross sectional structure was a conscious choice. I wanted to picture the process the participants underwent by sampling across a range of diverse experiences rather than following a smaller number across time. But it was also one of pragmatism. I needed to conclude the project in a timely manner (Ammon-Gaberson & Piantinida, 1988). Other sources of data not clearly outlined in the proposal that enriched the design include informal interviews and observations made in my practice and daily activities (Chenitz, 1986) and lay literature on cancer and on old age.

Sample inclusion criteria

The participant inclusion criteria were similarly constructed. My original literature review suggested that the process most common to many elderly would be experienced by those individuals with the most prevalent malignancies (i.e. lung, colon, breast, and prostate cancers). Age was rather arbitrarily assumed to be older than 65 years. I later dissected that assumption with the aid of Cole (1992). In fact, our cultural history and understanding of the change in social roles with old age has created the lower boundary at about the middle of the seventh decade. We have come to associate old age with transitions that tend to occur at about that time in life (e.g. retirement, grand-parenthood, widowhood). Therefore, reliance on the social construction of old age is appropriate to the nature of the study.

Requiring current or recent treatment experience was a pragmatic choice. Treatment was defined as any curative or palliative health care. Health care settings were used as participant enrollment sites for issues of access and convenience. I realized that I would then be selecting individuals who sought assistance from the established health care community and not primarily from other healing professions (e.g. herbalists, acupuncturists) (Cassileth, et al., 1991). That realization in no way implies relative value of health care source. Entry to the sites used to enroll participants was gained through professional connections.

The theoretical sample was then, at the out set, to be composed of individuals age 65 and over, diagnosed with one of the four most common solid tumors. Provisions were made for participant ability and comfort. Participants needed to have grossly intact mental status, speak English fluently, and be able to be interviewed for a minimum period of time (one hour). Representation of gender balance and ethnic diversity was also sought. The intent was to enroll more women than men and include African and Asian Americans and Caucasians. Access to potential participants was gained through entry at the oncology unit of a metropolitan teaching hospital that serves a population largely composed of African Americans, Jews, and Russian immigrants, many of whom are elderly.

Human Research Considerations

Protection of the elderly who were candidates for participation and for those who did participate was given much thought. Approval from the Committee on Human Research, University of California (CHR) was applied for, granted in May 1992, and renewed as required (see Appendix 3). All procedures for informed consent were strictly followed and there were no adverse occurrences. No incentives for participation were offered (Wineman & Durand, 1992). The reward for participation was the opportunity to review the results at the end of the study. Three people asked to review the results and all living participants will be sent an overview at completion. In addition, all participants were sent a hand written thank you note no later than 48 hours after the interview. The note acknowledged the personal contribution the participant had made to the study in keeping with the developmental theoretical perspective that entails completing the life cycle (Wineman & Durand, 1992).

Clinical Nursing Research Liaisons. The recruitment process was designed on the basis of my professional experience to protect potentially vulnerable candidates from unwanted intrusion and confusing approaches (Archbold, 1986). I developed relationships with the nurses who had daily contact with possible participants at each site: first at site (site M), then at its sub-site (site R), and finally at the second site (site V).

I called these nurses clinical nursing research liaisons (CNRL). There were eventually four CNRLs, two at each site. I explained the project to the

CNRLs, gained their support, and provided them with fliers describing the study and listing my phone number (see Appendix 4). The qualities of a good informant were discussed. The potential participant needed to be able to articulate something of her experience, feel well enough to talk, and have some interest in participating. Those who were apathetic, in crisis, or acutely ill were agreed not to be candidates.

The CNRLs then spoke with their patients whom they identified as likely participants. The flier was given to those individuals and the study was explained. The CNRLs drew on their relationships with patients to establish trust in the project (Souder, 1992). My experience before solidifying the CNRL role reveals the importance of trust for participants. I learned in my many attempts, at site M, to approach hospitalized patients with whom I had no relationship that the idea of an interview, even after going home, with a woman they did not know was unappealing to these individuals. To be visited at home for an interview by someone the nurse knew was far more acceptable. Recruitment, from initial contact to interview, was set up to protect the elderly participants and allow them control over the participation process (Souder, 1992).

Working with CNRLs also allowed me to plan follow up for any adverse occurrences in the interviews or problems assessed in participants during the interview. I came to the project with a strong sense of advocacy. I had decided, in advance of data collection, that if a dilemma arose around care for a participant, I would act in favor of facilitating appropriate care, at the cost of jeopardizing an interview. The CNRLs with whom I worked understood this and cooperated fully. We developed ways I could alert them to a patient problem without breaching confidentiality if necessary. Thankfully, it was never necessary.

Difficult moments did, however, arise in the interviews. This was expected, given the emotional nature of the topic. Many participants alternated from jesting conversation to tears. My professional experience has made me comfortable in discussing loss and death. These were the topics usually accompanied by tears. When participants cried, I allowed them time to do so, made appropriate reflections on the emotional content of our conversation, and took my cue from the participant as to when to move on. When appropriate, I would touch the participant to offer comfort. And, for one participant who was in pain throughout the interview but refused to stop or reschedule, I created frequent breaks and offered a light back rub to soothe her.

Pilot Interview

In May, 1992, a pilot interview was performed for several reasons. A pilot interview was necessary to improve my interview skills for, while I had interviewed nurses for a small research project the year before, I had never interviewed chronically ill elderly individuals for research. Additionally, my interview guide had been developed without direct input from elderly individuals. I was comfortable talking with elderly people and using language they understood. Nevertheless I was not confident that I had developed initial questions that would uncover the phenomenon I sought to explore (see Appendix 2).

Fortunately, a former patient, A., had talked with me about the project in January, 1992 and taken a strong interest in it. Participant A. contacted me for reasons of her own, asked about the project, and immediately volunteered to be interviewed. Participant A. was a 72 year old Caucasian woman with a metastatic gynecologic malignancy. She was divorced, lived alone though close to her daughter who was her primary care giver, and was a practicing Buddhist. Our interview was short, about one hour. The data it provided is clearly understandable in light of the findings but was nearly unintelligible at the time. Participant A. supplied complex, high level data and an opportunity to strengthen my interview technique and guide. A. died about four months after our interview without being able to review the findings in which she expressed such interest.

Early Data Collection

From May to July 1992, I recruited subjects at site M weekly. I attended oncology rounds on the inpatient unit and made frequent contact with my CNRL at that site. In June, 1992, the CNRL invited me to present the opportunity for project participation to her cancer support group. I did so and received one response from a 79 year old Caucasian man with esophageal cancer. He became informal participant B. Informal participants are those who, through social rather than research contact, provide information useful to the study (Chenitz, 1986).

Key informal participant B. is a Jew, married, and actively volunteering for several causes. I thanked B. for his response and declined saying that my participant criteria excluded him from eligibility. Participant B. chided me for excluding types of cancer other than the four common solid tumors. Participant B. precipitated the first leap actually linking design and analysis in the project.

I was spurred to rethink the assumption that the common experience was had by those diagnosed with the most prevalent tumor. What A. and B. revealed was that I sought a cancer-specific experience, not a tumor-specific experience. Never did they speak of experience in terms that implied unique features attached to the type of cancer with which they had been diagnosed. Rather experience was discussed in overarching terms of having cancer and being old. The symptoms and side effects were incidental to the larger experience. I discussed the leap with my Dissertation Committee and made application for revision to the CHR to broaden inclusion criteria. Approval was granted July 30, 1992.

Sub-site development. In August 1992, I spoke with one of the primary oncologists at site M. He offered me access to their patients. I then contacted and recruited their chemotherapy nurse who became my CNRL at site R.

During late summer and early autumn, I recruited for potential participants on a weekly basis. Census on the in-patient unit was low and average age was young. All five potential participants I contacted were too ill to be interested in an interview. These three months were characterized by despair at being unable to begin the investigation and unable to project completion.

In early autumn, the CNRL at site R began to provide return on recruitment visits. I received four referrals, all women, who became participants. At the end of the period in which I enrolled these women, I interviewed a man who volunteered to participate after hearing about the study from a family member. In the last three months of 1992, I continued to make frequent visits to the first site without luck, enrolled two more participants recruited from site R, and interviewed one volunteer participant who had heard about the study from another source. In December 1992, I had a pilot participant, a key informal participant, and eight formal participants. Of these, seven were women, three were men, and all were Caucasian. Most were also Jewish.

Theoretical Sampling: Pitfalls and Pragmatics

Theoretical sampling is a purposive means of collecting data for GT in which sampling strategies arise from and evolve with the emerging analysis (Artinian, 1988; Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Sources that will likely provide expansion of categories or necessary comparisons are actively sought (Artinian, 1988; Chenitz & Swanson, 1986). Glaser (1978) posits that theoretical sampling develops increasing theoretical sensitivity to the emerging analysis and hence produces a dense grounded theory. He further distinguishes theoretical sampling from selective sampling (Schatzman & Strauss, 1973). Selective sampling is the use of data sources based on preconceived ideas with which the investigator comes to the study (Schatzman & Strauss, 1973). Conversely, theoretical sampling is described as a strategy that is without preconceived notions, evolving only as the study evolves (Glaser, 1978; Glaser & Strauss, 1967).

Achievement of theoretical sampling as described in Glaser and Strauss' early writing (1967; Glaser, 1978) is somewhat difficult given the realities of the research environment. In fact, Charmaz (1990) points out that Glaser and Strauss (1967) actually assumed that solid professional experience preceded use of GT. This assumption then implies that familiarity with theoretical concerns and pertinent literature also precedes use of GT. The later iteration of GT discussed by Strauss & Corbin (1990) incorporates the logical extension of the assumption of familiarity into theoretical sampling. Theoretical sampling as discussed by Strauss and Corbin (1990) and explored by Charmaz (1990), honed by the realities of access and expedience, was the guide for sampling in this project.

The initial theoretical parameters of age and tumor type were, as I discussed in reference to participant B, quickly re-evaluated to be age and having cancer. I recruited diligently at sites M and R given these realigned parameters until late 1992. Nevertheless, I was able to recruit only two men. After this first phase of data collection, beginning in 1993, the need for men as participants was abundantly clear. A new enrollment site, site V, was accessed at that time. Six men were recruited as participants from this site. However, the average age of the sample began to drift downward as these participants were around age 70. The final participant was recruited on the basis of age (over 80 years old) and sex (female), as six men had been consecutively enrolled to that point. These were the major prospective theoretical sampling decisions.

Other decisions made with regard to collecting and selecting data for analysis were less distinct. These minor decisions generally had to do with returning to data already collected with a new question or coding schemata. This theoretical sampling, or re-sampling, strategy is illuminated by Strauss and Corbin (1990).

Despite careful attention to the theoretical sampling needs of the study, there were individuals that could not be accessed for participation and whose stories are not represented in the findings but of whose existence I am clinically aware. There are elderly individuals whom I excluded because of physical or emotional frailty and there are those who did not exhibit the process I will detail in chapter five. The individuals who participated and provided data selected themselves presumably because they had something to say. Self-selection bias is prominent in interview studies and is the most prominent bias in this study. I set up means to protect prospective participants knowing that it would promote this bias.

In addition, whether by nature of patient census changes or the unapparent nature of the population seen at the enrollment sites, I was unable to recruit Asian Americans and Hispanics, and individuals with head and neck and lung cancers. The CNRLs and I worked together to access these individuals, but the few who appeared to be candidates for participation did not speak English well enough, or were too ill or uninterested. The ramifications of self-selection bias and the absence of information from Asian Americans and Hispanics and individuals with head and neck and lung cancers will be discussed in the final chapter.

Parallel Personal Process

Human science, out of nature and chance, sometimes parallels life (Hill, 1991). So it was for me during the implementation of this project. On October 20, 1992, my favorite aunt and close friend was diagnosed with metastatic melanoma to the brain and lungs. Hers was the one in a million case: no warning, just a seizure when the brain lesion got big enough to cause edema; no primary tumor, just lethal metastatic disease. Barbara was 62 years old, single, healthy, working full time as an investment counselor, and devoted to her cat, Kitty, and her garden. She was initially treated with cranial radiation therapy, but Barbara knew from the beginning that she was likely to die very soon. Despite fatigue from the radiation and the concomitant baldness, Barbara was in great spirits. She did what she wanted and could, spent time with people she wanted to see, and began to wrap up the affairs of her life. She asked me to take care of her and made me promise not to let her suffer.

As autumn wore on I gradually dropped other activities in my life so that I could spend time with Barbara and take care of her whenever she needed me. I did my last participant interview for the calendar year 1992 in early December, and put the study on hold, just as Barbara was beginning to experience profound disability from her disease. We spent much time together during the winter. Barbara was left partially deaf by radiation therapy. Her brain lesion began to grow again and cause memory loss and confusion. In early January, Barbara had a cold that progressed to pneumonia. After a course of antibiotics in the hospital, Barbara told me she wanted to go home if I could arrange care for her there. She wanted no further treatment.

She went home to 24 hour care, a great visiting nurse, a cooperative oncology fellow, her minister, friends, family, and me. Decline was almost imperceptible from my daily perspective. She took up photography again. Kitty was her constant companion. In mid-March, I came in one morning to find Barbara could not breathe. She had air hunger from her pulmonary metastases. I spent most of the day in bed with her because she was really scared for the first time since her experience began.

Together, her nurse and I obtained morphine and oxygen for Barbara. She was comfortable except for one terrible night where her increasing need for morphine nearly outstripped the rate at which I could increase the infusion.

Four days later, after heart rending last rights, Barbara died. It was March 15, just five days short of five months since her diagnosis.

I miss Barbara beyond words. I can barely see the screen for the tears of loss and grief as write this, seven months after her death. But I write not because I cared for and miss her. Barbara gave me a tremendous gift by asking me to take care of her. She allowed me to witness the process of being diagnosed with, treated for, experiencing, and dying from cancer as an young old adult. Being present in her life forced me to do the best nursing I could do while still being her niece and to observe as she embarked on a journey of the self I could only watch and never truly join.

Breaking provider bias. Observing Barbara's journey from beginning to end allowed me to see the data for this study with new perspective. The new perspective arose as the parallel process broke my unconscious health care provider bias (Hill, 1991). Provider bias is what I term the relative state of using the lens of a health care provider, who considered herself to be already sensitive to the experience of cancer, to do GT (Hill, 1991). Caring for Barbara forced that bias away, helping me to see the experience of cancer with the eyes of a family member. I watched as she tried to navigate the physical premises of a major medical center and waited for hours to see physicians who rarely looked her in the eye. I experienced cancer in ways other than the cognitive. I knew cancer through physical burdens, sensory overload, and emotional highs and lows that colored my lens anew.

Breaking through provider bias shows up new aspects of process, behavior, and outcome. It does not, however, mean that I applied Barbara's experience or my experience with her wholesale to the data. I worked extremely hard to maintain distance between my personal and research lives. I treated discrete data from Barbara as informal interview material (Chenitz, 1986). And I stopped analytic work when she became disabled, resuming only after her death. Throughout my experience with Barbara, I was conscious of my obligation to my formal and other informal participants to tell a credible and rigorously discovered grounded theory (Burns, 1988; Chenitz, 1986; Sandelowski, 1988; Swanson, 1986a,b). Barbara helped me to do that by changing and deepening me as investigator and instrument (Field, 1991). For that I am humble and grateful.

Early Analysis

By the time I had enrolled participant nine in early December, 1992, the analysis was in preliminary stages. I had discovered the data all seemed to tell the same story with some variation and much personal detail. I had established, through the direct assistance of Juliet Corbin and Anselm Strauss, that the participants' lives and the relative importance of cancer were crucial. Hence, the question "Tell me about your life right now" became my initial statement in the interview. And I had an open coding list of some 25 prominent codes and countless others which did not hold up to continued comparison. Open coding was done primarily by me with assistance from my dissertation chair.

Identifying the process. I returned to the analysis in late April, 1993. Rereading the data and axial coding to condense the open code list produced a major analytic insight. I tentatively identified a process which I termed 'remaining engaged in living a life mostly lived' (Fagerhaugh, 1986; Glaser, 1978). The first phase of the process was 'redefining the thresholds of living'.

The second phase was 'remaining engaged in living'. The tentative characteristic of this early attempt at selective coding to identify the story is clear in the memo excerpted here (Strauss & Corbin, 1990).

> After months of little paper progress, I have made a reconnection and an analytic leap that I believe incorporates my interviews, clinical hunches, and my experience caring for Aunt B. It was I believe that process that cleaned my lens so that I could see the process my participants were describing more clearly and without the preconception that the diagnosis of cancer was pivotal throughout the entire process. In fact I had missed that there was a process at all. It looked - perhaps because it was one interview - like a snapshot. I didn't trust my informants enough in some way to look closely and see that the story they all told me in many variations was description of a dialogue with the self. Now to describe that from an analytic point of view.

Completing Data Collection

Six of the first eight formal participants enrolled in the project were women. A theoretical sampling decision was made in May, 1993 to access a site which would insure enrollment of men. Participants ten through 15 are men. Most were interviewed at home as the previous eight participants had been.

Two of the men, however, requested to be interviewed at the site. Privacy was assured and these interviews did not not differ appreciably in substance from those conducted in homes. Nevertheless, the addition observation of immediate personal context made to interviews performed in homes was highlighted by its absence in these two interviews. The character of the home and the evidence of daily living patterns appreciably supported interview data.

Data collection proceeded quickly at the second site. By September, 1993, men outnumbered women eight to six. The data and emerging analytic framework were scrutinized for gender differences. Those found were slight and the imbalance was accepted for theoretical discovery purposes. I sought enrollment of one last woman participant in her ninth decade for theoretical confirmation. Reasons for the decision were to equalize the imbalance somewhat, solidify the age range, and confirm the relative unimportance of gender differences. The sub-site was contacted and supplied a participant within a month. Data collection was closed at the end of October, 1993. Two participants, who had expressed earlier interest, were contacted to review the grounded theory for validation and confirmation.

The Final Formal Sample

The final sample consists of four major informal participants, two women and two men (aged 62 to 75 years, one African American, three European Americans) and 15 formal participants. The formal participants were about equally male and female (7/15 women, 8/15 men), largely European Americans (13/15) with two African Americans, both of whom were men, and mostly in their eighth decade of life (mean age = 74 years, with a standard deviation of 4.99 years, and a range from 66 to 85 years). Most lived alone (6/15 were widowed, 2/15 were single and 1/15 was divorced); however 6/15 were married and all but one of these were men. Forty per cent (6/15) reported participating in an organized religion, but 11/15 noted a religious affiliation. Of those with an affiliation, 5/15 were Jewish, 3/15 were Catholic, and 3/15 were Protestant.

Seven types of cancer were diagnosed in the formal participant group. Two participants had two primary cancers and so, the total number of cancers diagnosed is 17. The diagnoses were: breast cancer (4/17), colon cancer (3/17), prostate cancer (1/17), bladder cancer (2/17), ovarian cancer (2/17), renal cell cancer (1/17), lymphoma (any type) (4/17). Three participants had new diagnoses. Five participants described progressive, locally invasive or metastatic disease. Four participants had locally or distantly recurrent cancer after a period of initial remission. And one participant was in remission but had undergone permanent urinary tract diversion to achieve this state. The time since diagnosis varied widely. Participants had been diagnosed three months to 34 years at the time of interview with a median time of two years, a mean time of nearly 6 years, and a standard deviation of about 9 years.

All symptoms reported spontaneously in the interview were noted. From two to ten symptoms were reported and pain, nausea, and fatigue were most common. All informal and formal participants were observed by me to have some functional decline; that is, they were 'an ill group'. At this writing, two of the informal participants and four of the formal participants are dead. All died within a year of the interview and most died within six months of the interview.

Consolidating the Analysis

Selective coding continued from May to October, 1993. The analytic leap to true identification of the story and the core category of integration occurred in early summer. It is seen in this excerpt:

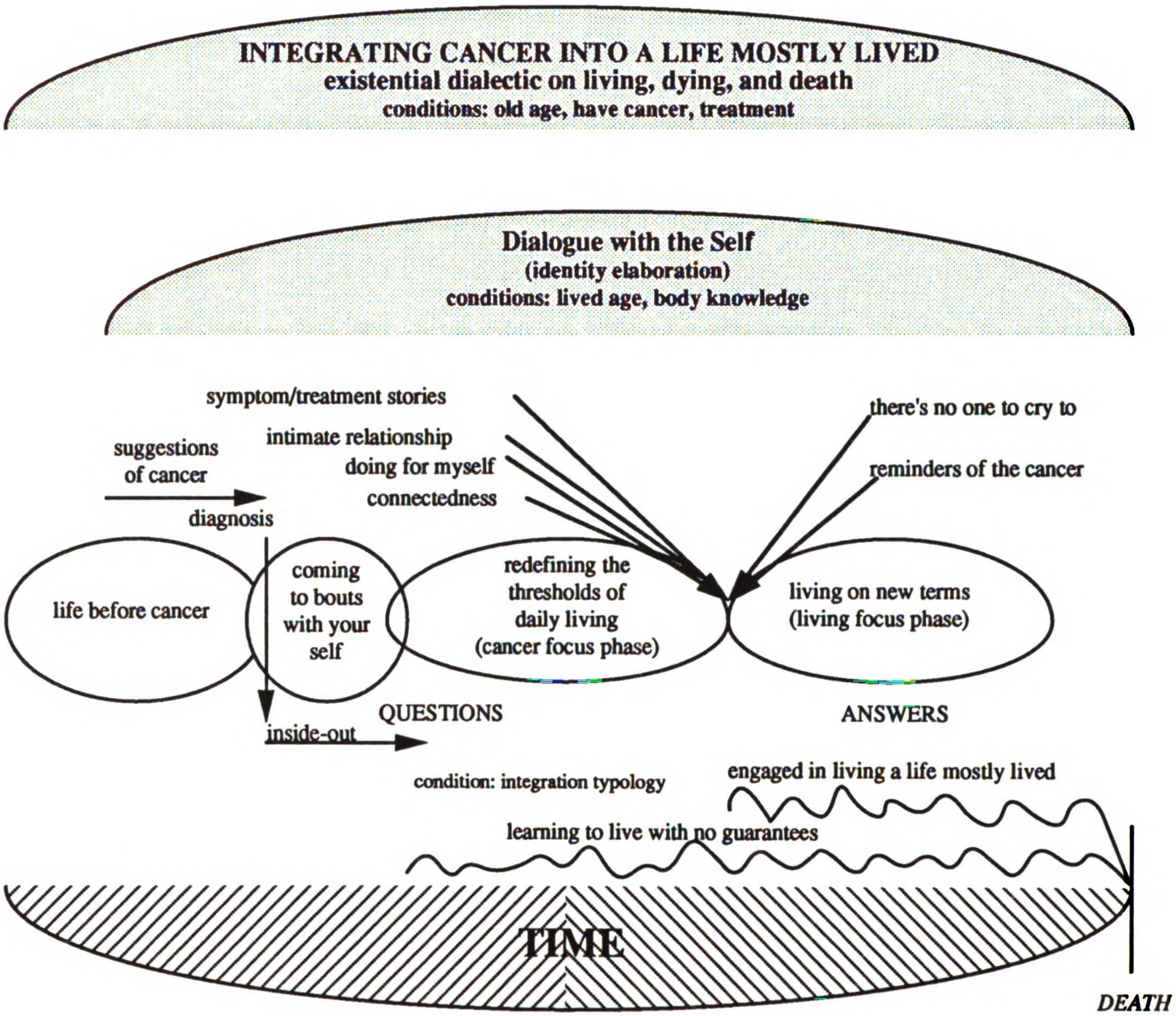
> * I think the central category, the process 'remaining engaged in living a life with no guarantees' is misnamed and misrepresented if the interpretive stance of 'cancer in the context of aging' is fitting. It should be 'integrating cancer into a life mostly lived'. Talks about aging, talks about cancer, alludes to process and range of variation.
>
> * Aha! if 'integrating' is the process, then 'coming to bouts with your self' (3,1,16-17) is the in vivo code for the first phase of the

> process where you are faced with the diagnosis of cancer as yours, something that will play a part in your life.
>
> *Outcome of the process is 'remaining engaged in living a life with no guarantees'.
>
> * Phase two of the process is 'redefining the thresholds of living'; implies cancer and aging set up conditions whereby the level and intensity of engaged living must sometimes be redefined (depends on disruption?).

Later work revealed the process at hand was in fact composed of four and not two phases. The phases are: 'life before cancer', 'coming to bouts with yourself', 'redefining the thresholds of daily living', and 'living on new terms' (see Figure 1).

Detailed dimensionalizing of supporting codes began after the identification of the story to illustrate the story that had been sketched out. All interviews were transcribed and coded at at least one level. During the period of theoretical coding, the analysis was presented to Corbin and Strauss' seminar once and to external groups of nurse researchers three times. Response to the process and the schematic model of it was collected, recorded, and incorporated where appropriate. Numerous informal opportunities for verification and critique were taken to judge fittingness and understanding (Artinian, 1986; Glaser & Strauss, 1967). Aspects of the emerging grounded theory were presented to my student data analysis group, two participants, and lay people. Preliminary critique from the dissertation committee was also elicited. Refinements to enhance understanding and to clarify implications for nursing were made on the basis of the responses gained (Glaser & Strauss, 1967; Strauss & Corbin, 1991).

FIGURE 1


INTEGRATING CANCER INTO A LIFE MOSTLY LIVED
existential dialectic on living, dying, and death
conditions: old age, have cancer, treatment
Dialogue with the Self
(identity elaboration)
conditions: lived age, body knowledge
symptom/treatment stories
intimate relationship
doing for myself
connectedness
suggestions of cancer
diagnosis
there's no one to cry to
reminders of the cancer
life before cancer
coming to bouts with your self
redefining the thresholds of daily living (cancer focus phase)
living on new terms (living focus phase)
QUESTIONS
ANSWERS
inside-out
condition: integration typology
engaged in living a life mostly lived
learning to live with no guarantees
TIME
DEATH

Achieving Saturation. Saturation is the case of having heard the stories of the data repeatedly (Glaser & Strauss, 1967; Strauss & Corbin, 1991). It is a mechanism by which to insure credible, fitting grounded theory (Artinian, 1986; Sandelowski, 1986; Strauss & Corbin, 1991). I struggled with saturation as it is described by GT methodologists and as it presented itself in these data. Have I heard this time and time again and at what level of detail? Saturation was revealed in layers throughout the study.

A pattern of the same basic story emerged early in the first phase of data collection in 1992. I began to hear something along the lines of "I have no real problems but I'd like to talk to you" which turned into slow revelation of serious symptoms and profound change attributed to cancer. A comparison, akin to Taylor's (1983) use of downward social comparison followed. The comparison resulted in a summing up that went "but I really have no problems, I'm much better off than many people I know and I've enjoyed the life I've had". Little did I know at that time that what I was hearing would evolve into the core category, a process called "integrating cancer into a life mostly lived".

Saturation was achieved on the core category and all other major categories, including the philosophical dialectical stance, all conditions, the process phases, and the observable manifestation of the process, by the end of data collection. All participants fit easily into one of the four categories in the integration typology. I cannot, however, be confident that I saw all means of integration in these data. Saturation cannot be assured on this aspect of the process. More than 15 participants and investigation in the emergent mode are needed.

Maintenance of Rigor

Solicitation of critique and verification was the last several means to insure intellectual and analytic rigor in the project (Burns, 1988; Corbin, 1986a; Stern, et al., 1984; Strauss & Corbin, 1990). Throughout the research process, I adhered to the precepts of GT. The means by which rigor was maintained throughout the project and credible findings produced are fourfold. First, I kept written accounts of all research interactions. All formal interviews were followed by observational notes on content, context, and process. Informal data was recorded as it was collected. These accounts include the system of observational, methodological, and theoretical notes in field work proscribed by Schatzman and Strauss (1973). Writing memos to track emerging codes and theoretical ideas was done as described by Corbin (1986b), Glaser (1978), and Strauss and Corbin (1990).

Second, I began to systematically record daily thoughts, ideas, and activities in a formal audit trail diary as described by Lincoln and Guba (1985) (Rodgers & Cowles, 1993). I used the audit trail to pace my use of methodological, theoretical, and data-based literature. I studied the nursing and sociology GT literature as means of being as richly informed about the method as possible. Throughout the project, I paced exposure to new theoretical and scientific literature so as to develop sensitivity within myself as an instrument without impeding the analysis and without altering the process and rigor of the study itself (Glaser, 1978; Sandelowski, 1993; Strauss & Corbin, 1990).

Third, I measured out the study of SI, cultural history, the Life Cycle, and comfort, as well as other less applicable theory, to sensitize myself to new approaches for data collection and analysis. I came to the project with some familiarity with GT, SI, some issues of cultural history, Erikson's Life Cycle, and the meta-concept of comfort. I was careful not to inhibit analysis with excessive reliance on these models. The need for fitness, consistency, and neutrality demanded that I produce concepts grounded in the data and not borrow them from existing theory (Charmaz, 1990; Glaser, 1978).

Data-based literature was used to maintain theoretical sensitivity throughout data collection and analysis in a manner congruent with that described by Corbin and Strauss (1990). I consciously paced exposure to data-based literature to preserve the originality of my coding (Glaser, 1978). A concept was only held up to comparison with something from the literature after it had been fully coded and had been used in coding a new interview or two. For example, the partial congruence of Taylor's (1983) idea of downward social comparison with my notion of "a view from the inside", the attitude that having cancer is easier than you imagined because you perceive that you are doing better than other people with cancer, was not established until after coding and saturation had established "a view from the inside" as a salient aspect of the process. The bulk of literature used as comparison information was read closely at the end of analysis because many of the categories were not fully developed until the last three months of the project.

And fourth, I participated in the GT research community (Glaser, 1978). I allowed my work to be scrutinized by others familiar with the method. The grounded theory discussed in the next chapter emerged in a rich, rigorous research environment.

CHAPTER V

"Integrating Cancer Into a Life Mostly Lived"

"Integrating cancer into a life mostly lived" is a process revealed through constant comparative analysis of the data provided by the participants in this project (Glaser, 1978; Strauss & Corbin, 1991). It captures how these elderly individuals dealt with and experienced cancer through symptoms, treatment, and interactions in daily living. The process of "integrating cancer into a life mostly lived" is schematically represented in the model in Figure 2 which provides an orientation to the discussion of the components of the process as they are discussed in this chapter. To provide a background to this discussion, an overview of the major concepts is presented first followed by a description of how these concepts will be addressed in the remainder of the chapter.

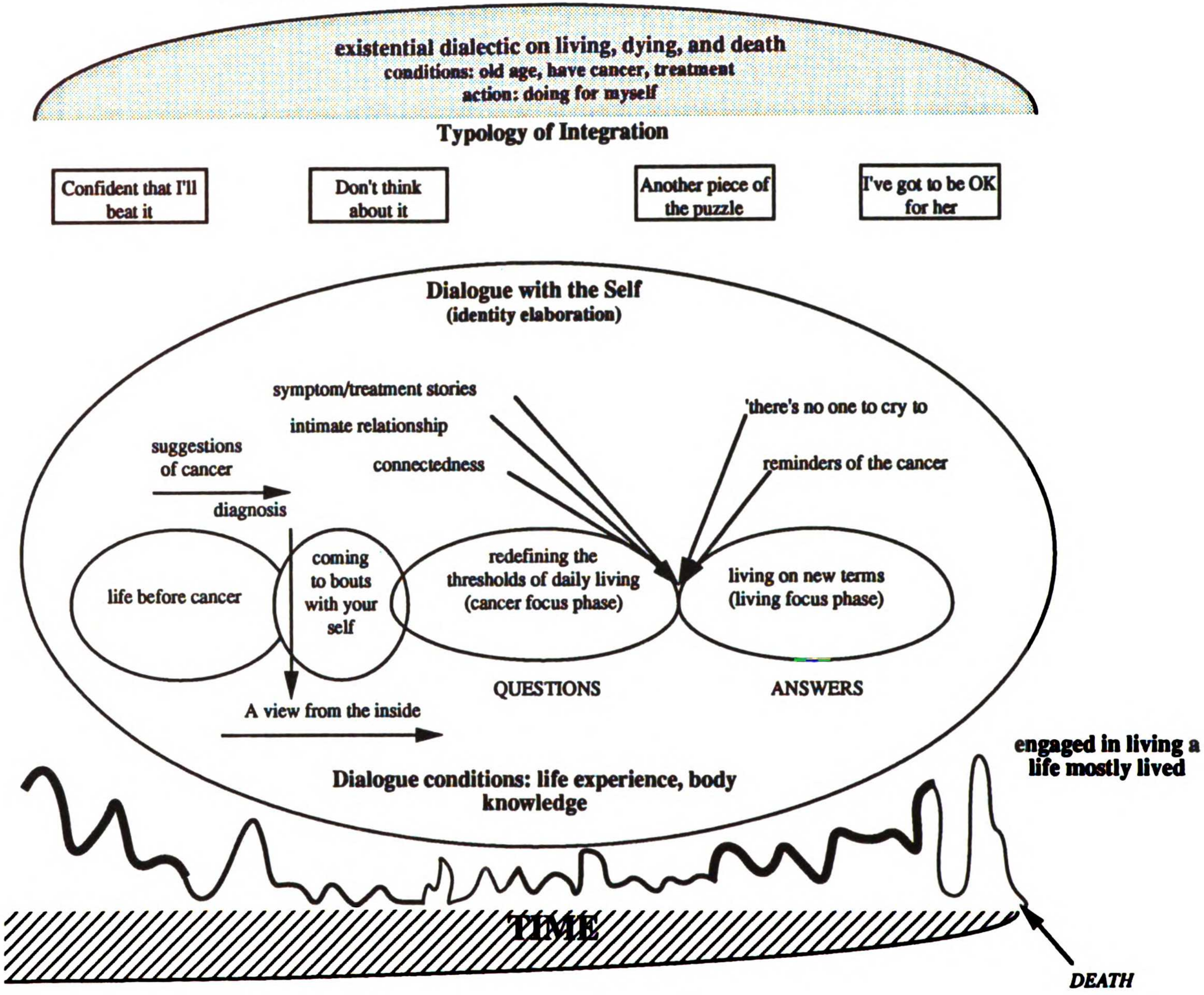
Overview of Major Concepts

There are five components within the model that incorporate the core concept and nine major concepts. These nine concepts comprise the components of the process of "integrating cancer into a life mostly lived". The conditions for the process are being old, having cancer, and undergoing treatment. The over-riding conceptualization (i. e. the core concept) of the process is "integrating cancer into a life mostly lived". This conceptualization captures the outcome of the existential dialectic on living, dying, and death and the internal process of the dialogue with the self over time under the conditions of the entire process. The existential dialectic represents the search for the larger meanings attached to one's life.

The internal process component, represented in the center of the model (see figure 2) is the dialogue with the self. This dialogue is about the meaning of

FIGURE 2

INTEGRATING CANCER INTO A LIFE MOSTLY LIVED



old age and cancer for a particular individual's life and occurs as the individual moves through the phases of "life before cancer", "coming to bouts with yourself", "redefining the thresholds of daily living", and "living on new terms". The phases after "life before cancer" are non-linear and interactive and are conditioned by life experience and body knowledge. Life experience and body knowledge come from experiences during the phase "life before cancer", which comprises the bulk of the "life mostly lived".

The external, or observable part of the process is "engaged in living a life mostly lived", represented by the randomly wavy line. This observable behavior is a consequence of the existential dialectic and the internal dialogue with the self in interaction with the larger context in which the elder with cancer lives. The mode of integration seen in a particular individual is described conceptually in the typology of integration that is found directly under the existential dialogue in the model. These modes of integration bridge the internal and external aspects of the process of integration and shape the questions and answers of the dialogue with the self and the behavior of "engaged in living a life mostly lived" given the condition of having cancer and receiving often arduous Western medical treatment. Finally, the existential dialectic is mirrored by time, the concept that orders the other pieces of the process of "integrating".

Statement of Purpose

The purpose of this chapter is to describe the process, just highlighted, in several ways. The description begins with the core concept of "integrating cancer into a life mostly lived". The existential dialectic on living, dying, and death is described next. The typology of integration that guides the process follows. The observable manifestation of the process, "remaining engaged in living a life mostly lived" is detailed next to allow immediate access, for the reader, to the picture these people present. Time is discussed as the processual substrate on which "integrating cancer into a life mostly lived" exists. Lastly, the core of the model, "the dialogue with the self" is presented.

The discussion of the major components of the model is followed by a review of the schematic and participant paradigms. Participant paradigms are used to tie the pieces of the process together by employing the modes of integration from the typology to frame the stories of selected participants. The participants selected exemplify the ways in which the mode of integration differentially shapes the internal and external aspects of the process (see Appendix 5, figures 2a-d).

The Process of "Integrating Cancer Into a Life Mostly Lived"

The major conditions for the core concept, which is the process of "integrating cancer into a life mostly lived", are old chronological age, having cancer, and receiving some form of Western medical treatment. These conditions were characteristic of all participants in the study. The process is about living with and managing rather than waging war on cancer: "I think you've just got to live with it. No use . . . I don't think there's no use making a big to-do about it." (11,15,534-6)

"Integrating cancer into a life mostly lived" requires a dialogue with the self in the context of old age given cancer and cancer treatment. "A life mostly lived" is about having had most of the opportunities of a lifetime fulfilled: "At 77 -- I'll be 78 in October -- I'm on my way. I've seen a good part of what life's all about." and "Oh, I think it (having cancer) would be much more difficult. It would be much more difficult (if one was young). <In what ways?> Well, because you have life ahead of you. You have experienced things, at my age, and I think you can cope with it better." (3,5,175-80) "A life mostly lived" is also a life with accumulated losses of capacity, function, and relationships. A participant describes the impact of declining vision on her need for assistance:

> "She's . . . I like her to come earlier because I like to take my shower before I go (to the doctor), and I like to have somebody here so I don't fall in the tub, because I do -- I'm . . . uh . . . I . . . don't have the vision in my left eye. And with the steam and then . . . at my age I could fall. And the last thing in the world I want is my hip broken." (7,31,1243-50)

These losses are summed up, in understatement, by a participant who has two cancers, a paralyzed arm, and had lost four family members to cancer: ". . . as we get older, we all have our own little problems, whether it's your eyes or your hips or your whatever." (8,5,178-80)

The overarching mediating conditions to which variation among individuals in the process is ascribed are characteristics of the self and one's social environment. They are: gender, ethnicity, socio-economic status, and the personal meaning attached to being old and having cancer. The process type is psychological, in that it occurs largely internally on emotional and cognitive levels (Glaser, 1978). This is a process that involves the self and understanding of one's self. It is a process which takes place within the individual. In terms of SI, partaking of the process, then, indirectly influences interaction with others in that it shapes the self and meaning an individual attaches to others with whom she interacts (Blumer, 1969).

The 'words' of the self-dialogue are composed of questions about the meaning, action, and consequences of being old and having cancer at that particular time. Questions seem to take the form of:

* what does this mean for me?

* for the ones I love?

* for my expectations about the remainder of my life?

* what am I willing to give up now and what is currently not negotiable about the way I live my daily life?

The questions of the self posed here arise from the meaning attached to identity rather than of identity itself. They generally ask "what does this mean for me?" rather than "who am I?". These questions comprise an identity elaboration, as opposed to the common notion of an identity crisis. The threat to self discussed by Lynam (1990) with regard to the response of a sample of younger individuals with cancer to their diagnoses seems too confrontational to describe the tenor of these data. The participants in the current project show no evidence of personally participating in the "War on Cancer" (Patterson, 1987). A participant displays a typically accepting attitude about his diagnosis and prognosis:

> "Well, there wasn't much I could do about it (having cancer). So I ... they came and asked me if I'd go with their treatment and they told me it's a 50% chance. I said, I'll take 50% on anything. I'll take it. So I ... I took it. And it hasn't bothered me that much really." (11,6,196-202)

Most broadly, then, "integrating cancer into a life mostly lived" is about the psychological work of responding to having cancer when one is old. Cancer is integrated into an existing life and into patterns of daily living. That life has a long history and a recognized end in mortality. Cancer does not take over the life or sit in opposition to it. Rather, in this process, cancer is one of several losses in health, function, or both, that must be included in daily living.

The findings are also in contrast to the analysis of data from adolescents completing cancer therapy offered by Weekes and Kagan (in press). Weekes and Kagan (in press) suggest that adolescents saw cancer as the central focus of their lives during therapy and as invading every aspect of their lives as long as treatment continues.

The Existential Dialectic on Living, Dying, and Death

A philosophical dialectic is apparently essential to the internal and external components of the process. I use the word 'dialectic' to indicate a search for the personal truth about the meaning and value of one's life and living in relation to human life on an existential level. This is akin to the adaptive mode posited by Erikson (1982) in his eighth stage of the Life Cycle. All the participants unwaveringly espoused the same dialectic. It is a ongoing valuing of living, dying, and death.

The dialectic is specific and involves sorting out the conditions under which one will not live and deciding above what thresholds one is unwilling to put up with discomfort and disruption. The specificity appears to be hinged upon "a life mostly lived" and the notion that one has done most of the living and seen most of one's opportunities. The condition of the dialectic is one's proximate, possibly less uncertain death. This proximate death seems to be a product of the combination of old age and having cancer: "You know, I take it as it comes, and . . . I'm 70 and I've lived a good life, so, you know, I'm not bitter about anything." (5,4,147-50)

Living is valued when it has 'quality'. One participant drew a painful contrast between the deaths of her two sisters from cancer and the quality of living at hand in each:

> "She (one sister) was living, up until that . . . that night. She died that night. And it was such a surprise -- not a surprise, but we didn't . . . I had spent the whole day with her and had dinner with her. My older sister (the other

> sister), unfortunately, was in the hospital and in a great deal of pain, a great deal of pain." (8,21,870-6)

When living no longer has quality, death is preferable. Death itself is not the concern: "I really and truly don't think about death. But it isn't a worry . . . at all." (8,30,1222-4) Data offered by the participants indicated that hanging on to life without living is dying. Dying is the human process, both physiological and emotional. Death is the physiological event. Differentiating between the two is the concern of the philosophical dialectic seen in the participants' data.

Dying involves giving up and not 'doing for myself' to the extent one is able. A participant put it this way: "If I just sit down, you know . . . just sit there . . . I would get sick . . . or worse." (11,10,362-4) It involves fears of incapacity and dependence. Dying was universally unacceptable to all participants. They avoided it by remaining "engaged in living a life mostly lived", through the action of "doing for myself", to the extent each was able. Living to the point of death was the goal for all. A participant with a new diagnosis of cancer and weekly treatment expressed this way: "I don't care if I die in my boots. You know what I mean . . . Because it's no good to hold you back . . . keep going, keep active. Yeah, like that. Because you're the other way, you go down hill fast." (15, 489-96)

The dialectical nature arises out the interaction between the understanding of oneself as old with an accepted mortality and the addition of cancer. One participant described the idea of her old age this way: "And you have a sense of knowing . . . without the cancer . . . I'm 80 years old . . . I've had a sense for a long time, even though I come from a long-lived family, I've had a sense for a long time that my days are numbered." (16,12,538-43) On the highest plane of human existence, the dialogue involves a continual refining of one's understanding of self in relation to mortality and a completed life. This is the existential dialectic that is necessary to and part of the process at hand. "Integrating cancer" would not be the same process or be particular to the elderly without the dialectic and the resultant dialogue with the self that is the heart of "integrating cancer into a life mostly lived".

Variations on "Integrating"

"Integrating" is a means of responding to and experiencing cancer in old age. It is fitting cancer into an already established life through an evaluation and elaboration of the self. Individuals who integrate cancer in old age are making room and shifting ideas and behaviors to accommodate cancer. They do not make a "career" of cancer as younger individuals may with cancer (Conrad, 1987). This conceptualization of "integrating cancer" is akin to Kagawa-Singer's (1993) core category of self-integrity in a reconceptualization of health in living with cancer. It is also similar to biographical accommodation described by Corbin and Strauss (1987), and is in some ways parallel to the story of normalization in response to living with a chronic illness reported by Robinson (1993). "Integrating" does not, however, connote the dichotomy that normal with its antonym, abnormal, suggests. Rather, "integrating" suggests a range of variation.

The Typology of Integration

There are types of integration, each with its own primary property of intensity. Integrating does not take one form, existing as a continuum in whatever form it takes along some dimensions. Rather four types are seen in these data, each with its own range of variation. The types are: "confident that

I'll beat it", "don't think about it", "another piece of the puzzle", and "I've got to be OK for her".

"Integration" conditions. The conditions for integration, regardless of type, are: "life experience" and "body knowledge" (which are the product of "life before cancer" and the conditions for the dialogue); the nature of cancer and its treatment, current health and social problems; and a current intimate relationship (Here and throughout, I use 'intimate relationship' which encompasses spousal or partner relationships without regard to social acceptability or legal standing).

"Integration" properties. Intensity, also regardless of type, is the degree to which integration is achieved and individuals vary in this sense. It ranges from strong to weak yet no one in the participant group exhibited evidence of externalizing or objectifying cancer so that there was no intensity of integration whatsoever. Cancer was a part of both self and daily living for all participants, but it varied with time and the conditions of a particular life. This characteristic of variation precipitates the process itself. The process would be illogical without the quality of varying but never absent integration. The word "integration" was chosen for its quality of action, as opposed to "integrated" which does not connote action or the possibility of variation.

"Confident That I'll Beat It" Type

"Confident that I'll beat it" is about maintaining control over one's life toward the aim of not letting it be overtaken by cancer. Participants who exhibit this integration type have confidence that they will remain 'on top'. They also, however, accept their own mortality. Beating it is generally not about cure. It is about living the life one desires to live given current conditions. If current conditions are unfavorable, unchanging, and untenable for a particular individual, "confident that I'll beat it" says death is preferable to giving up to the cancer.

Sub-types of "confident that I'll beat it". There are two sub-types of "confident that I'll beat it". The first is "good doctors, good medicine". These individuals have confidence that the people who are treating them are well-trained and using the best available treatments. The combination offers the security of knowing one is using the best available means to control cancer. This leads to an inner understanding that one has the best possible chance to continue living with cancer. A participant with recurrent breast cancer articulates this stance and the role of life long patterns in the following passage:

> "They can't really understand why someone -- especially when I had the metastasis to my liver -- they were all wailing and down in the dumps. And I said . . . what difference does it make? I said, I'm going to handle it and I'll beat it. I have good doctors; I'm getting good care; I'm doing what they say, except for smoking -- which I still haven't given up -- and they've just given up on me. They say, well. . . I told them . . . I said . . . the only vice I have -- at least let me enjoy that. I just figure I'm going to beat it and that's it. <Have you always been that way in the rest of your life?> Always. Yeah. I had a hysterectomy in '83. And I've always -- as long -- I go to the doctor and I have an opinion that they know what they're doing, and there's nothing else I can do anyway. And if I'm going to sit and weep into my coffee or whatever, it's not going to make me feel any better; in fact, I'll feel worse. So that, the only thing that's changed in my life is the fact that I can't walk as much and I can't do several -- you know, a lot of things that I used to do, because I don't have the stamina. But outside of that, my life hasn't changed." (2,3,97-125).

Only once or twice were cure or survivorship mentioned. A participant who spoke of cure lived daily under nearly intolerable conditions. He was one of the youngest participants and lived with chronic major mental illness which seemed to limit his insight, and dangerous living conditions. He had some difficulty with the philosophical dialectic, that is, his expression of it was at the less intense end of the intensity dimension. He was barely able to speak of death in the face of on-going auditory hallucinations:

> "Well it (cancer) will kill you if you don't treat it in time. If you catch it early and treat it in time, it's cured. I just hope they got it all. They said they suspect there's a few cells floating around in the bloodstream that they want to kill with chemotherapy. But they believe they got it all in the main surgery. But if you don't get it all, it can be a very worrisome, very frightening disease. <So you feel pretty confident, do you? Sounds good.> Pretty confident that they did a good job." (10,8,268-80)

This participant lives under extremes of the conditions for integration and the philosophical dialectic. He is a young elder, had cancer diagnosed only several weeks before the interview, and had a limited fund of "life experience" and "body knowledge" on which he could draw because of his serious mental illness. He spoke only briefly of cure and, yet, his words reveal his situation. Observation of his living situation and description of his activities shows the low intensity with which he can engage in living his life. Nonetheless, he was "engaged in living" on terms he defined.

Talk of surviving "as the only thing" was also mentioned by another participant. She placed it in the contradictory light of discussing what were unacceptable conditions under which to live with cancer and under which it would be better to be dead. This participant had seen her son die of cancer and found the sort of pain he suffered to be absolutely unacceptable.

Control over daily living choices was the objective of "good doctors, good medicine". Almost paradoxically, these individuals could incorporate frequent or arduous treatment and symptoms attributed to treatment into patterns of daily living. They seemed to be more flexible in daily living because of the confidence medical treatment inspired.

A less common variant of "confident that I'll beat it" is "Jesus is my doctor". This pattern of integration hinges on an all encompassing belief in a personally active Christian God. That belief provides the confidence that living will take precedence over a cancer-filled life in God's greater life plan for that individual.

> "And of course I don't want to espouse too much religion, but I've told every doctor in this hospital that's ever touched me, that I hope they don't think they're doing it on their own because the greatest physician in the world has ever known is Jesus Christ, and He is guiding what they're doing, as far as I'm concerned. He's my healer, He's my physician, he's my savior. And I just have to . . . believe that He said, ask anything of me in faith and it will be done. So I . . . it will be done." (14,3,132-143)

As with those who drew confidence from "good doctors, good medicine", those who said "Jesus is my doctor" aimed for some control in choices around daily living. However, choice was couched in the language of faith. This way of integrating cancer appeared to offer similar flexibility in incorporating evidence of cancer into their lives. New events were seen as part of God's larger plan and therefore had immediate acceptance.

"Don't Think About It" Type

A more common way of integrating cancer into a life mostly lived was "don't think about it". In "don't think about it" cancer is acknowledged as a part of one's life, but it is given low priority in relation to other issues in daily living. "And I don't have any worries about my cancer. I give it very little thought. And I've had so much other things on my mind (laughs) . . . so I haven't been bothered about that. And it's only a trifle." (7,5, 195-8). So said one of the oldest, widowed participants despite that she had been struggling with faulty urostomy bags for several days before the interview. The issue of thinking or not thinking about cancer is similar to Lev's (1992) conceptual map of strategies used in adapting to cancer treatment. In the map, thinking or not thinking about cancer guides adaptation strategies.

Individuals who integrate cancer with don't think about it are not denying the cancer or avoiding symptoms or other issues attached to it. On the contrary, they fully acknowledge cancer and its relative importance in their lives. This manner of integration underscores the notion that aging may hold problems of far greater import and impact for individuals. For the participant quoted above, her greatest fear was a broken hip not cancer.

"Another Piece of the Puzzle" Type

"Another piece of the puzzle" is almost the reverse of don't think about it. For some individuals, aging supplies or exacerbates a long list of health and social problems. Here cancer competes for priority in every day living. "I go from day to day and some days I feel worse and just . . . I don't know . . . I've been used to feeling bad for a long time, so it didn't hurt me so much this time". (15,207-10). Cancer fits right in such lives. It is just one more thing that brings on discomfort and limits function. Cancer is just one more thing to manage. These individuals seemed almost weary or resigned and played down the influence of cancer on their daily lives more than others did.

"I've Got to be OK For Her" Type

The fourth way of integrating cancer is seen only among married men and bespeakes the power of an intimate relationship. A participant summed up "I've got to be OK for her":

> "Again, as I say, I was more fretful about the situation as it affected her than how it affected me. I didn't fear it in the same sense. I'm more concerned about her final years than I am mine, you see. We've been

> together for . . . '39 . . . We've been married since '45, but we've been together since '39. So we've known each other for almost 55 years". (13,21,959-67)

Years of a strong, intimate relationship in which the man was often responsible for certain aspects of function for the couple (e.g. driving an automobile) appeared to create a protective, altruistic atmosphere. What keeps him going is his concern for her. Unlike the other types of integration, "I've got to be OK for her" is heavily reliant on gender and the definition of self in relation to an intimate relationship. The other types depended more on "life experience" and patterns of handling earlier problems. Lessened capacity to accept declining function, especially when it involved things his partner could not easily take over, characterized this type of integration.

Engaged in Living a Life Mostly Lived

"Integrating cancer into a life mostly lived" is a process more easily approached from the outside, through description of the observable manifestation of the dialogue, than from the inside, through the 'words' of the dialogue in the processual phases. The behavioral outcome of integrating is "engaged in living a life mostly lived". It is what the generalized other observes the person who is going through the process to be. The specific behaviors are shaped by the type, or mode, of integration. The "engagement" of someone who is of the "confident that I'll beat it" type looks different behaviorally than that of an individual of "another piece of the puzzle" type.

Elderly individuals who are "integrating cancer" are engaged in living in a manner that represents the consequence of the philosophical dialectic and the inner 'words' of the dialogue. The engagement is experienced at the immediate level of tasks and activities in daily living and at the existential level that is the manifestation of the dialectic on living, dying, and death. Daily living is fluid and changing, depending on changing conditions: "Learning to live with not having guarantees. And I think that's part of it. You know, having to make decisions with no guarantees of how it's going to work out." (9,17,740-3).

The action of "doing for myself". Engagement is "doing for myself" in a manner defined by the individuals themselves: "I mean, what you're capable of, you do, and the rest of it can wait until another day." (2,9,345-7) Therefore, engagement is not the success of usual and successful aging (Rowe & Kahn, 1987). Engagement is what the individual decides is how she can and wants to live. It is, therefore, the manifestation of the philosophical dialectic on living, dying, and death. The participant who made the following statement has been chronically mentally ill for decades and lives in a single room occupancy public housing apartment in one of the most dangerous sections of the city: "Well, my social life has been very slow, I haven't -- not that I don't want to . . . it's just that I'm not able to. It's a chore. But I'm improving. I talk to people at the bar on the corner. Bill, Woody, Gloria . . . Ralph . . ." (10, 11-12, 396-401.

Conditions of "engagement". The conditions that influence engagement are those of the individual's capacities, with decline in them attributed to age, cancer, and other health problems. Additionally, there are conditions of immediate context including ability for "doing for myself", living situation, and socio-economic status. As one participant noted: "I find I don't have . . . I don't have the desire to run around the block two or three times on a straight go, but I can move about, I mean, I still drive. I still get about. We still go out. So I'm remaining as active as I can". (13,4,168-73).

Furthermore, engagement is conditional on the philosophical dialectic and personal meaning attached to one's personal valuing of living, dying, and death (e.g. belief in an afterlife, desire to close certain aspects of one's life). For example, a participant expressed his view of death, made sanguine by his belief in God, by noting: "When He pulls my string up there, I'll go." (11,15,551) The contextual and philosophical conditions create an intensity of engagement that then varies with the phase of the dialogue or internal process. The varying intensity in engagement, especially in shifts between the cancer and living focus phases (discussed later in this chapter), accounts for variation between and within individuals in the observable elements of "integrating cancer into a life mostly lived".

Time

Time structures the participants' stories that reveal the process of "integrating cancer into a life mostly lived". Time organizes participants description of daily living. These are functions of time that are also discussed by Richardson (1990) in relation to human narrative. Time is difficult to adequately describe in relation to "integrating cancer into a life mostly lived". It is the processual substrate in that it orders the process. Data relayed by the participants is generally in the form of stories which have the temporal order of a beginning, a middle, and an end. Hence, the participants' stories and the process could not be described without time. Time appears in the data both in linear, chronological fashion and in non-linear, narrative fashion.

The data suggest that perception of time and the internal process influence each other. Discomfort and disruption from symptoms or unexpected treatment (what will later be discussed as "reminders of cancer") protract time. Managed disruption smooths the perceived temporal flow.

Dialogue with the Self

The internal process, "dialogue with the self", occurs in four phases: "life before cancer"; the entry phase of "coming to bouts with yourself" and its diagnostic co-process; "redefining the thresholds of daily living" which is the cancer focus phase; and "living on new terms" , the living focus phase. Each of the phases is characterized by its own set of specific conditions, behaviors, and corresponding intensity of engagement.

Life Before Cancer

"Life before cancer" is the phase that precedes cancer and consequently provides the conditions essential to the dialogue. This phase encompasses the two conditions, "life experience" and "body knowledge",. Previous patterns of daily living become emblematic of "life before cancer" because once cancer is diagnosed and life is changed, "life before cancer" is just that, permanently relegated to the past. "Life experience" and "body knowledge" are distilled from those patterns and events and become the supporting conditions for "integrating cancer". It is also likely that the integration types are based, in some way, in "life before cancer".

The participants all freely spoke of "life before cancer". In the stories they told they described the people they knew themselves to be. I have labelled this simply "self-definition". "Life before cancer" and "self-definition" are congruent with Erikson's (1982) conception of the final psychosocial stage of life. It is also echoed in Kaufman's (1986) discussion of self-definition through themes. She posits that: "In the description of their lives, people create themes -- cognitive areas of meaning with symbolic force -- which explain, unify, and give substance to their perceptions of who they are and how they see themselves participating in social life." (Kaufman, 1986, p. 25) So it was throughout the data for the current project.

Many participants discussed themselves in relation to me, as their audience. I, as a much younger person, was the beneficiary of their accumulated knowledge: "How old are you? <30> "Yeah. Well, just enjoy everything, because it's such a wonderful time. My girls are older than you. My . . . Gail just had a 50th". In addition, the participants' altruism seemed further motivated given that they knew I would be distilling their stories into information that would help others and disseminating it. There seemed to be a consistent desire, at varying levels, to make a contribution. One participant with no children noted: "The end of . . . you know . . . it's the generations . . . there's nobody in either -- let's see, it's my generation where the lineage went out. And that makes it more important to contribute something." (9,39,1742-7)

Self-definition of "life before cancer". Participants defined themselves, partly as a response to the condition of having cancer, in terms of the way they had always been in their lives. They detailed salient events, behaviors and feelings they saw as characterizing their current selves. A participant who died about eight weeks after the interview spoke of returning to her daily activities after the major surgery that confirmed her cancer:

> "As soon as I could -- I also have a part-time job on Sundays for five hours. I work (laughs) . . . everybody laughs . . . I work in the office at S____ Memorial Chapel doing routine office work and the most important thing is answering the telephones, because the men who are there on Sunday, the directors are busy handling cases. And very often there is service, and so . . . in fact, I had worked there. . . after my

> husband died I went to work there for almost a year, two days a week. And that was an eight hour . . . a seven hour day. And . . . uhm . . . I . . it sort of helped me to put things into perspective -- his death. It's more. . . I mean, your parents, you know, can go. But when it's your husband, it's different. And so . . . and it helped me put his . . . and my own into perspective. And hopefully it has helped. And I go there on Sundays. I work from nine until two, and then I leave, and if I want to do something on my own, I can. And they've been so great about it. They all say, we need you . . . and . . . we appreciate that you come in on Sunday. They can't get anybody to work on Sunday." (4,5,191-216)

The same participant led from her work and death into religion in defining her self:

> "And then the rest of the week: Thursday is hair day . . . and I doce . . . I'm a docent at Temple E_____ . . once a month, and also co-chair of the docent committee . . . which takes time at home. . . setting up. And . . . uh . . .I don't know what else. And I'm involved in the sisterhood there. And, you know, I mean it's like that. <Yes. It's a great temple > Attending services . . . I've been involved in Temple E_____ since I was in the fourth grade. I went to Sunday School, I was confirmed, and I worked there for 15 years. I was secretary to one of the rabbis and the secretary of the religious school. So my affiliation there has been almost life long" (4,6,225-48)

Another participant with recurrent cancer who had recently had an iatrogenic brush with death discussed her increasingly comfortable acceptance of her own mortality in relation to growing old and changing some life patterns:

> "It feels very good (to feel comfortable with your own death). But what felt even better was not playing the little death dance of presenting yourself as something that would be the least burdensome or the least onerous or the least guilt-laden, or whatever it would be -- trying to out think your kids and what their moods or wants were. So that was . . . that was dropping a lot of baggage -- a lot of unusable baggage. See, growing old . . .without this experience . . .is partly that (shedding baggage), anyway. It's a lonely experience because you're constantly dropping the emotional baggage that you don't really want to carry with you, but you thought it wasn't nice (to drop it). You maintain a friendship with a friend . . . I never really cared for . . .but the friend was crazy for you and so attached to you that you don't want to hurt her feelings, so you spend time with that friend and not the friend you want to be with. And you spend time doing for that friend because it's so appreciated and so lavish, when it's not what you want to give. And, as

> you grow old, regardless of this, you begin to drop some of that baggage. You don't have as much energy to attend to so many stories as you had before. And you drop that and it feels a little like death. It's very depressing, because it feels as if, by giving up that friend, you're giving up that thing that you did. Maybe you were involved in a project, like teaching literacy, which I never really enjoyed teaching, so why should I be doing something I don't enjoy. I'm going to drop it -- which in earlier years you couldn't do -- your conscience wouldn't let you do it. You wouldn't be a good person; you wouldn't be a nice person. You wouldn't be a useful person if you did that kind of thing. So . . . it comes under the heading of being more self-centered and more selfish, but it's perceived initially as a kind of death and it's depressing. I t could be -- I've often wondered about it -- that perhaps you can do it to someone else and someone else can do it to you, and that may be what feels like death about it. <Oh I see. Someone can leave you . . . as you left them?> That's right." (16,10435-86)

In explaining an emotional piece of her aging, the participant reveals the fluid nature of the self. These who are living the process are people with complex, established, but not static lives.

"Life Experience" and "Body Knowledge"

The consequences of self-definition in moving from "life before cancer" to one with cancer are an acknowledgement of "life experience" and "body knowledge". The acknowledgement may not entirely motivated by having cancer, but also by aging itself. "Life experience" and "body knowledge" become the conditions for the remaining phases of the self dialogue.

The conditions of "life experience" and "body knowledge" are both brought to bear on cancer through the dialogue and are, at the same time, inexorably changed by having cancer. "Life experience" is the cumulative product of living, until you can be labelled elderly, that is reflected in the self. It encompasses the trial and errors, the knowledge and the savvy, and the wisdom of being the person one is after living most of a life. "Body knowledge" is the specific knowledge that comes of living a life in the same body. It involves knowing patterns of physical capacity, weaknesses, and discomforts, and recognizing loss with aging and illness. Both of these concepts, like the others that comprise the process, vary greatly given the heterogeneous "life experiences" of current elderly cohorts.

"Life experience" is usually discussed instrumentally and not directly, unlike the "self-definition" of "life before cancer". A participant who was in the process of writing his memoirs while trying to handle two primary cancers started his interview in this way:

> "Well, to put it into a very succinct way: At the age of 77, one looks at life differently than a person such as your age, you know. Both my wife and I have participated in quite a bit of activity during the course of our time, and both of us recognize things for what they are." (13,1,4-10)

Another participant, who is in her 80s, identified her life experience in a very succinct comparison with a family member:

> "She's 34. And . . . she likes to give advice. But she's had such little experience, and like . . . I always said, well, you don't know who you're talking to, because you don't know my background. You know, what I've been through." (7,34,1374-79)

"Life experience" has an established core, continues to develop through daily living, and is employed in a flexible way to shape daily living. It becomes a recursive, reflexive entity. This is seen in the way "life experience" informs self-definition in "life before cancer". A participant alluded to the nature of "life experience" rather humorously: "I think, when you get older, you get up in years, you don't get as hysterical about things, and . . . and hysteria never accomplishes anything. Your attitude is more . . . becomes more refined . . . and you think things out." (14,16,702-7) It is evident too in the recursive relationship between "life experience" and philosophical dialectic. A similar emotion, more sharply articulated, is heard in the first stanzas of a poem, "How could I not be among you?" by Rosenthal (1973), a young man with ultimately terminal leukemia. The contrast offered by the innermost thoughts of a young adult with data from participants in this study is remarkable:

> "Though you may find me picking flowers
> Or washing my body in a river, or kicking rocks,
> Don't think my eyes don't hold yours.
> And look hard upon them
> and drop tears as long as you stay before me
> Because I live as a man who knows death
> and I speak only the truth
> to those who will listen.
>
> Never yield a minute to despair, sloth, fantasy.
> I say to you, you will face pain in your life
> You may lose your limbs, bleed to death
> Shriek for hours on into weeks in unimaginable agony.
> It is not aimed at anyone
> but it will come your way.
> The wind sweeps over everyone."

The nature of "body knowledge" is analogous to that of "life experience", except that it pertains specifically to the physical body. A participant expressed his finely tuned body knowledge in this way:

> "I don't think mine (experience of cancer and symptoms) would compare with theirs, or theirs would compare with mine. Because I never drink. I don't smoke. So I've been an athlete all my life, and a lot of those people were not athletic. So . . . their body structure wouldn't be as mine is, see. So I don't know. I wouldn't like to compare mine with theirs. I have to deal with mine every single day. So it could be . . . that . . . because of the asbestosis or the cancer or the herniated discs . . .it could be any number of things is why that I fall . . . or you might even go so far as to say it's because of my boxing career . . . might have some adverse effects, I don't know. I don't think so, and I've . . maybe it might have something along with this in the eyes of others . . . would dispute that you see. But I . . . I don't think that my career as a fighter had anything to do with my sense of balance or my equilibrium. I think it comes from the operation on my discs in my neck." (12,9,345-66)

"Body knowledge" has an element acceptance in relation to aging and decline in capacity and function. This is dissimilar to the notion of body failure posited by

Corbin and Strauss (1987) in that it does not hold the same nuance of opposition. The expectation of functional loss with aging that is a part of "body knowledge" may smooth the path for the experience of cancer. This would further differentiate the process from that experienced by younger adults with cancer.

Inevitably, the "self-definition" of person and the experience of life and particularly of the body bear upon the experience of cancer. One copes with the loss associated with cancer in ways one dealt with other loss. Several participants lost spouses to cancer, one lost two husbands and two sisters, and another lost a child. And one knows something of the way symptoms will be experienced in cancer based on prior experience with acute or chronic illness. The way cancer is integrated into a particular "life mostly lived" is reflexively dependent on "life before cancer". "Life before cancer" is the phase that delineates and supports the rest of the internal process. It shapes the philosophical dialectic and is, in turned, shaped by it. It also supplies the individual's options for type of integration. For example, a person who has no intimate relationship will not integrate cancer through "I've got to be OK for her". Another person who has always had faith in Western medicine and must worry and fuss about problems in order to handle them will likely integrate cancer through "good doctors, good medicine".

Entry Phase

The entry phase, "coming to bouts with yourself", is generally the most traumatic, struggle-filled phase in the "integrating" experience of cancer. A participant provided the in vivo label in this excerpt: "Well, I feel the most difficult thing for anyone is to be faced with cancer. Otherwise, I mean, once you've come to bouts with yourself, you just have to go forward". (3,1,15-8) This is echoed by another participant: "And I said, I can't be dramatic and I can't feel sorry for myself. I wish I didn't have to go through this . . . but . . . OK". (4,11,400-3).

"Coming to bouts with yourself" manages the response to diagnosis, the first major disruption caused by having cancer. It initiates the process of integration through the beginning of the dialogue with the self. A dialogue with the self about the meaning of cancer and cancer treatment for the self is characteristic of the response. A participant talks about his initial questions to himself after cancer surgery: "And then you . . . when you're sick, you're worried about getting well. Am I . . . how long am I going to be this way and all that kind of stuff." (15,5,197-200) Reaction to the disruption of being diagnosed with and having cancer is analogous to the discontinuity that stroke creates in a life-course described by Becker (1993a). Becker (1993a) illustrates how rehabilitation is about regaining continuity. It could be said of the living and cancer focused phases of the process that they are about regaining continuity after the diagnosis of cancer.

Connection to "life before cancer". The entry phase is heavily linked with "life before cancer": "See, whenever people have cancer, it depends on the condition you're in to begin with." (15, 652-3) The conditions for the entry phase are: "something is wrong", "suggestions of cancer", and entering the health care system. These internal perceptions and overt behaviors immerse individuals into new experiences with associated feelings, fears, and interactions.

"Something is wrong" and "suggestions of cancer" often overlap or they may be entirely separate and temporally ordered depending upon the integration type, life experience, and body knowledge.

> "I know when I'm going wrong, or what I'm doing right. I don't need anybody to tell me that. I remember when I was going through this process, testing, when they were determining if I had cancer . . .I was talking to my doctor and I told him . . . I kept telling him there's something wrong. That was before they discovered I had cancer. I kept telling them. I said, I don't feel right, there's something wrong". (12, 31, 1333-42)

> "The beginning was rough because . . . I've always had to watch my weight because I'm very short, and when I first . . . the thing that bothered me -- all of a sudden I lost all this weight, like about seven pounds, and I knew there was something wrong with me."" (5,3,114-20)

One participant experienced physical symptoms as "something is wrong" when he first sought help for what was diagnosed as lymphoma. When it recurred, the same physical signs were "suggestions of cancer". Of his response to having difficulty swallowing, he said:

> "Oh, I think it borders on anger and frustration. Because what happens is, you say . . . oh, for crying out loud, here it is again. Well, I thought it was gone. The first time you develop it and you suspect that you might have something that is cancerous -- a growth or something -- you think to yourself, man, why me? Why did this have to happen to me? Well, the truth of the matter is, we should never stop and say why me, because . . . my understanding is that we all have the potential of cancer in our bodies, and anytime that imbalance is there, there's a potential of developing cancer. So, you know, I don't know why we make such a big thing out of it." (14,4,169-85).

However, another participant was less clear on the "suggestions of cancer" because of a belief common to this group, albeit a mistaken one: No pain. I didn't have any pain. ('No? Did you expect pain?') Well I thought that was one of the symptoms when you had cancer, but I didn't have any". (10,2,54-7) In time, however, the self knowledge that one does indeed have cancer takes shape.

Transition Into Living With Cancer

Overcoming fear and uncertainty. "Coming to bouts with yourself" exists on two levels. The first is a dramatic transition from "life before cancer" into the dialogue with the self around having cancer. In the transition one must face distinct change and fear associated with having cancer. A participant who reveals that she integrates cancer by "don't think about it", talks about the fear cancer wields:

> "The main thing is not to dwell on the fact that you have cancer. I thought -- oh, many times I've thought -- years ago . . . that I would be scared to death to have cancer. (And how do you feel now?) And I've never had one bit of fear about it -- never, since I had it. The only thing is . . . that I . . . that I was so happy to see the light of day after the operation that (laughing) . . . I've been grateful ever since." (7,29,1165-75)

Others observed, however, that the fear associated with cancer in the past was changing because societal attitudes were changing. This participant highlighted her "life experience" with cancer and diminished fear:

> "I think it's so frightening. It's a frightening disease. You know, it's really very very good now, because my generation -- we didn't even use the word cancer. My God, it wasn't even . . . we'd have never said it out loud. Now, of course, it's spoken, and it's better. I think it's better. <You think that's a change for the better?> It is. <Yeah.> But I don't feel that . . . I'm not frightened any more, because I've been in remission so many times (laughs), and I feel it's going to be all right." (8,23,932-45)

In all, there is a varying combination of overcoming fear and learning to live with cancer that comprise taking action to handle it. The combination and balance of fear and living come with passing through "coming to bouts with yourself":

> "Oh, I know it (cancer) can kill you. I know it can kill you. But it doesn't scare me. If I had it, I had it. There's nothing . . . you have to do something about it." (11,14,495-9)

Entering the process involves the unknown. At the time of diagnosis, individuals do not know what lies ahead. "Coming to bouts with yourself" is characterized by uncertainty which abates somewhat, depending on the intensity of integration, in next processual phases. The uncertainty drives the questions that initiates the dialogue with the self. A participant talks of her reaction to being diagnosed with cancer:

> "I guess . . . because, at 76 years old, you figure only older people have this (cancer), although it's children . . . we know . . . young people die . . . uh . . . and you say, what a waste and isn't it sad. But my mother died of cancer and she was eighty. So I guess I didn't relate to it in my younger years. I knew that it existed and that it could happen. But, you know, you don't think about it. You dismiss it. And I had a happy marriage, and my husband and I traveled a great deal. He was an artist, as you can see. <Yes. I can> And so my world was his. And so . . . it just never . . . I never thought about it. You sort of have the feeling -- oh dear God, I hope I never get it. But . . . other than that, I never dwelt on the subject. <So, when you were diagnosed with it, did that reaction change?> No. I mean, I just . . . I thought . . . I didn't really think about it much. I knew I had it, and as I said to you on the telephone -- why did I need this? (laughs) And I say that every once in a while -- why did I need this?" (4,4-5,154-80)

This participant articulates her particular approach to cancer and being diagnosed with it. Her questioning takes a humorous form as she draws confidence from her physicians and nurse in her integration. The dialogue takes highly individual forms, centering on what the cancer means to the self. For example, another individual's questions may revolve around what having cancer means for retirement plans, as they did for a participant who had retired to be outdoors more only to find that fatigue from lymphoma prevented that. Other questions may revolve around what this means for one's intimate relationship and family life.

The diagnostic co-process

The second level of the entry phase is the diagnostic co-process. Either "something is wrong" or "suggestions of cancer" or vague amalgam of both demands seeking help. The diagnostic co-process is filled with increasing activity within the realm of Western medicine and developing new relationships with medical technology, health care providers, and the system itself. This co-process sets up one of the major conditions for the entire process: seeking Western medical treatment.

"A View From the Inside"

The co-process is tied to the early dialogue with the self through a change in perspective, "a view from the inside", that develops as a result of entering cancer care and becoming aware that one has cancer. This "view from the inside" is exemplified in comments like this one: "You never know what it is about something until you're in it yourself". (15,413-4) and "Now I feel relieved about it. I feel more relieved about it (cancer) now". (419-20) "A view from the inside" is about finding that having cancer is easier and less scary than one thought it would be.

"Becoming a member". "A view from the inside" has two interrelated parts. Achieving "a view from the inside" moves an individual from the entry phase to the living- and cancer-focused phases where the bulk of processual time, until that individual's death, is spent. The first part is linked to declining uncertainty as one compares the reality of having cancer with one's expectations about it. This pertains to "becoming a member". On entering the process of "integrating cancer", one revalues oneself as a new member of the "being old and having cancer" group. The action of revaluing, under the condition of "becoming a member", has the consequence of "a view from the inside". This view makes one see things differently. One sees the cancer diagnosis differently. One sees others similarly afflicted differently. And one sees the thresholds under which one is willing to live differently.

Choices are made in response to the current situation about what is too much with which to put up. The larger thresholds under which you are willing to go on living at that particular time are defined. When these thresholds are breached, the perception is that the situation would be too disruptive to living and, therefore to one's sense of self. This is a manifestation of the philosophical dialectic. The dialectic aids in the definition of thresholds because it pertains to the more abstract issues of living and dying. A participant talked about her living will:

> "My executrix. And everybody has copies. And the doctors have said, everybody should have this anyway. So I have taken care of that so that . . . my wishes will be followed. I don't want to be kept alive on tubes. I don't want to be kept alive unnecessarily . . . and suffering. I want to go out easily. I always remember, I read something in the paper when Alfred Hitchcock died. He said, he wasn't afraid of death; he was afraid of dying. And I've always remembered that, and I think that has been something that has been important. It's dying. It's not death. We don't know what we're going to be. Somebody said, gee, you might wake up dead! I said that's fine. (laughs) Maybe I'll see my mother and father and my husband again." (4,15,563-579)

"The hierarchy of affliction". The second part of "a view from the inside" is a second consequence of "becoming a member", with the action of "taking one's place in the hierarchy of affliction", that has the consequence of "downward" comparison of one's own experience with that one observes in others who have cancer or who are old. The response to the relief of declining uncertainty about having cancer on "becoming a member" was constant comparisons by the participants themselves with other elderly people or with others who had cancer. In these comparisons, the participants were inevitably better off. The structure for the comparisons is "the hierarchy of affliction", a grouping of others perceived to be in similar situations. One takes one's place in the "hierarchy" and then readjusts it based on the perception of relative strife. Movement is always upward. No one ever said I am so much worse off than someone else. Hence, "the down-ward" direction of the comparison. Additionally, "down-ward" comparison appears to exist regardless of type of integration.

"Down-ward" comparison. A participant, who reported several disruptive symptoms, articulates this aspect of "a view from the inside": "Fortunately, I've been one of the very lucky ones that haven't had too many problems." (2,1,11-3) Part of the comparison is relying of self-definition from "life before cancer": "I've been very lucky with my whole situation. And . . . I have a . . . what is it? A low threshold or a high threshold of pain? I can handle pain." (8,12,479-82) And the same participant offers one of the most poignant comparisons:

> "I just . . . you know, I feel lucky that I'm here. I lost my two sisters, two gorgeous, wonderful sisters -- very young, with cancer. And I'm very close to their children. Their children are like my children. And they're missing everything. And look, I was spared that. So you've got to be grateful for some things. An I think that's . . . I'm very grateful that I'm here to see my girls and . . . grow up . . . and my sisters' children . . . grow." (8,15,595-605)

The "down-ward" comparison is what Taylor (1983) and colleagues describes as downward social comparison, a cognitive strategy to enhance self esteem (Buunk, Collins, Taylor, VanYperen, & Dakof, 1990; Taylor, Lichtman, & Wood, 1984). This sort of comparison is also found by Lev (1992) in a study of strategies for adapting to cancer treatment. This body of research presents the notion that the only socially feasible comparison left to the ill elderly is with other ill elders. However, the data from the present study suggests that comparison with terminally ill younger adults is also possible on the basis of opportunity lost. Younger adults have more opportunities lost with serious illness at a young age. But older adults have fulfilled most opportunities their lives offered. This is a key aspect of "a life mostly lived".

"A view from the inside" tends to remain a constant through the subsequent phases of the process. It becomes a condition for maintaining perspective on the process of "integrating cancer" through comparisons with others and with one's life before cancer. This sort of comparative evaluation is seen in the following passage:

> "So that, the only thing that's changed in my life is the fact that I can't walk as much and I can't do several -- you know, a lot of the things that I used to do, because I don't have the stamina. But outside of that, my life hasn't changed." (2,3,120-5)

A participant discussed his own context-bound analysis of "coming to bouts with yourself" that transmutes into telling his own most recent diagnostic co-process and "a view from the inside":

> "OK. I think what happens is . . . the mental . . .the mental thing that happens . . . the thing that mentally happens to people when they say . . . they tell them they've got cancer . . . is they go through a period of oh, gee, not again or . . . the first time . . . no, not me. Then they do the biopsy and, of course, you're in a hospital and you go through . . . they take a sample of bone marrow and they give you a spinal tap and they put you in that MRI tube, and they give you a CAT scan. And they put you through on the nuclear heart machine. And they do all of these things to you. And during that period of time you're saying, oh, gee, you know, am I going to make it? But if I have any fear of expiring because of the cancer, that fear would have been dying during the process of them doing those things to me. In other words, every time you went in and climbed in the MRI or the CT scan or anything, you signed a consent form saying, hey, do it, but there's a chance of dying. You know, maybe it's a very slim chance. Now, that part weighed a little heavy on me. But once they came back and said, hey, you know, we're going to start

> chemo again, and your body is healthy enough to withstand the chemo. My mind said hey -- this is a walk in the park; I've been through it before." (14,2-3,94-123)

This passage illustrate one individual's particular entry phase, in a range of experiences that varies widely. His entry phase was shaped by "Jesus is my doctor", his mode of integration and a sub-type of "confident that I'll beat it". It reveals life experience and body knowledge, especially as this is recurrent disease he believed to be cured. He details parts of the diagnostic co-process. And he shares the beginnings of the dialogue he had with himself.

Cancer Focus and Living Focus Phases

The primary phases of "integrating cancer into a life mostly lived" are those in which either cancer or daily living are most prominent. By primary, I mean these are the most sustained phases of the process. They are those in which most chronological and narrative time is spent. The entry phase passes with "becoming a member" and the consequences of "a view from the inside" and "down-ward" comparison. What remains is a need, with the conditions of the philosophical dialectic, to continue living while being old and having cancer. Hence, the primary phases have to do with daily living and the times at which cancer disrupts daily living.

There are two primary phases. "Redefining the thresholds of daily living" is that phase in which, because of disruption in daily living by cancer symptoms and treatment, the individual must focus attention and energy on cancer and managing the disruption. Focus on daily living in "living on new terms" returns when disruption is managed and exists at a level below thresholds of acceptability for the individual. These phases are not temporally ordered. Rather, an individual moves between them with the relative pertinence of one's "life experience" and "body knowledge" to the current disruptions in daily living, and as the disruptive conditions of symptoms and treatment and relationships change. With shifting conditions, cancer is moved to the foreground or background of daily living. The primary phases can then be said to be conditionally ordered. I discuss them here with the cancer focus phase first only for the sake of discussion and understanding.

Cancer Focus Phase

As disruption occurs with "reminders of cancer", the dialogue with the self becomes active and cancer is foregrounded. Engagement in daily living is typically less intense. The type of integration mediates intensity of "engagement". For example, those who exhibit "I've got to be OK for her" may maintain even engagement patterns because of the buffering effect of the intimate relationship. In contrast, those who exhibit "another piece of the puzzle" may display widely varying intensity of engagement because they must manage relatively more disruption without buffers.

Questions such as 'what causing this?', 'how can I tolerate this and at what level of discomfort?', and 'what will manage this?' are asked in "redefining thresholds". They are answered through attribution and perception of importance, and through actions taken to manage the disruption. Redefinition and management strategies are the shapes the answers to the dialogue take. The dialogue quiets as the answers are found to be the right ones for that individual. Successful management closes the "reminder of cancer" into a "symptom or treatment story". This closure signifies managed disruption, a reduction in discomfort to acceptable levels, and a refocusing on daily living. With this, one moves into "living on new terms".

Conditions for Cancer Focus Phase. In "redefining the thresholds of daily living", energy and attention must be focused on cancer when daily living is disrupted by the conditions of cancer symptoms and treatment that is unanticipated or differs from the usual treatment. Disruption is caused by the discomfort associated with cancer symptoms and treatment. When discomfort exceeds levels an individual finds acceptable, at that point in time, daily living is disrupted. A participant clearly describes this point:

> "That moves, too, Sarah. That perception point moves and changes -- depending on mood, depending on surroundings, depending on upbringing, depending on what else has been happening. If I . . . I wouldn't have perceived this . . . the discomfort with this procedure if I hadn't felt pretty pushed and shoved. People have been hassling me lately. So my perception of this hasn't much to do with pain or the alleviation of it". (A,1,17-26)

She goes on, later in the interview, to give an example of the potential fluidity of thresholds:

> "I'm fairly comfortable right now with this thing (Back and pelvic pain). But sometimes this gets too be too much. And I permit myself to dispense (pain pills) . . . but . . . that's a fairly narrow manipulation point." (A,9,317-21)

The description of discomfort and disruption in the data is congruent with the contextual definition of comfort suggested by Hamilton (1989a,b). They also are similar to the definition of discomfort in chronic illness, offered by Charmaz (1983), as suffering that is the loss of self or damage to the idea of "who one is as a person". At the point of disruptive discomfort, either the disruption must be reduced so that it and the discomfort exist below the threshold exceeded or the threshold must be redefined to incorporate the existing disruption. This becomes the general question of "how much can I take?" in the dialogue and has directly to do with the meaning attached to disruption by virtue of the philosophical dialectic.

Thresholds

Thresholds are personally defined, flexible and ever changing standards for with what level of discomfort and disruption one is willing to live. Therefore, they define whether the conditions of cancer symptoms and treatment are disruptive to daily living. Thresholds become conditions for action toward disruption.

Action of "redefining thresholds". Redefinition of thresholds occurs in two ways. The first are in response to choices about cancer and treatment. The thresholds of acceptable levels of time spent and discomfort borne in daily living are redefined out of necessity when one seeks Western medical treatment. To choose the treatment the participants did is to choose to redefine thresholds. Often redefinition is implicit, as it was for these participants:

> "My life's the same as it was before, except that I have a lot more pills and stuff to take. And I . . . my wife and I . . . we get . . . we don't do what we used to because we can't be gone long enough. Have to get treatment, have to take shots for seven days. By the time that seven days is over, those shots make me nauseated to my stomach, and I don't feel like doing much. It depends on . . . now Monday . . . or Tuesday, they'll start . . . I'll start picking up a little. Thursday or Friday I'm doing pretty good." (11,1,7-18)

> "Again, I wasn't ill or anything -- in other words, I could lead a . . . my life as I always had, except that I didn't feel as though I could go out of town or anything like that everyday." (5,2,60-4)

The second way in which thresholds are redefined is in response to the disruption of symptoms or unusual treatments. Here dual efforts can be made to manage the discomfort and redefine the threshold at which discomfort becomes disruptive. One participant did this sort of redefinition in relation to fatigue and the expectations of activity: "And I've found, if I can't clean all the rooms in the house, do one . . . it will keep. You know, there's nothing that's really pressing on me." (2,7,280-3) This may mean that complete comfort is not achieved, but because of the threshold redefinition, disruption is managed:

> "I started out . . . first of all, after my mastectomy, I was on tamoxifen, which was relatively side effects-free, except for vaginal dryness, which drove me insane. And I couldn't take any estrogen cream because of the breast cancer. So I finally wound up just using K-Y jelly and let it go at that." (2,1,13-20)

Often redefinition revolves around shifting the attribution of a symptom or reducing the concern it elicits. "Life experience" and "body knowledge" from "life before cancer" generally play a role in this part of redefinition. A participant talks about redefining a threshold around impotence:

> "Yeah. Yeah. It . . . well, part of it was, I didn't like it (impotence) . . . like that sense of being incomplete. And the other part of it (impotence) was -- oh God, one more thing I have to learn to live with. But all in all it's processed out pretty well. <That process of -- oh, this is one more thing I have to learn to live with.> Yes. <Tell me a little bit more about that. What sort of things can you identify that you've had to learn to live with?> OK. The first was learning to live in the drinking world as a person who doesn't drink. That's one. Then . . . learning to live in the world where I'd agreed, because I'd been married before and the Episcopal church is stuck here about remarriage and the Roman church is. But, at any rate, learning to agree that I would live a celibate life . . . and therefore would have no intimate relationship . . . that was something I had to learn to live with. And then when Ray and I were talking . . . I . . . had a couple of physical injuries -- having to learn to live with -- not being able to do what I want to because of physical limitations. <Your shoulder.> The shoulder and the knees. And then this hand -- I still -- the doctor says that if it gets bad just live with it. I've dislocated all the bones and broken the bones in this hand. And learning to live with physical impairments, but also having . . . you have to learn to live with this. And then when I went through the period of time where I had to have help going across the street because I couldn't see traffic and that sort of stuff. And . . . well . . . having this rapid onset of cataracts. Learning to live with not having guarantees. And I think

> that's part of it. You know, having to make decisions with no guarantee of how it's going to work out." (9,16-7,701-743)

Here also health care providers may be instrumental in providing information to promote that change. A participant describes such an interaction as part of a "symptom story" in which he has both managed the disruption and redefined the threshold through a new understanding of the symptom:

> I had a couple of days . . . I also told the doctor . . . where I felt like I was flushed and warm. And she said, well . . . she said, did you. . . take your temperature? And I said, I didn't have a fever, so I didn't take a temperature. And then she explained to me that . . . just like being over toxic on medication, that the chemo could be catching up with me a little bit and, as I take more and more of it, it's going to have a different effect on my system -- like being over-medicated. And I understand that, so it doesn't bother me in the least.

Conditions for "Redefining Thresholds of Daily Living". The primary conditions that create disruption are "reminders of cancer". "Reminders of cancer" are symptoms or treatment that cause unmanaged disruption. A symptom or treatment that does not cause disruption which exceeds the threshold is not a "reminder of cancer": "<Have you noticed anything else about the tamoxifen when you take it -- no hot flashes or . . . > Well, a few . . .I mean, a few . . but nothing that's uncomfortable. <Yes. So it didn't really . . . > It really has not bothered me." (3,3,82-8)

In "reminders of cancer", the individual is without automatic strategies to reduce the disruption caused by the discomfort of the symptoms or treatment. "Reminders of cancer" are at first often quite complex in the recognition and attribution they require. One must attribute a cause to a symptom which breaches a threshold and is disruptive.

Attribution to cancer or aging is often difficult and salience of a symptom may play a role in perceived discomfort. Additionally, the type of integration moderates perception of discomfort. One who integrates through "don't think about it" may have greater ability to minimize discomfort than does one who integrates through "another piece of the puzzle". Attribution and salience are usually conditional upon "life experience" and "body knowledge". Vigilance for cancer symptoms can then promote "reminders of cancer: "You get a pain in your leg and you think there's something down there. So that . . . that is . . . you know, you're always kind of on the alert, as they say (laughs)." (5,8,321-4)

Participants rarely spoke of "reminders of cancer" directly. Disruption from unusual treatment, over which an individual has less direct control, was sometimes described as being left unmanaged.

> I had a CT scan about two months ago and the CT scan and the chemo came almost on top of each other. That was overwhelming. I can only say that it brought me down to the point where it was more than I would want anybody to be exposed to, you see". (13,6,252-5,57-60)

<u>The role of symptoms.</u> Unusual and extreme disruption from the discomfort of pain, nausea, and fatigue was described retrospectively. A participant with bone pain describes her most intense experience of it. The total disruption the symptom causes is keenly stated as causing a "hole".

> "<Tell me about what it's like to have that kind of pain.> Maniacal. It's . . . you sit around, get on the floor, you put your head down and you curl up in any kind of shape . . . you'll do anything that will change the nerve touching whatever it's touching so that the . . . you just gasp . . . you just don't know what to do. You want anything to be out of it." (16,19,847-853)

Nausea can be equally damaging to the pattern of everyday life. Here a participant, who integrated cancer through "good doctors, good medicine" and seemed stoic in his responses to my questions, talks about his reaction to a larger than normal dose of chemotherapy:

> "That made me sick (nauseated). Really sick. <When they increased it by 50%?> Yeah. Really sick. That time I did vomit. They gave me some pills . . . when I start to think of it, the medicine then . . . through the pills . . . to drink . . . you know . . . for the stomach . . . for nausea. And I drink that and I couldn't sleep. And I lost some weight when that happened." (11,2,42-50)

Fatigue may also be profoundly disruptive to an individual's life. A participant, who usually managed the disruption from fatigue he experienced after every chemotherapy cycle, found himself faced by extraordinary tiredness:

> "Yeah. I think -- I'm almost inclined to feel that the fatigue is a by-product of the chemo. This is my feeling. I'm able to cope with it as such. Now yesterday it was a little bit overwhelming. There was nothing . . . I couldn't even sit at a desk and do any writing, you see. So . . . yesterday I just decided that . . . oh, it's one of the days when I'm going to take it off, you see. I don't owe anybody a thing, so I'm going to take it off. But other than that the fatigue comes on. Now I'm inclined to feel that the fatigue is related to a great degree to the effects of chemo. Now whether I am completely correct or not, I'm not sure, but I feel that way. In the six phases I've gone through, I've been more or less able to assess it and see that there is a pattern, you see." (13,4-5,176-94)

Imbedded within this "symptom story" of recognition, attribution, and management is a case where the threshold, defined by activity was breached and "fatigue" once again became a "reminder of cancer".

The absence of an intimate relationship. The loss and absence of a loved long-standing intimate relationship, labeled as the condition "there's no one to cry to", potentiates "reminders of cancer". If the partner who shared and absorbed disruption in daily living is no longer present, then disruption is perceived to be greater and more difficult to manage. The participant who lost the beloved husband who saw her through a mastectomy and initial treatment said it this way:

> "See . . . I think it's very . . . as I said, it's very difficult to be alone and ill. I mean, like I was really upset today, not having the treatment, because I was hoping to be able to go to Florida and be finished and all sorts of things. And not to have anybody to really tell about it. And I'm not going to tell anybody. I certainly didn't tell my daughters, and I'm not going to tell anybody. I'm going to go next Thursday and that's as far as it goes. But I would have loved to have come home and kind of cried to somebody. And . . . it would only be a husband". (8,27,1071-84)

This important function of absorbing daily disruption, related or not to cancer, is reflected in this simple statement:

> "It's the noise in the house, I think [that keeps me awake]. I think that's what I miss more than anything . . . since my husband isn't here . . . is just the idea of not having anyone . . . another voice . . . so that you can say, did you hear that or did you see that? And there's no one there." (2,13,512-8)

Strategies for managing disruption

Strategies used by an individual that enable management of disruption are the actions that move that individual from the cancer focus phase to the living focus phase of "integrating cancer into a life mostly lived". Conversely, changes in cancer symptoms or treatment because of changes in the disease itself move an individual back into "redefining thresholds of daily living". The strategies employed to manage disruption are of two kinds. Management of disrupted daily living is the positive consequence of taking action about "reminders of cancer".

Strategies are based in the self-definition of "life before cancer" and incorporate "life experience" and "body knowledge": "Luckily, I'm not one of these people that gobbles pills. I'd rather do the exact opposite. They give me Vicodin, so I take half, and if that doesn't work, then I take the other half."

(2,14,555-9) Strategies are categorized in relation to the disruption rather than with regard for the kind of action they involve, as with Strain's (1989) pathways to care for symptoms in old age.

Blanket strategies. Blanket strategies manage disruption directly. They are targeted at disruption broadly whether from symptoms or treatment and are often used by those individuals who integrate through "don't think about it". In addition, those who exhibit the sub-type, "Jesus is my doctor", are likely to use prayer or meditation as a blanket strategy. The blanket strategies minimize discomfort through distraction or protection. Changed patterns of activity, as reported by the man quoted above, prayer, listening to music, and watching television are commonly used blanket strategies. A participant in her 80s used both music and prayer:

> "But anyway, we always had music. So I went in and turned the TV on or the radio on, and I enjoyed it so much. And immediately my nerves calmed right down. So every day I've been putting on music . . . It's helped me. And, of course, prayer. I'm not overly religious. But, especially when I go to bed at night and I try to get to sleep, I try to pray. And that helps too." (7,4,152-64)

Less commonly used blanket strategies, that seem to be more common among younger people, are support groups and self help books. Only one participant attended a group, and then only once, and two participants reported reading popular self-help books for the seriously ill.

Sometimes, however, participants would reveal more unique strategies, such as the one here to manage disruption after monthly chemotherapy:

> "When I feel that way, I stay home and I . . . I hate to tell you, but I really stay in bed for a good part of the day, don't get dressed, which is fine. Like Monday, I didn't feel very well. I've been having a little -- feeling more tired than I ever did. So Monday I stayed home and I was in my robe and nightgown, and at five o'clock, I took a shower, changed my gown, had a little dinner, went back to bed. And it worked. And I

> watched all the crazy TV programs which . . . I didn't read . . . but it was fine. I had to have a day alone. And I think that just . . . I think that that's important." (8,9,344-57)

> " Myself . . . I prepared myself to be sick. And I had the Compazine out and I had everything out by my bed that, if I was going to throw up, and throw up in a hurry, that I would be in bed and I would be able to decide . . . I wasn't going to have anybody there to take me to the bathroom. So if I had to do it from my bed, I would do it." (8,46,1871-8)

Specific strategies. Specific strategies are used to reduce discomfort from a particular symptom, or less often, treatment. These individuals who integrate through "good doctors, good medicine", "another piece of the puzzle", and "I've got to be OK for her" often use specific strategies in preference to blanket strategies. Disruption is then indirectly managed by reduction of discomfort. Taking off clothing is used to alleviate the discomfort of hot flashes for the participant quoted above. Other commonly reported specific strategies involve using medication to reduce discomfort. Indicators of threshold breach often aid in knowing when to employ a strategy to manage the disruption. A participant describes the point at which she knows to do something about pain:

> "Vicodin. And it works fine. And I don't take it every night. I'll just take it, you know, when I feel I'm just am that uncomfortable. <Ah, so you kind of have a definition or a threshold of . . . I know when . . . > Yes, That's right. When I find myself really squirming around and not settling down, not finding a place for myself, then I do it." (8,22,907-16)

Common items are sometimes used as specific strategies. Another participant used a wig to reduce the disruptiveness of alopecia:

> "Eventually, you figure out a way to deal with it. The only thing I haven't been able to deal with is my hair falling out. I think that bothered me more than anything. You know one of the reasons why it bothers me? I wear a wig when I go out now. Everyone I would meet -- I used to have very nice hair -- and they would . . . the first thing they'd say -- what happened to your hair? And then you'd have to go into this long explanation where you don't want to really get into the whole thing

> and say I had this and I had that. And then you get all the sympathy which you don't need -- or I don't need, anyway -- and I think that bothered me as much as anything else." (2,4,148-63)

A participant who takes an emetogenic chemotherapeutic agent uses a specific strategy to combat nausea and blanket strategies to deal with the symptoms caused by the strategy in this "symptom story":

> "So now I'm on Adriamycin, which doesn't seem to have too many side effects. I still have the slight nausea, so I take Compazine every once in a while. And I'm still -- you know, I can . . . by about 2:30 or 3:00 in the afternoon, I start running down , so I take a nap, and then . . . in an hour or so I get up and I feel fine again. Because I'm a night person anyway. So I sit and watch these idiot television programs. I don't know what I would have done without the television, I tell you the truth. It's a real good companion . . . since I live alone." (2,2,56-69)

In this story, the ramifications of strategies and the relative utility of medications are clear. The fact that solutions have side effects adds to the complexity of managing disruption and reducing comfort. Something that manages the disruption of one thing may produce discomfort and concomitant disruption that is more unacceptable than or, at least equal to the initial disruption. Redefining the threshold of acceptable disruption may be the more attractive alternative.

> "(Chemotherapy) presented a few more problems than the tamoxifen. And with that, mainly, was the nausea. And I was -- Dr. G_______ gave me Compazine to control the nausea, but that itself had side effects. It makes me very sleepy. I mean, I would sit down and fall asleep. So, I finally worked out where . . . if I kept eating -- like soda crackers or something -- it would take away the nausea. As soon as my stomach got empty, then I would start getting the nausea again. Unfortunately, I gained ten pounds, so that has its side effects too! (Both laugh)" (2,2-3,37-50)

Living Focus Phase

The dialogue with the self is quiescent and cancer is backgrounded as disruption is managed and continues to exist under a threshold of acceptability for the individual in "living on new terms". The type of integration becomes less prominent as the work of integration becomes less intense. The philosophical dialectic also moves to the background. The individual lives on the "new terms" proscribed by the cancer (e.g. incorporating symptoms that are present but not disruptive; making time for treatments) and defined by herself (e.g. deciding to allow a symptom to exist at a level of disruption higher than previously accepted). The focus on daily living persists until disruption that breaches a threshold occurs, creating a "reminder of cancer" and forcing a change in focus to cancer.

In "living on new terms", questions posed by the disruption in the entry phase and in "redefining the thresholds of daily living" are answered. Answers are, of course, highly variable given that the questions and what goes into answering them are highly individual. Thresholds are redefined as necessary and disruption is managed: "You must accommodate. At least that's my philosophy. You must accommodate, to the greatest degree possible, to the natural forces around you and how they affect you. And that's my philosophy regarding this condition". (13,8,346-51) The dialogue with the self becomes quiescent and cancer is backgrounded. The focus is on daily living.

Daily living on "new terms" is experienced by all for whom this process is valid. There is always some redefinition and it varies depending on process conditions and the nature and meaning of the cancer and its treatment. Choosing Western medical care for "something is wrong" and "suggestions of cancer" necessarily implies, at the very least, the change that care will demand. Typically, there are many "new terms" as an elderly individual integrates cancer, with all the attendant changes of symptoms and treatment, into her life. However, many of these "new terms" are often 'invisible', taken for granted through integration and reliance on "a view from the inside" with the evaluative conclusion that sounds like this: My life really hasn't changed" when it indeed it has changed.

Conditions for "Living on New Terms". "Symptom and treatment stories" are the central condition for focus on living. Without these stories, disruption would remain unmanaged and the individual may then be obligated to focus on cancer. "Symptom and treatment stories" are characterized by a story-like structure in description. An individual begins by telling about recognition of the disruption and description of the discomfort. The text of the story is about the successful strategies that manage the disruption. And the story concludes with the consistent comfort and disruption that exists under the threshold that management brings. The stories are told to oneself as part of the dialogue with the self, but they can also be relayed to interested others (e.g. health care providers). Additionally, "symptom and treatment stories" function to promote integration. They fit into patterns of daily living so as to smooth out narrative time and the larger personal story of having cancer while one is old.

The role of managed disruption. The briefest sort of symptoms story is told by a participant who took tamoxifen: "I had a few hot flashes, but not too much. I learned how to dress so that I could take things off if I got too uncomfortable". (2,1,25-8) Other are more complex.

> "The doctors there . . . this last chemotherapy treatment now . . after about the seventh or eighth day after the treatment, I had a few days when I felt more exhausted than I felt I should have. But . . . but . . . I didn't sit down and quit because of it. I drove myself a little bit, and I'm glad I did because, if I had sat down and thought about it, I'd probably . . . my mind would have magnified it and would have felt worse. I had a

> couple of days . . . I also told the doctor . . . where I felt like I was flushed and warm. And she said, well . . . she said, did you. . . take your temperature? And I said, I didn't have a fever, so I didn't take a temperature. And then she explained to me that . . . just like being over toxic on medication, that the chemo could be catching up with me a little bit and, as I take more and more of it, it's going to have a different effect on my system -- like being over-medicated. And I understand that, so it doesn't bother me in the least. All I know is that I sleep well at night. I eat well. I seem to be able to do all my chores. I don't think I've got any problems." (14,8,343-370)

In this complex story of post-chemotherapy fatigue from an individual who integrates through "Jesus is my doctor", the blanket strategies of forced activity and not thinking about fatigue are used to minimize disruption. But the addition of new knowledge from the physician redefined the concern the fatigue causes and thereby redefined the threshold so that the fatigue was no longer considered disruptive.

The roles of intimate and other personal relationships. The presence of an intimate relationship and "connectedness", which encompasses all other relationships, potentiate "symptom and treatment stories". They are promoting conditions for "living on new terms". Positive personal relationships can buffer disruption in daily living and, hence, promote management of disruption. This gives "stories" endings. In the converse of what occurs with "reminders of cancer", these relationship conditions minimize the disruption of a symptom or treatment and therefore aid in management.

An intimate relationship of positive character, as relayed in this data, is unlike other relationships. In the case where there is a partner, disruption is shared. This is a key connection with "I've got to be OK for her", the integration type in which the intimate relationship not only buffers disruption but becomes the means for integrating cancer into "a life mostly lived". Individuals feel supported and as though they are not alone: "I have wonderful support. My husband is marvelous. He wouldn't think anything else if you're all right. He's wonderful". (3,5,159-61)

In "connectedness", friends and family diffuse disruption by offering emotional and physical support:

> "Well, I found that my friends are very supportive about calling and coming in and getting together and that sort of thing. In the beginning we talked a lot about it, but now I just sort of go along and we don't discuss it an awful lot. If I have some kind of crisis where, you know -- the pain under the arm -- then they want to know what happened, and they follow up on that". (5,8,298-304)

Here the participant outlines the pattern of disruption and response she and her friends have developed around symptoms of her lymphoma. The emotional result of such a pattern is revealed by a participant who is talking about what her family and friends do for her:

> "I guess just caring. Like, usually, after my treatment, I go to my daughter's because I'm a little sick afterwards. So then . . . this time I decided I didn't want to do that. I think it was enough. Let me try to handle it. Well, I had three friends plead, beg me to come to their home. They've got room, please stay. And they've called . . . and dinner's being dropped off by somebody now . . . and I just have . . . I can't tell you the warmth and the love that I have that surrounds me. Really and truly." (8,2,53-64)

The absence of or limited "connectedness" could very much be felt by individuals depending on the degree of disruption they faced.

Timing of interviews in relation to primary phases. Assessment of the primary phase a particular individual was analytically explanatory as the study approached completion. Either the disruption was managed and became a "symptom or treatment story" and the participant was in the living focus phase of the process, or the disruption overwhelmed the participant's daily living and she was struggling to find answers to questions about what the disruption meant for her, how long it would last, and what she could do to control it. Most interviews took place while the participants were "living on new terms."

Three participant interviews took place when they were "redefining thresholds of daily living". In each case, the participant was struggling with unsuccessful attempts to manage the disruption of a tenacious symptom, fatigue or bone pain. And, in two cases, the participants were considering death as a favorable alternative: "I deserve this peace." (that she associated with a resuscitated cardiac arrest and the thought of immediate death) (16,6,257-8) The focus was on cancer and escaping discomfort because the degree of disruption was too great to bear and was perceived to be unmanageable.

The Process Schematic

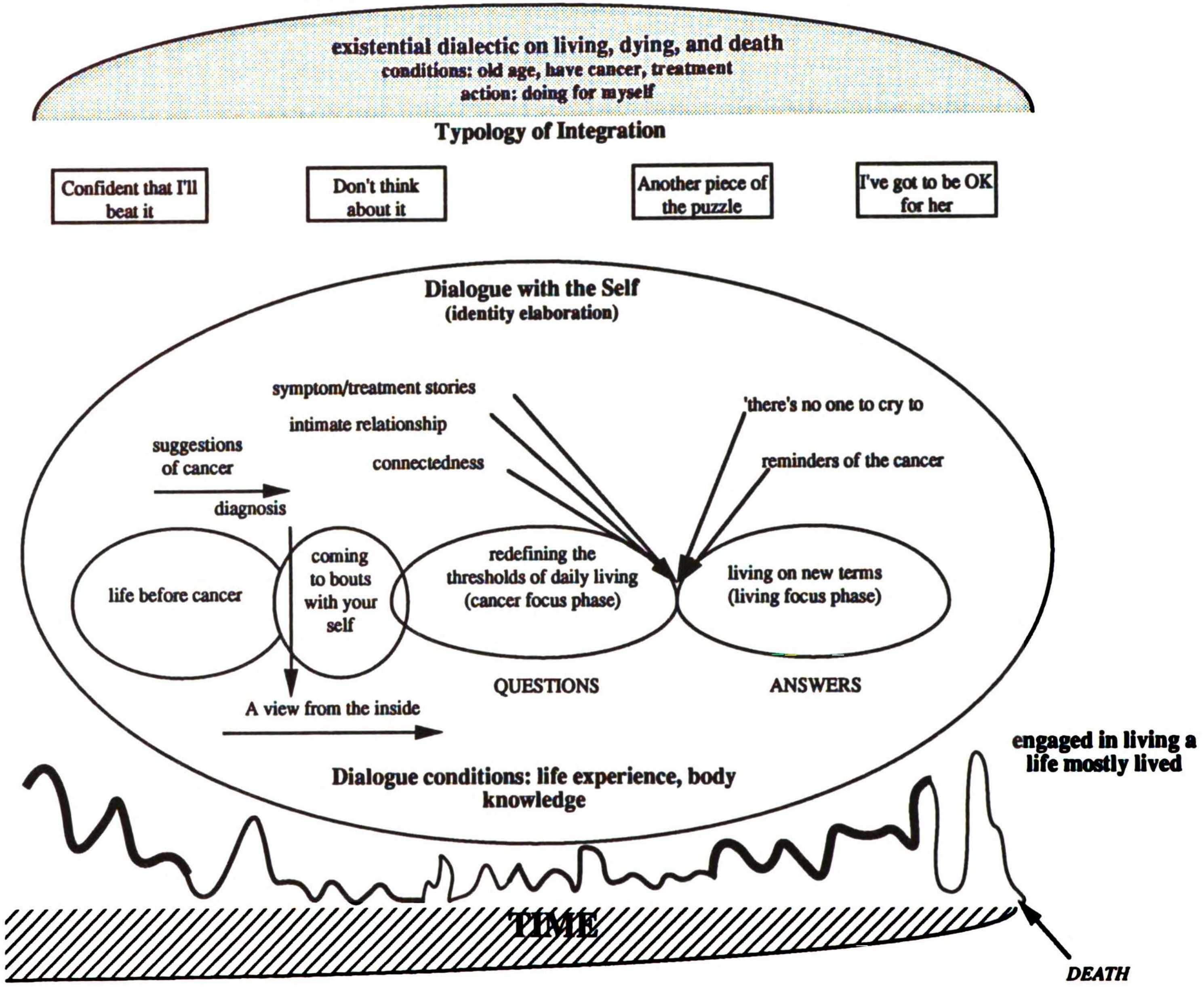
Adequate graphic representation of a human process is a challenge. That challenge is magnified when the process occurs largely at an internal level. Two dimensions cannot fully reveal the fluidity and many dimensions of the human mind and self and the amazing variation of human behavior. Nevertheless, "integrating cancer into a life mostly lived" is more easily apprehended, because of its complexity, with a figure. Figure 2 replaces Figure 1, shown in the discussion of methods as a point in the analysis. Figure 2 is more complex and has five, rather than three, horizontal components. Furthermore, some of the concepts have been refined and re-labeled.

The Phases of the Dialogue with the Self

The internal dialogue with the self is comprised of the four process phases. "Life before cancer" precedes the other three phases and is followed by "coming to bouts with yourself" and the diagnostic co-process. The primary

FIGURE 2

INTEGRATING CANCER INTO A LIFE MOSTLY LIVED



phases, "redefining the thresholds of daily living" and "living on new terms", are represented in linear order as they were discussed. However, as with the discussion, this is done for purposes of explication. In fact, these phases are superimposed upon each. One moves into the foreground as the other moves into the background as the individual's focus changes. The condition arrows for the primary phases represent the push into the phase to which they point.

"Engagement" and "Time"

"Engagement in living a life mostly lived" and time are the most elliptical representations. The engagement line represents the highly variable nature of daily living in the process and from one individual to another. How, without art, does one represent a life in the living? I haven't found an answer. Consequently, I include a random line of varying thickness to show variation in pattern and intensity. Time is shown as a non-linear shelf on which the process rests, because it is perceived individually and conditionally and supports all else. It is shaded with linear hatching to represent that daily living and the process exist in chronological time. The shelf shape offers a representation of contracting time as one proceeds through life toward death. Death is included hypothetically as no participant was interviewed when death was imminent. However, my gestalt of the process suggest that it ends when living collapses into time and personal time ends.

Integration Paradigms

Paradigms, by integration type, illustrate "integrating cancer into a life mostly lived" in all its complexity, fluidity, and variability. I use particular participants' stories (without any identifying information) which typify the four integration types to show the process in a synthetic fashion.

"Confident That I'll beat It" Paradigm

Individuals who integrate cancer through "confident that I'll beat it" with the more common sub-type of "good doctors, good medicine" spend most of the process centered in "living on new terms". Figure 2:a (see Appendix 5) shows a possible reshaping of the schematic for these individuals. Disruption is generally managed with a fair amount of reliance on health care providers for information to aid redefinition and management. "Connectedness" is then more intense and "reminders of cancer" less so as attribution and disruption management are supported by medical interactions. Reliance on health care is imposed on top and is concomitantly part of the individual's "life experience" and "body knowledge".

Mrs. V. integrates cancer into her life through "good doctors, good medicine". Mrs. V. is a 67 year old woman with recurrent, metastatic breast cancer. She was widowed several years ago. She and her husband led a very active life as he was a career military officer. Mrs. V describes herself as positive and active, in a quote used earlier:

> <Have you always been that way in the rest of your life?> Always. Yeah. I had a hysterectomy in '83. And I've always -- as long -- I go to the doctor and I have an opinion that they know what they're doing, and there's nothing else I can do anyway. And if I'm going to sit and weep into my coffee or whatever, it's not going to make me feel any better; in fact, I'll feel worse. So that, the only thing that's changed in my life is the fact that I can't walk as much and I can't do several -- you know, a lot of things that I used to do, because I don't have the stamina. But outside of that, my life hasn't changed." (2,3,111-25).

Mrs. V. leads an active life that she describes as being without change or problems despite weekly chemotherapy and reporting ten symptoms she attributes to cancer. And Mrs. V. takes herself to appointments by taxi cab and does her own housework. Mrs. V. has a network of friends and family on whom she relies for support. She feels, however, that they worry about her too much. She has a close friend, who lives next door, who looks after her "like a mother hen". And Mrs. V. sees her son and daughter-in-law frequently and finds them very supportive.

Mrs. V. redefines thresholds around symptoms by relying on close relationships with her oncologist and her oncology nurse:

> "But you have stupid little questions, like my skin is extremely dry . . . from all the treatment. And I forget those kind of things when I'm talking to Dr. G_____. I'm more interested in -- what did the CT say . . . and this kind of thing. But when I get in with I___, then we just -- while she's giving me the shots and everything, I can ask her anything, and she solves all these little problems for me. And I can talk to her very freely. She's a very easy person to get along with -- which makes a real difference. If I got someone who was very rigid or very what I call uncaring about not just your medical but your personal life, I think it would make a big difference." (2,10,394-410).

She redefines thresholds around the disruption these symptoms cause by changing her expectations about housework and social activity: "Whereas now, my husband is gone and I'm by myself, so that really, my time is my own. And I've found, if I can't clean all the rooms in the house, do one . . . it will keep. You know, there's nothing really pressing on me." (2,7,278-83)

"Don't Think About It" Paradigm

Those individuals who integrate cancer into their lives with "don't think about it" spend little time in "redefining thresholds of daily living". Redefinition is almost automatic in many cases, especially around treatment, because the individual is focused on daily living and does so to handle cancer. Figure 2:b represent a form the schematic might take for such a person. Intensity of engagement varies more for these individuals as redefinition in response to disruption occurs. This is in contrast to being forced back completely into the cancer focus phase by 'reminders' instead of maintaining the living focus phase. Typically, "there's no one to cry to" is not particularly prominent. Additionally, these individuals tend to prefer blanket strategies to handle concurrent disruption from any source.

Mrs. S., an 85 year old retired nurse, typifies "don't think about it". Mrs. S. supported an invalid husband and a son with her 50 year career as a nurse in private duty, and later in emergency room positions. Later in their life together, she cared for her husband at home as he was dying of prostate cancer. Three years ago, Mrs. S. was diagnosed with bladder cancer and urinary diversion surgery resulting in a urostomy. She manages the urostomy herself, lives alone, and spends much of her time alone. To ameliorate the loneliness of fewer visits from family and friends -- which she attributes to her age as well as to being ill -- Mrs. S. spends much time following politics.

The greatest current concern Mrs. S. has is how poorly her tenants upstairs are treating her. This situation makes her nervous. She listens to music to alleviate this nervousness. Mrs. S. also has a fear of falling and breaking her hip. This fear limits her outside activity and she relies on her son to assist with shopping and a friend to aid in personal care. Her cancer is one thing Mrs. S. does not worry about or fear: "And I don't have any worries about my cancer. I give it very little thought." (7,5,195-6) When Mrs. S's worries get to be too much, she helps herself feel better with music and prayer at bedtime. These strategies minimize disruption, from cancer or other causes, in her daily life.

"Another Piece of the Puzzle" Paradigm

"Another piece of the puzzle" is the manner in which elderly individuals who are used to having many, often long standing problems tend to integrate cancer into their lives. They draw on particularly complex life experience, specifically that related to health and function, and body knowledge to handle cancer. They are often found moving from one primary phase to the other with greater frequency than the other types. "Reminders of cancer" and "symptom and treatment stories" are both prominent. Engagement is generally more variable in pattern and intensity than is seen in other types. Figure 2:c reveals a likely form the schematic of the process would take for someone who integrates cancer with "another piece of the puzzle".

Mr. G is such a person. Mr. G. is a 73 year bachelor who alternates his time between a single room occupancy hotel, his brother's house, and the home of an "elderly woman" (she is 89 years old to his 73) whom he assists with housework. Mr. G. is a retired painting contractor and a veteran. He says he has brain damage from this work. This compounded the effects of a psychiatric diagnosis, "psychoneurosis", for which he was once hospitalized. The brain damage causes constant tinitus and sensitivity to certain foods. He described the connection among his health problems this way:

> "Well, I'm back up to a par. How would I say . . . I will walk around quite a bit. Gee, before, just to go a block or so . . . would have really effected me is the brain trouble I'm having to begin with. <So is that a bigger problem?> Oh, well certainly. It's just like having diabetes and then having cancer on top of that. It complicates it, see. Yeah. <Tell me how it's complicated it?> Me? <The ringing that you got from the brain damage . . . and getting the chemotherapy every week. How does that work?> Well my brain is sensitive. I can take, say, an orange or a grapefruit or something like that that's got that acid, bitter -- that affects me worse. And the medication -- the same thing, I think. Because the girl wears something before she puts it into me, so there must be something dangerous to that. " (15, 4-5,163-83)

Three months ago, Mr. G. complained of severe fatigue and was found to have colon cancer. He underwent a colectomy and now receives weekly chemotherapy. For the most part, Mr. G. is independent and says he is used to limited capacity because of his prior chronic illness. When he did need help, his brother was there: "But you realize, after you get sick, the people that have to take care of you -- I was lucky to have my brother -- but if I was alone and had nobody . . . oh, what a fix. You'd be in a room, sick, and . . . and then before you know it your money all goes." (15,5,187-192) While he found surgery to be quite disruptive, Mr. G. tolerates disruption in his daily life (e.g. daily loose stools) with this sort of attitude: "I'm not completely -- what's it called -- depressed about it, or . . . or in a lost state. I just keep going." (15,6,239-41)

"I've Got To Be OK For Her" Paradigm

Finally, men who integrate cancer into their lives with "I've got to be OK for her" tend to move between the primary phases fairly equally over time. However, movement into the living focus phase tends to be facilitated by the strength and obligation of the intimate relationship. Conversely, movement into the cancer focus phase is impeded by the buffering effect of the perceived care from the partner. "Engagement in living" tends to be more evenly patterned but of still varying intensity, compared with other types, because of the damping effect the intimate relationship seems to have on disruption in daily living. Figure 2:d shows a possible pattern for such a man.

Mr. E. embodies integrating cancer with "I've got to be OK for her". Mr. and Mrs. E. have been together for 55 years: "And with all the problems in life we've been able to cope with them. That's the secret of life -- knowing how to cope. Not knowing how to cope . . . attempting to cope. You find the answers when you attempt." (13,21,967-72) Mr. E. is 77 years old and has two primary malignancies. He had a nephrectomy for renal cell carcinoma at the time of his staging surgery for lymphoma four years ago. He is being treated for recurrent lymphoma for the third time in the four years.

Mr. and Mrs. E. do most things together, in part because she does not drive a car and in part because they like it this way. In observing them together, it is easy to see how Mrs. E. buffers her husband from disruption. She anticipates his needs, expresses concern, and allows him to air frustrations. Mr. E. is still active, but chooses his activity carefully in the face of profound fatigue. Mr. E. expresses few concerns for himself. He is hard at work on his memoirs, and has considered the end of his life in detail:

> "I have no desire to end life. I think that if I were in extreme pain, if I were in deep suffering, I think possibly I could try to find a way out. There's more than one reason -- not only for myself -- but I wouldn't want her to be exposed to this kind of a situation, per se. She may feel bad about it, but once it's over, you adjust to that, too. I've always considered that death was part of living." (13,10,418-28)

His concern is for his wife and the effect of the way he handles cancer will have on her.

Conclusion

Mrs. V., Mrs. S., Mr. G., and Mr. E. are very different people, albeit of the same generation, leading very different lives. Each, in her or his own way, has integrated cancer into her or his life. At the level of behavior, this integration is unique to the individual because of the individual conditions of life experience and living patterns which shape it. At the level of self, however, the process which frames the behavior and is concomitantly guided by life experience is essentially the same.

The overarching conditions of old age, having cancer, and receiving treatment are common to all four paradigm participants. All do for themselves to the extent they are capable. And all four have experienced the process of a dialogue with themselves that can be abstracted to the phases "life before cancer", "coming to bouts with yourself", "redefining the thresholds of daily living", and "living on new terms". The highly individual manner in which each of these participants goes through the process is expressed in their particular ways of being "engaged in living a life mostly lived".

CHAPTER VI

Discussion of "Integrating Cancer Into a Life Mostly Lived"

Introduction and Statement of Purpose

The results of any scientific investigation, from either the naturalistic or the positivistic paradigm, must be evaluated by established criteria to judge internal structure, external utility, and the contribution made to knowledge of the phenomenon studied (Lincoln & Guba, 1986). Grounded theory, and qualitative methods broadly, has accepted criteria by which to evaluate internal structure and aspects of external utility.

It is my purpose to apply those standards to "integrating cancer into a life mostly lived". I will approach other issues of external utility and the contribution to knowledge of the experience of cancer for the elderly around the task of applying the standards. First, I will discuss the adequacy of "integrating cancer into a life mostly lived" as grounded theory. Here, I detail the limitations of design and sampling. Second, I will argue the significance of "integrating cancer into a life mostly lived" in light of current knowledge and the possibility of alternate explanations that may offer greater explanatory power. This is, in part, a discussion of the limitations of the investigator as instrument. Third, I suggest implications the grounded theory has for nursing. And fourth, I conclude with directions for future research in the experience of cancer for the elderly and their symptoms.

Adequacy as Grounded Theory

Several sets of classic standards exist for evaluating the adequacy of qualitative research. Lincoln and Guba (1985) offer one of the most comprehensive and widely used set of standards in the naturalistic paradigm.

Sandelowski (1986) based her explication of the controversy over comparability of quantitative and quantitative evaluation standards on the four issues of trustworthiness outlined by Lincoln and Guba (1985). They are truth value, applicability, consistency, and neutrality. I will use consistency and neutrality to discuss the possibility of alternative explanations of the data.

Glaser and Strauss (1967) offer the classic criteria for evaluation of grounded theories. Strauss and Corbin (1990) offer evaluation criteria as a set of seven useful questions. The seven questions are designed in somewhat greater detail while being equivalent to the content covered by Glaser and Strauss (1967). Glaser and Strauss (1967) and Strauss and Corbin (1990) also touch on issues similar to those addressed by Burns (1989). Burns (1989) offers a set of standards intended for use in nursing. I will not use the standards offered by Burns (1989) because they are not specific to GT. For parsimony and precision in this discussion, I will use the four criteria of fitness, understanding, generality, and control initially posited by Glaser and Strauss (1967). Fitness is roughly analogous to Lincoln and Guba's (1985) truth value. And understanding, generality, and control are largely issues of applicability as discussed by Lincoln and Guba (1985).

Fitness. Fitness is the idea that a grounded theory must fit the phenomenon under study (Glaser & Strauss, 1967). "Integrating cancer into a life mostly lived" is grounded in the words of the people who live the phenomenon. I have used as many quotations as possible to secure that grounding. More importantly, I "tried out" partial "integrating cancer" interpretations of the last three participant's experiences on them after their interviews. "Integrating cancer" felt like it fit for them. This was one of my greatest assurances of fitness.

Further, a validation interview was completed with the only participant who had offered to review the findings and who was still alive and well enough to do so at the time of completion. Another participant desperately wanted to review the findings but had just undergone unproductive Taxol therapy for her recurrent ovarian cancer. She, on the telephone, was so intensely focused on cancer in "redefining the thresholds of daily living" that an interview would have been too much to bear.

The validation interview was structured to allow time for clarifying questions left from the first interview. The participant was then given a copy of a presentation outline that included supporting quotations and figure 2 from chapter five. The figure was explained logistically and with a tandem theoretical interpretation of this participant's experience. She said, as I have it in my notes: "Amazing. This is what I would have said if I could articulate it in this way."

The participant was unable to stop reading the outline, despite nausea and another appointment. As the participant read, she would stop and compare the quotations with her own experience. And, all the while she marveled at my ability, she said, "to tell it like this and draw it too." Finally, she stopped reading and asked permission to take the outline and figure to an 85 year old friend who had lung cancer so that she too could have the information it provided. Certainly, returning to the source for critique is one of the strongest sorts of affirmation available to GT.

Understanding. I have sought reaction to "integrating cancer" as a way of judging understanding. Does it correspond to the realities of the experience of cancer for the elderly for people who know it? (Glaser & Strauss, 1967) To date, I have presented these findings to oncology nurses, nurse researchers, student nurses, and lay people who have had experience, directly or indirectly, with cancer for the elderly. In all cases, people have said that "integrating cancer" is congruent with their perceptions of the experience of cancer for the elderly. The grounded theory appears to feel right for people who hear it described.

Generality. In order to be at all useful, a grounded theory must be able to account for many conditions and variation in a process (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Several aspects of "integrating cancer" were developed during the analysis to insure generality. Conditions attached to each aspect of the process were specified, and behavior was described where possible. It is the response of people who have familiarity with the phenomenon that "integrating cancer" can encompass the specific experience with which they are familiar.

Control. One must be able to have sufficient control of common situations that pertain to a phenomenon in order to use a grounded theory (Glaser & Strauss, 1967). This notion is the reverse of generality. A grounded theory must be broad enough to represent variation, but detailed enough to be useful in real life. Again, when it is presented, people begin to manipulate "integrating cancer" and apply it to situations with which they are familiar. Additionally, the fact that I will draw implications (and later discuss them) for nursing from the grounded theory also supports its quality of controllability.

On the whole, by the standards set out by Glaser and Strauss (1967), "integrating cancer into a life mostly lived" is adequate grounded theory.

Limitations of Design and Sampling. While "integrating cancer" appears adequate as grounded theory it is still limited by science and reality. There are flaws in the design and sample, let alone the real life considerations of limited funding and a need to complete this project in a timely fashion. I fully acknowledge them in relation to myself, as novice investigator, and to the project as the first step in what I hope to be a long walk toward understanding the experience of cancer for the elderly.

The cross-sectional design aimed to gather information from as diverse a group of participants as possible in a timely fashion. I acknowledge that it is impossible to observe the process over time in this manner. I was given a retrospective account by individuals and had to piece together 'snap shots' of individuals at different points in time in order to produce the 'movie'. This alters the perspective and the consistency of the grounded theory.

Several groups were not accessed in the sample and I acknowledge the loss of representativeness in sample this creates (Morse, 1986). Cancer is, as the saying goes, an 'equal opportunity killer'. It affects all people, especially the elderly. Both genders and all ethnicities, socio-economic strata, sexual preferences, and religions are affected. Therefore, the following characteristics limit the representativeness of the sample:

* men outnumber women, albeit slightly
* only two African American participants were accessed and both were men
* no Asian and Hispanic American elderly participated

* no homosexual elderly participated

* no elderly individuals with upper gastrointestinal, head and neck, and lung cancers participated in the formal sample

* only one participant had to deal with care at home that involved high levels of technology

The stories of elders with these characteristics will certainly refine and may change "integrating cancer into a life mostly lived" because they are different in substance and likely in form. Representation of gender is important because women are more likely to live longer than men; hence, women are more likely to be widowed and to live alone when they are old. Ethnic diversity is essential to knowing the full range of the experience of cancer in the elderly. In particular, individuals of different cultural backgrounds may be influenced by different meanings of what it means to be old and to have cancer than are the participants of the present project. This may also be true for homosexual elders. In addition, the life experience of these elders may reveal new categories in the integration typology.

Individuals with upper gastrointestinal and head and neck cancers are at greater risk for symptoms around eating and oral health (Wilson, Herman, & Chubon, 1991). Those with head and neck tumors may also have disfiguring surgery, the effects of which are readily observed (Langius, Bjorvell, & Lind, 1993). Individuals with lung cancer have an increased chance of respiratory symptoms, including dyspnea (Gift & Pugh, 1993). The experience of these symptoms was not commonly reported in the data for this study. These do, however, seem to be disruptive symptoms as described in current literature and in my clinical observations. Collecting data from individuals for whom they are prominent, then, seems to be in order.

The experience of highly mechanized or procedural care at home where the burden of care falls to the elderly person, family, or friends is also not represented in the data for this project. This experience is becoming very common as cost constraints in health care grow tighter. Consequently, analyzing the ramifications of such experience on "integrating cancer" for elders who may have diminished sensory-perceptual capacity required to manage this sort of care seems essential.

However, those individuals who participated informally and formally all contributed dense, diverse data of high quality. Therefore, the sample is still satisfactory when evaluated by the criteria set out by Morse (1986, 1991). A non-probability sample is judged satisfactory, but not optimal if, even though the sample is considered inappropriate because it is not fully representative, yet the data obtained are of high quality and diversity and therefore are adequate.

The Significance of "Integrating Cancer Into a Life Mostly Lived"

The process I have described through constant comparative analysis of the data collected from my participants is quite unlike anything in the data-based literature exploring any aspect of the phenomenon under study. The review in chapter two supports this conclusion. The current study employs the GT method within the naturalistic paradigm to induce theory rather than deduce group characteristics or between group differences. It is informed but not structured around existing theory as discussed in chapter two. The influence of developmental theory was apparent to a participant: "My sense is that . . . that your research project has to do with including cancer as a part of life, but not all of it, and that in order to . . . it might be useful to help others see it in that sense" (9,40,1768-73) This grounded theory, like all others, is intended to offer conceptual descriptions that may become useful beyond the group studied to groups having similar characteristics. At no time does the grounded theory intend generalizability to the population of all elderly who have cancer.

"Integrating cancer into a life mostly lived" is, despite its perspectival and methodological departure, similar in certain respects to issues highlighted by positivistic literature that investigates aspects of the phenomenon and with findings of particular research performed outside this area. This grounded theory validates symptom experience for the unobservable symptoms. These symptoms, like pain, nausea, and fatigue, commonly reported by the participants, may be more serious for the elderly because of limited functional reserve (Becker & Cohen, 1986). Greenberg, et al.. (1993) and Love, et al. (1991) offer similar confirmation from a positivistic perspective. They suggest respectively that radiation-related fatigue and tamoxifen, a purportedly benign treatment, are experienced at profound levels by elderly people with cancer. "Integrating cancer into a life mostly lived" underscores the significance of symptoms by placing them in context and revealing how they disrupt daily living.

Like Brown (1993), Edlund and Sneed (1989), Larson, et al. (1993), and Nerenz et al. (1986), the process of "integrating" dispels myths of fragility and predisposition to disengagement among the elderly who have cancer. While the data suggest the participants were all quite ill, and close to death in some cases, all functioned at some level and often required some assistance. Death as an escape arose in discussion infrequently and the contextual notes underscored that these were not overwhelmed individuals. The participant group was generally too white and too male to be demographically representative of our current elderly population. Nonetheless, the group was not selected for high functional status or minimal disease. These participants and their data support "integrating" as a process which does not contribute to myths about the elderly and cancer.

"Integrating cancer into a life mostly lived" emphasizes the importance of many levels of context that other studies have proposed as important. Aging changes, from Satariano, et al. (1991),and life experience combining multiple problems and loss that amplify with age, from Baider, et al. (1992), Ganz, et al. (1985), Goodwin, et al. (1991), Heidrich and Ward (1992), and McGill and Paul (1993), are all incorporated to some degree in the process. The process of "integrating" is nothing without layers of context from the philosophical dialectic to engagement in daily living with all attendant conditions. These layers of context reveal a richer understanding of symptoms and the experience of cancer for the elderly.

Achieving the aim and making a distinct contribution. Much of "integrating cancer into a life mostly lived" lies beyond the communalities with existing literature examining aspects of the experience of cancer for the elderly. "Integrating cancer into a life mostly lived", through a new perspective and inductive approach, offers a conceptual understanding of the experience and the place of symptoms within that experience. The aim of gaining a conceptual understanding through study of symptoms is achieved in the process identified.

It is, albeit, an emerging understanding. "Integrating" is a beginning not found elsewhere. No existing published work accomplishes the scope or the density of this grounded theory. Indeed, no other work is grounded directly in the data given by elderly people who have cancer in a manner where they guided what information was shared. In these ways, "integrating cancer into a life mostly lived" makes a unique contribution to knowledge of the phenomenon studied.

Alternative explanations. The grounded theory, while making a contribution, is not held up as the definitive understanding of symptoms and the experience of cancer for the elderly. That claim is beyond the method and the paradigm. I agree that different investigators may arrive at a grounded theory that looks different from the one I produced. Two issues are at hand here. They essentially are questions of investigator as instrument and analyst. The first is posed as the question of consistency and maintenance of dependability by Lincoln and Guba (1985) (Sandelowski, 1986). The second is the question of neutrality and maintenance of confirmability (Lincoln & Guba, 1985; Sandelowski, 1986).

Consistency and dependability are concepts analogous to reliability in evaluation of quantitative research. An adequate grounded theory must be consistent in structure and explication to be useful and relevant. Rigorous application of GT is necessary to achieve a consistent, dependable product. In the discussion of methods, I discussed the manner in which I employed GT and means used to maintain the rigor in that application. That discussion confers a level of auditability on "integrating cancer". The reader is given insight into the process of data collection and analysis in the hope of confirming dependable findings.

Neutrality and the maintenance of confirmability is akin to objectivity in positivistic science (Sandelowski, 1986). In the naturalistic paradigm, subjectivity is valued and achievement of objectivity questioned. It is unlikely that other investigators, given the same participants and method, would produce exactly the same grounded theory despite that I laid bare the application of method. The investigator is the instrument for data collection in studies such as this. I collected data that was as consistent and neutral as possible in each interview. The study began and continued with careful self-examination (Lipson, 1986). The early discussion of theoretical underpinnings is evidence of that examination as it pertained to world view. Other investigators, with different world views, would likely have seen the data through a different 'colored' lens thereby synthesizing a grounded theory with other 'colors'.

In addition, I and my work developed over the course of the project with a necessary measure of reflexivity, as with all qualitative work. Part of that development is discussed in chapter four. Again, my development during the course of the study was uniquely mine. I worked toward self-knowledge in order to maintain the greatest degree of neutrality possible. Development other than mine as I experienced it would likely generate grounded theory of different shape and language than "integrating cancer".

I argue that "integrating cancer" is nonetheless both dependable and confirmable. The use of GT is presented for the reader to judge dependability. Confirmability of the nature of the grounded theory is seen in the parallels made with references to existing literature in chapter four. These are the evidence presented to make a case for consistency and neutrality in "integrating cancer into a life mostly lived".

Implications for Nursing

The grounded theory presented here is a product of GT in the discovery mode (Artinian, 1988). The categories and relationships at hand in the phenomenon are presented, in the form of a grounded theory, toward the end of a conceptual understanding. It is the conceptual understanding which offers ideas that may be transferred to groups other than that studied (Artinian, 1988; Lincoln & Guba, 1985). In no way are the characteristics and specific patterns exhibited by the participants themselves generalizable.

The implications of the study findings for nursing are, because of the mode of GT and the nature of qualitative applicability, perspectival and conceptual. "Integrating cancer" requires further confirmation and refinement with GT in the emergent and intervention modes to draw specific conclusions for nursing. The small sample size warrants expansion in future studies to obtain a volume of data sufficient to confirm saturation and refine concepts. Nonetheless, there are suggestions for nursing that come out of new understandings generated by "integrating cancer into a life mostly lived" .

I often say to nurses that I am not revealing anything wildly new. In fact, I argue, what I am now articulating has existed all along and many among us may have apprehended bits and pieces of it. I am only synthesizing the experience of cancer for the elderly in a new way and affording it accessibility as a whole. Therefore, the primary implication of "integrating cancer" is a new potential understanding, or gestalt, of symptoms and the experience of cancer for some elderly. It will not work for all elders who have cancer and it may offer insight into the experience of some elderly who have other, similar illness.

Specific philosophical and theoretical implications are suggested by the nature of "integrating cancer into a life mostly lived" and the tenor of the data. "Integrating cancer" implies, through the absence of the language of dichotomy and war, that these historically-based cultural understandings of old age and cancer, respectively, are not salient for the elderly who have cancer themselves (Cole, 1992; Patterson, 1987). The understandings may, however, be part of the world view to which nurses and other health care providers, who are neither old nor have cancer, subscribe.

The grounded theory underscores some of the notions I posited in the theoretical foundations for the project. First, none of the participants described themselves as without some purpose and role in society. This is congruent with Cremin's (1992) findings about perception of old age. The notion of success and failure, or usual and successful, in Rowe and Kahn's (1987) terms, never arose in the interviews. The participants acknowledged loss of capacity and relationships as part of aging, not the whole of it. The pictures of their lives that the participants conveyed were seamless and marked by their own experiences, not by old age.

Second, none of the participants described waging an all consuming war against cancer. Integration is truly at the heart of the data and, hence, at the heart of the grounded theory. No participant was "living in the cancer" with all aspects of daily living taken over by cancer. All data collected here points to making cancer fit in to existing patterns of daily living in a well established life.

The absence of dichotomous old age and "War" metaphors in the elders' language suggests that nurses and other health care providers, who may use these culturally defined understandings in their work with the elderly who have cancer, might re-evaluate their approaches to these individuals. The possible mis-match between the meanings of old age and of cancer brought to health care interactions by patients and providers may inhibit optimal nursing and health care. "Integrating cancer" implies that apprehending the elderly individual's own construction of what it means to be old and have cancer is important.

"Integrating cancer into a life mostly lived" implies that attention to context is also important to nursing practice and research. The significance of contextually-bound comfort, the concept developed by Hamilton (1989a, b) and Kolcaba (1992) in relation to the elderly, is underscored by "integrating cancer". The data and the grounded theory reveal that not the symptoms themselves, but the disruption they cause, which breaches a threshold of discomfort, is what is managed in the experience of cancer. Disruption and discomfort are defined in terms of life experience, body knowledge, and current patterns of daily living. Those terms may include chronic illness and other problems that are of far more concern for a particular elder than is cancer. Context defines what needs to be managed for an individual. Hence, this grounded theory emphasizes the need for nurses, and other health care providers, to assess the context in which an elderly individual is experiencing cancer.

New Directions for Research

Clearly, this grounded theory is a beginning. There is much work to be done to verify the adequacy of "integrating cancer into a life mostly lived". Work in the emergent mode of GT is required. The process, philosophical dialectic, integration typology, process phases, and behavioral outcome must all be tested, refined, and confirmed with new data and emergent mode analysis. Research for the next gains in understanding the experience of cancer for the elderly should, then, likely go in two directions.

A longitudinal study, or series of studies, that addresses the groups not represented in the current sample is needed. Data must be gathered as individuals are followed through the entry phase and through an extended period of the primary phases. The addition of participant observation, as an unobtrusive measure to inform the study about the experience of elders who cannot or will not participate in a formal interview would be helpful (e.g. individuals who appear disengaged from daily living; those unable to speak fluently or intelligibly enough for an interview) (Denzin, 1989).

Collecting information about the experience from "something is wrong" before diagnosis to, possibly, death will likely reveal greater detail and help refine "integrating cancer". Of special interest is the need to isolate the beginning and end of the process. The data for the present study strongly suggests that the process of "integrating cancer into a life mostly lived" begins with the entry phase and the transition from "life before cancer" into one that includes cancer. The end of the process is less clear.

My clinical experience implies that the process of "integrating" ends with death. However, the philosophical dialectic on living, dying, and death suggests a distinction between physiological death and a perceptual death. Physiological death is the end of life. A perceptual death may be the state when the thresholds for acceptable quality of living defined by the individual are breached and cannot be redefined. Death is then seen as preferable to current patterns of living. Data from elders who are very close to death and able to be interviewed is necessary to confirm or disconfirm perceptual death.

Another study in the emergent mode that uses comparison groups within the group of the elderly who have cancer is also needed. As is evident in the description of the final sample in chapter four, there are three basic patterns of having advanced cancer. There are those individuals who have constant, progressive cancer over the time since diagnosis. There are those with recurrent cancer. And there are those with two, or perhaps more, unrelated malignancies. The role these patterns play in "integrating cancer" is unclear from the existing analysis. Uncovering the role, if any, is necessary to fleshing out "integrating cancer into a life mostly lived" and would be of clinical utility as the patterns are easily recognized. A comparative study employing sequential interviews with individuals experiencing cancer in each of the three patterns would elucidate the role in "integrating cancer into a life mostly lived".

Conclusion

"Integrating cancer into a life mostly lived" offers understanding of a process in the experience of cancer for some elderly individuals. Perhaps the concepts generated in the constant comparative analysis of the data the participants provided will, after continued work, illuminate aspects of other phenomena. However, "integrating cancer" represents something more than a fledgling contribution to science for me. This grounded theory represents synergy between me and the 19 elderly individuals with cancer who had rarely been asked 'what it is like to have cancer at your age?'.

Most of the participants indicated directly to me or to the CNRLs that I had, in some way, made a difference in their lives by asking that question and promising to spread their words, their stories. That contribution on their parts was important even without their names attached. We completed the psychosocial life cycle, they and I, person to person and face to face. I was able to give voice to the stories they shared with me and to learn from them. I hope that the voice I give them will inform other health care providers as it did me and, perhaps, free other elderly people to speak once they know they will be better heard. But, even if it does not, what my project and I offered made some difference for the elderly people I came to know as well as promoting my growth and knowledge.

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APPENDIX ONE

A Grounded Theory Exploration of Symptoms in Elderly Individuals with Common Solid Tumors

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Specific Aims

The proposed study seeks to explore qualitative aspects of the perception and experience of symptoms (e.g. pain, nausea, fatigue) in elderly individuals with the most common solid tumors (i.e. lung, colon, breast, and prostate) and develop a preliminary conceptual understanding of this area. Grounded Theory (GT), with its roots in Symbolic Interaction (SI), (Glaser and Strauss ,1967; Strauss and Corbin, 1990) provides the philosophical, theoretical, and methodological basis for investigating and developing a conceptual understanding of the question ' what symptoms are perceived as important and how are they experienced by people over 65 years of age with lung, colon, breast, and prostate cancers'?

A theoretical sample will be constructed within the parameters of tumor type and age (Morse, 1986). Age will be interpreted as the decade of peak tumor incidence. The incidence of lung and breast cancers peaks in sixth decade; colorectal cancer peaks in the seventh decade; and prostate cancer peaks in the eighth decade (Groenwald, 1987). Representative gender and ethnic distributions will also be sought (Good, Good, Schaffer, & Lind, 1990).

Significance to Nursing

Investigation of the perception and experience of symptoms for elderly individuals with solid tumors is inherently of concern to nursing and particularly to oncology nursing. The study of symptoms, as a response to disease and illness, falls within the scope of nursing practice as defined in the Social Policy Statement (American Nurses Association, 1980).

Furthermore, it may be construed that the professional Oncology Nursing Society may soon identify symptoms in geriatric oncology as a priority area for research. Symptom management was a leading priority area in the 1991 Research Priorities Survey (Mooney, Ferrell, Nail, Benedict, & Haberman, 1992). Additionally, several of the expert survey respondents identified cancer in the elderly as an area deserving of research (Mooney et al., 1992).

Understanding qualitative aspects of symptom experience for elderly individuals with cancer will comprise, in part, the basis for future work around comfort and symptom management in this needy population (Eisenberg, 1977; Given & Keilman, 1990; Hamilton, 1989; Hunt, Jordan, & Irwin, 1989; Jacox, 1989; Kleinman, Eisenberg, & Good, 1978; Tripp-Reimer, 1984). Jacox (1989) offers an illuminating theoretical discussion of comfort, found in relief from discomforting symptoms like pain, fatigue, and nausea. She posits the idea, pertinent to the proposed research, that the phenomena created by the experience of such symptoms should be studied contextually and without separation in exploratory research. Pain, fatigue, and nausea often occur together, especially in cancer (Jacox, 1989). Study of them and other symptoms within the context in which they occur preserves valid description of the larger experience.

Hamilton (1989) achieves this preservation of context in her study 'Perceptions of comfort by the chronically ill hospitalized elderly'. The qualitative study revealed five themes in the responses of 30 institutionalized elders to a semi-structured interview. The five themes are: a) disease process, including pain, bowel function, and physical disability; b) self esteem, incorporating how subjects felt about themselves, decision making ability, and faith; c) positioning, including both physical position and environmental considerations; d) approach and attitudes of staff; and e) hospital life, encompassing most of the routinized and social aspects of institutional life. These five themes underscore the idea that the experience of symptoms, and relief from them, is one of the symptoms themselves and of the environmental and interpersonal context in which they occur. The perception and experience of comfort for this sample is rooted in interaction.

The results of this study are limited with respect to conceptual validity for the population of the proposed study. However, it is interesting to note that the results are reported to be congruent with those of Hamilton's unpublished 1985 study of the perception of comfort in 14 terminally ill individuals with cancer. Hamilton's (1989) assertion of congruence between results in the two samples, which together encompass the key aspects of the sample delineated for the proposed study, is intriguing. It implies support for the contextual investigation of symptoms in elderly individuals with solid tumors as outlined here.

Background

Cancer in the elderly has reached epidemic proportions. The statistics are startling and reported with increasing frequency. Baranovsky and Meyers (1986) show that people aged 65 and older account for 59% of all cancers diagnosed in males and 52% of all cancers diagnosed in females. Yet that age group currently accounts for less than 15% of the entire United States population (Baranovsky & Meyers, 1986; Given & Given, 1989). Tumors of the lung, colon, breast, and prostate are the most common tumors for all ages by virtue of their prevalence among the elderly (Boring, Squires, & Tong, 1992). The magnitude of cancer in the elderly is increasingly obvious. Yet the quality of the perception and experience of cancer for elderly individuals is largely unexplored.

There has been a proliferation of clinical literature to guide care of these individuals (Author, 1991). Symptoms and side effects of cancer in the elderly have become an important focus. However, this literature is largely without empiric support (Author, 1991). It is punctuated by a few descriptive, quantitative studies (Nerenz, Love, Leventhal, & Easterling, 1986; McMillan, 1989; Satariano, Ragheb, Branch, & Swanson, 1990). Such studies assume certain symptoms are significant to the population on the basis of experience with younger populations. Most aim to quantify differences in symptom intensity on the basis of age (Nerenz, Love, Leventhal, & Easterling, 1986; McMillan, 1989; Satariano, Ragheb, Branch, & Swanson, 1990).

Other research reports, such as that offered by Ferrell, Rhiner, Cohen, and Grant (1992) do not pursue age as a variable in the investigation of cancer symptoms. Nevertheless, advanced age of samples is reported. Ferrell et al. (1992) investigate pain experience for individuals with cancer and their family caregivers using a Quality of Life framework and content analysis, with reliance on Phenomenology. The mean age of subjects was 62 years (range=26-95 years, SD=13.47). The mean age of caregivers was 54 years (range=22-85 years, SD not reported). The advanced age of the sample is apparently viewed as part of the demographic character of the population under study. The possible contribution of the extremes in age seen in the sample to the experiences described is not explored by the authors.

Interjection of age into the clinical picture created by cancer adds complexity at every level from the physiological, with differential chronological and disease related change, to the psychosocial, with individual and cohort level influences (Balducci, Phillips, Davis, Files, Khansur, & Hardy, 1988; Benson, Kaplan, & Olsson, 1987; D'agostino, Gray, & Scanlon, 1990; DeMaria & Cohen, 1987; Edlund & Sneed, 1989; Guadagnoli, et al., 1990; Manton, Wrigley, Cohen, & Woodbury, 1991; Palinkas, Wingard, & Barrett-Connor, 1990). Such issues alter the perception, relative importance, and experience of symptoms and may increase variation within the population. Investigators have begun to establish that symptoms (e.g. pain, nausea, and vomiting) may be experienced less intensely by elderly individuals with cancer (Nerenz, et al., 1986; McMillan, 1989; Satariano, et al., 1990). However, no one has yet explored whether these symptoms are of significance to elderly individuals, or whether others are of greater consequence. In addition, no one has investigated how prominent symptoms are perceived and experienced over the cancer trajectory.

Literature Review

Two pertinent research reports are illustrative of the state of the literature. In addition, they highlight gaps in the literature and methodological issues. These reports address the difference age creates in symptoms of cancer and its treatment. Nerenz et al. (1986) studied alopecia, nausea, and fatigue. McMillan (1989) investigated nausea, vomiting, and pain.

Nerenz et al. (1986) employed a descriptive design to examine correlations among alopecia, nausea, and fatigue with levels of emotional distress, difficulty, and disruption. The convenience sample was comprised of 238 individuals, receiving chemotherapy for lymphoma (n=71) or breast cancer (n=167), who were interviewed five times over the first six months of treatment. Age of subjects ranged from 19 to 83 years (mean=51.7). When the effect of age was controlled in the analysis, there were no significant differences in the correlations for older as opposed to younger subjects.

The suggestion that the elderly subjects with breast cancer or lymphoma experienced no greater level of distress, disruption, or difficulty from alopecia, nausea, and fatigue is intriguing given the conventional wisdom that these people are less able to withstand the rigors of cancer treatment. However, this study is marred by the absence of a) a true control group; b) illogical sample construction and description with regard to age, malignancy, and comorbidity, and c) inadequate discussion of the limitations these and other flaws create for internal and external validity. Little confidence can be placed in the conclusions offered by Nerenz et al. (1986).

McMillan (1989) reports on nursing research which explored the relationship between age and the self reported intensity of pain, nausea, and vomiting. The study itself is a secondary analysis from two earlier studies of symptom intensity and age in convenience samples of outpatients receiving chemotherapy for breast and lung cancers (nausea and vomiting, n=25; age range=33-72, mean=58.3) and inpatients with various cancers (pain, n=99; age range=23-82, mean=53.2). Age was found to be moderately negatively correlated (r=-.22 to -.46; p<.05) with self reported symptom intensity, as measured by the visual analog scale for pain and the Index of Nausea and Vomiting. The exception was for vomiting alone where the correlation was not statistically significant (McMillan, 1989).

McMillan's (1989) findings echo those of Nerenz et al. (1986). They are substantially strengthened by a sophisticated and honest discussion of the study's limitations. The author discusses problems around self report of symptoms. She places emphasis on the possibility of underreporting by the elderly and the importance of individual versus group differences when considering issues of practice for the elderly, a population known to be physically and psychosocially heterogeneous (Balducci et al., 1988; DeMaria & Cohen, 1987; Given & Keilman, 1990).

These research reports suggest differences in the quantifiable aspects of symptom experiences exist in elderly individuals being treated for cancer when they are compared with younger individuals. The qualitative aspects of these experiences, however, must be addressed through appropriate methodologies to create a more complete and informative understanding of the process elderly individuals with cancer undergo. Understanding the qualitative experience of symptoms is achieved through methods which elucidate individual differences and conceptual themes among heterogeneous samples (Artinian, 1988). McMillan (1989), in discussing the limitations of her study, implied the need to explore these aspects of symptom experience.

Methods

Grounded Theory offers two primary advantages when researching questions such as that posed in this study. The first advantage is theoretical. Grounded Theory is a theory generating methodology which provides conceptual schemata of phenomena under study (Artinian, 1988; Glaser & Strauss, 1967; Strauss & Corbin, 1990). It does so, however, without superimposing predetermined theoretical frameworks on unknown realms. Rather, GT relies on SI, a sociological theory which assumes human communication is symbolic and meaningful, for broad philosophic and theoretical structure (Glaser & Strauss, 1967; Mead, 1962; Turner, 1968). Symbolic Interaction is particularly suited to achieving the aim of this study. The perception and experience of symptoms in cancer is both influenced by and influences communication with others (Good et al., 1990; Kleinman et al., 1978; Morris & Sherwood, 1987; Patterson, 1987). .

The second advantage lies in the product of GT. Grounded Theory reveals conceptual understanding of a phenomenon , unlike more traditional quantitative designs which offer statistically generalizeable results. Generalizeable results are necessary to an empiric description of a phenomenon. Nevertheless, it may more useful to an area in need of both research and theory development, as with cancer in the elderly, to gain conceptual understanding in preliminary work. It is the conceptual product of GT which is judged generalizeable, or fitting, based on the merits of the research (Conrad, 1990).. The conceptual results can then form the basis for further study, suggest new directions, and offer more immediate clinical applicability (Artinian, 1988; Morse, 1986; Corbin & Strauss, 1990).

The proposed study will utilize a G T approach. Data will be collected through detailed, open ended interviews with participants. Employing the constant comparative technique central to GT, each interview will be compared with subsequent and future data as well the investigator's and her committee's clinical experience to ground the analysis (Corbin & Strauss, 1990). The final conceptual model will be validated with several participants as well.

A theoretical sample of 16 to 20 individuals with confirmed diagnoses of lung, colon, breast, or prostate cancers who are 65 years of age or older will be recruited from a university medical center (Morse, 1986). Even distribution of four to five participants from each diagnostic group will be sought. Approval from the institution's Committee on Human Research will be obtained. Access to appropriate candidates for participation will be gained through the oncology clinical nurse specialist associated with the medical center. She will make preliminary judgements about whether particular individuals meet inclusion criteria and are interested in participation. Final decisions to offer participation to individuals who meet the criteria will be made by the co-principal investigator. Informed consent and permission to tape record the interview will be sought from each participant.

The theoretical parameters for sampling, gleaned from extant research, are age and common solid tumor types. Heterogeneity within the sample for age, ethnicity, and disease course will be deliberately pursued to maximize variation and avoid premature saturation of analytic categories (Ammon-Gaberson & Piantinida, 1988; Good et al., 1990; Morse, 1986). Even distribution between genders and among tumor types will be sought for the same reasons. Participant accrual will end when analytic categories are judged saturated by the investigator and her dissertation committee. Saturation is the case in which participants are no longer conveying new conceptual information (Corbin & Strauss, 1990; Morse, 1986).

Specific sample inclusion criteria are: 1) the participant must have the ability to communicate verbally with the investigator in English; 2) the participant must have had treatment for the tumor within the past six months but be at least three months from diagnosis; 3) the participant must have no current evidence of mental status changes, whether from age-related comorbidity or metastasis; 4) the participant must be aware of the diagnosis of cancer; and 5) the participant must feel well enough to be interviewed for at least 30 minutes. Demographic data, including heterogeneity and inclusion criteria, will be reported.

Procedures

The primary instrument is the open ended interview between each subject and the co-principal investigator. The interview will begin with an introductory statement about the aims of the study and a broad opening question about the perception and experience of symptoms. Examples and focusing questions will be used as necessary (Corbin & Strauss, 1990). The typical interview is expected to last between one and three hours. Each interview will be tape recorded, if permission is given by the participant. Notes will be taken during the interview if permission to tape record is not given. Each interview will be followed with anonymous, observational notes by the co-principal investigator (Glaser & Strauss, 1967). These notes will focus on the contextual aspects of the interview not assessed by audio records and are included to enhance credibility, or internal validity, of the study (Sandelowski, 1986).

The co-principal investigator is the essential part of the instrument for the study. She will sharpen analytic skill through the avenues to develop and maintain theoretical sensitivity outlined by Glaser (1978) and Corbin and Strauss (1990). Analytic rigor is necessary to achieve credibility and fittingness of the conceptual results of qualitative research. It will be pursued and maintained through constant comparative techniques, consultation with the investigator's dissertation committee, validation with a subset of participants (Artinian, 1988; Sandelowski, 1986). The committee includes an acknowledged nurse expert in G T, an oncology nurse researcher, and a gerontological nurse researcher. The evolving codes will be compared with incoming data and with the clinical experience of the co-principal investigator and her committee to maintain valid codes. Significant questions are to be referred back to participants, who have given permission for telephone contact, for clarification.

Constant comparative analysis and the techniques for data coding and memo writing specific to G T form the core of the analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Conceptual categories will be sought in the data, developed, and refined. The end point of the analysis, along with the end point in subject accrual, will be seen in saturation of these categories (Ammon-Gaberson & Piantinida, 1988). The final result shall be a conceptual description of the perception and experience of significant symptoms, and the conditional matrix in which that process of perception and experience exists, for the sample of elderly individuals with solid tumors (Burns, 1989; Strauss & Corbin, 1990).

Validation of the conceptual description and conditional matrix is the final planned step of the proposed study. It will occur through presenting this information to participants, their caregivers, and health care professionals who work with the population under study for review and response. The credibility and fittingness of the result will be judged through the response of those to whom it is presented and the degree to which it truthfully represents the experience of participants and echoes similar experiences of others (Conrad, 1990; Sandelowski, 1986).

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APPENDIX TWO

A Grounded Theory Exploration of Symptoms in Elderly Individuals with Solid Tumors

Protocol

Study Aim

The proposed study seeks to explore qualitative aspects of the perception and experience of symptoms (e.g. pain, nausea, fatigue) in elderly individuals with the most common solid tumors (i.e. lung, colon, breast, and prostate) and develop a preliminary conceptual understanding of this area. Grounded Theory (GT), with its theoretical basis in Symbolic Interaction (SI), (Glaser and Strauss ,1967; Strauss and Corbin, 1990) provides the philosophical, theoretical, and methodological basis for investigating and developing a conceptual understanding of the question ' what symptoms are perceived as important and how are they experienced by people over 65 years of age with lung, colon, breast, and prostate cancers'?

A theoretical sample will be constructed within the parameters of tumor type and age. Age is interpreted as the decade of peak incidence (incidence of lung and breast cancers peaks in sixth decade; colorectal cancer peaks in the seventh decade; prostate cancer peaks in the eighth decade) (Groenwald, 1987). Representative gender and ethnic distributions will also be sought.

Background

Investigation of the perception and experience of symptoms for elderly individuals with solid tumors is inherently of concern to nursing. The study of symptoms, as a response to disease and illness, falls within the scope of nursing practice as defined in the Social Policy Statement (American Nurses Association, 1980).

Grounded Theory offers two primary advantages when researching questions such as that posed in this study. The first advantage is theoretical. Grounded Theory, as a theory generating methodology, will guide conceptual exploration of symptom perception and experience in elderly individuals with common solid tumors through collection and analysis of interview data (Artinian, 1988; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Grounded Theory relies on SI, a sociological theory which assumes human communication is symbolic and meaningful. Hence, the central theoretical assumption made for the proposed study is that the perception and experience of symptoms is meaningful and may disrupt communication with and by these individuals (Glaser & Strauss, 1967; Mead, 1962; Turner, 1968).

The second advantage lies in the product of GT. Grounded Theory reveals description of a phenomenon, like that of the proposed study, at a conceptual level. The end product of the proposed study will be a conceptually, as opposed to statistically, generalizeable description of the perception and experience of symptoms for elderly individuals with breast, colon, lung, and prostate tumors. The description will be discussed within the context of conditions, called the conditional matrix, under which the phenomenon occurs(Strauss & Corbin, 1990). These results can then form the basis for further study, suggest new directions, and offer more immediate clinical applicability (Artinian, 1988; Morse, 1986; Strauss & Corbin, 1990).

Design

The proposed study will utilize a G T approach. Data will be collected through detailed, open ended interviews with subjects. Employing the constant comparative technique central to GT, each interview will be compared with other data as well the investigator's clinical experience to ground the analysis (Corbin & Strauss, 1990). The evolving analysis will be validated against the investigator's and her committee's clinical experience, as well as with several subjects. In this way, the conceptual substance of the analysis will evolve and be refined.

Subject Population

A theoretical sample of 16 to 20 individuals with confirmed diagnoses of lung, colon, breast, or prostate cancers (four to five from each diagnosis) who are 65 years of age or older will be recruited from Mt. Zion Hospital and Medical Center. Access to appropriate candidates for participation will be gained primarily through the Mt. Zion Oncology Clinical Nurse Specialist. She will make preliminary judgements about whether particular individuals meet inclusion criteria. Final decisions about whether individuals meet inclusion criteria will be made by the co-principal investigator.

The theoretical parameters, gleaned from extant research, are age and common solid tumor types. Heterogeneity within the sample for age, ethnicity, and disease course will be deliberately pursued to maximize variation and avoid premature saturation of analytic categories (Morse, 1986). Subject accrual will end when analytic categories are judged saturated by the investigator and her dissertation committee. Saturation is the case in which subjects are no longer conveying new conceptual information (Corbin & Strauss, 1990; Morse, 1986). Even distribution between genders and among tumor types will be sought for the same reasons. Demographic data will be collected and recorded.

Specific subject inclusion criteria are: 1)the subject must have the ability to communicate verbally with the investigator in English and understand the consent process; 2)the subject must have had treatment for the tumor within the past six months but be at least three months from diagnosis; 3) the subject must have no current evidence of mental status changes whether from age or metastasis; 4)the subject must be aware of the diagnosis of cancer; and 5) the subject must feel well enough to be interviewed for one hour with time allotted for breaks, as needed, every 15 to 30 minutes (therefore, the minimum interview time may be slightly less than one hour).

Procedures

The primary instrument is the open ended interview between each subject and the investigator. The interview will begin with an introductory statement about the aims of the study and a broad opening question about the perception and experience of symptoms. Examples and focusing questions will be used as necessary (Corbin & Strauss, 1990). The typical interview is expected to last between one and three hours, minus time for breaks. Each interview will be tape recorded, if permission is given by the subject. Notes will be taken during the interview if permission to tape record is not given. Each interview will be followed with anonymous, observational notes made by the investigator (Glaser & Strauss, 1967). Specific permission for follow up contact by telephone, should questions arise during the analysis, will also be sought.

Risks

The potential risks and discomforts to subjects center around loss of confidentiality and discussing the often emotionally distressing subject of cancer. The methods which will be used to minimize these risks are 1) to make the opportunity to discontinue the interview and follow up telephone calls <u>at any time</u> part of the consent and interview process; 2) to identify all study materials with subject number only; and 3) to keep all study materials in a locked file drawer in the co-principal investigator's home.

Benefits

There is no direct benefit to subjects from participation. The potential indirect benefit to subjects will arise out of the opportunity to discuss symptoms with the co-principal investigator. Benefits to the population under study and contributions to nursing science will stem from conceptual description of the elderly subjects' symptom experiences. These findings may serve as pilot work for future investigations of age-related differences in cancer symptoms.

Consent Process and Documentation

Informed, signed consent will be obtained from individuals interested in participating in the study. Initial contact will be made by the Mt. Zion Oncology Clinical Nurse Specialist. She will refer individuals who meet inclusion criteria to the co-principal investigator. The aims of the study, procedures, risks, methods to reduce risks, benefits, and the right to decline participation without any jeopardy will be discussed with each potential subject. The consent form will be reviewed with each potential subject. If consent is given, the subject will be given a copy of the consent form to keep. Signed consent forms will be kept in a locked file drawer in the co-principal investigator's home.

Qualifications of Investigators

Margaret I. Wallhagen RN,PhD is assistant professor, Department of Physiological Nursing, University of California San Francisco. She is the co-principal investigator's dissertation sponsor. The proposed study is the co-principal investigator's dissertation research.

Sarah H. Kagan RN, MS, OCN is a PhD candidate, Department of Physiological Nursing, University of California San Francisco. She has completed course work necessary to the PhD, including work in research methods and substantive areas of nursing science. Ms. Kagan is also a practicing oncology nurse. She will be responsible for all interviews of subjects. Ms. Kagan will be closely supervised in the research process by Dr. Wallhagen and the other Dissertation Committee members, DeLois P. Weekes RN, DNSc., and Juliet M. Corbin RN, DNSc..

References

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Strauss, A. & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: Sage Publications.

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Subject Selection Checklist

__ 1)Communicates in English, understands consent process.
__ 2)Treatment within past six months; at least three months from diagnosis.
__ 3)Intact mental status.
__ 4)Aware of diagnosis of cancer.
__ 5)Feels well enough to be interviewed for 1 hour, with time allotted for breaks as needed every 15 or 30 minutes..

Interview Guide

Opening Statement

Thank you for agreeing to participate in this research study. I would like to tell you a little bit about the study so that we can begin the actual interview. I also want to remind you to ask me to stop the interview if, at any time, you should not want to continue for any reason.

The purpose of this study is to find out how people of your age with cancers like the one you have, deal with the symptoms of cancer and its treatment. Symptoms are the way you feel being ill, like pain, getting sick to your stomach, or feeling really tired. I'm interested in what symptoms you have, how bad they are, how much they get in the way of your activities, and anything else you want to tell me about them -- like when you have them and what you do for them. Does this make sense to you? Do you have any questions before we begin?

Focusing Questions

Focusing questions provided here are examples and will be used at the co-principal investigator's discretion.

A) How would you describe your experience with cancer?
B) Tell me about when you learned you had cancer?
C) What kind of treatment have you had for cancer?
D) How does the cancer make you feel?
E) What part of you, what percentage of your life is cancer?
F) How does the treatment or therapy you have had make you feel?
G) What symptoms or feelings have you had with therapy?
H) When do you have these symptoms?
I) What do you do for these symptoms?
J) How do people who are close to you react to your symptoms?
K) What do they do?
L) What is a difficult experience with cancer and therapy? easy?
M) What effect do you think your age has had on your experience of cancer and therapy?

Revised Interview Guide

Opening Statement

Thank you for agreeing to participate in this research study. I would like to tell you a little bit about the study so that we can begin the actual interview. I also want to remind you to ask me to stop the interview if, at any time, you should not want to continue for any reason.

The purpose of this study is to find out how people of your age with cancers like the one you have, deal with the symptoms of cancer and its treatment. Symptoms are the way you feel being ill, like pain, getting sick to your stomach, or feeling really tired. I'm interested in what symptoms you have, how bad they are, how much they get in the way of your activities, and anything else you want to tell me about them -- like when you have them and what you do for them. Does this make sense to you? Do you have any questions before we begin?

Focusing Questions

Focusing questions provided here are examples and will be used at the co-principal investigator's discretion.

A) How would you describe your experience with cancer?
B) Tell me about when you learned you had cancer?
C) What kind of treatment have you had for cancer?
D) How does the cancer make you feel?
E) What part of you, what percentage of your life is cancer?
F) How does the treatment or therapy you have had make you feel?
G) What symptoms or feelings have you had with therapy?
H) When do you have these symptoms?
I) What do you do for these symptoms?
J) How do people who are close to you react to your symptoms?
K) What do they do?
L) What is a difficult experience with cancer and therapy? easy?
M) What effect do you think your age has had on your experience of cancer and therapy?

APPENDIX THREE

University of California, San Francisco
Consent To Be A Research Subject

A. Purpose and Background

Sarah Kagan RN, MS, OCN and Margaret Wallhagen RN, PhD, in the Department of Physiological Nursing, are doing a study of symptoms in elderly persons who have cancer, which I am being asked to participate in.

B. Procedures

If I agree to be in the study, the following will occur:

1. I will be asked to give some demographic information about myself, like age and marital status.

2. I will be interviewed by Ms. Kagan about symptoms I have experienced since having cancer and being treated for it. The interview will take place at a time and in a place convenient to me. It will last about 1 and no longer than 3 hours, with time for breaks as needed.

3. If at any time during the interview I should become tired, I may stop the interview, reschedule it for another time, or take a break and resume the interview.

4. If I agree, audiotapes will be made of the interview.

5. If I agree, Ms. Kagan may call me at a place and times specified by me to clarify interview content. These telephone calls will be brief and will take place no longer than 3 months after the interview.

C. Risks and Discomforts

1. Some of the interview questions may make me upset. I am free to decline to answer any questions I wish not to answer, and to stop the interview at any time.

2. The interview may make me tired or fatigued. I am free to stop the interview at any time, reschedule the interview, or take a break and resume the interview when I feel less tired.

3. Sometimes the follow up telephone call may make me upset or be inconvenient. I am free to decline follow up telephone calls or to decline to answer any questions.

4. Confidentiality: Study records will be kept as confidential as is possible. No individual identities will be used in any reports or publications resulting from the study. Study information will be coded, and kept in locked files at all times. Only study personnel will have access to the files and the audiotapes. After the study has been completed and all data has been transcribed from the tapes, the tapes will be destroyed.

D. Benefits

There is no direct benefit to me from participation. There is potential indirect benefit to me from participation in that I will be discussing my symptoms with Ms. Kagan, who is a registered nurse, specializing in Oncology. My participation may benefit others through the knowledge gained from the study.

E. Alternatives

I am free to choose not to participate in this study.

F. Costs

There will be no cost to me as a result of participating in this study.

G. Reimbursement

I will not receive reimbursement for this study.

H. Questions

I have talked to Ms. Kagan about this study, and have had my questions answered. If I have further questions about the study, I may call Ms. Kagan at 415-731-3908 or Dr. Wallhagen at 415-476-4965.

If I have questions or comments about participation in this study, I should first talk to Ms. Kagan or Dr. Wallhagen. If for some reason, I wish not to contact them, I may contact the Committee on Human Research. The Committee is concerned with protection of volunteers in research studies. I may reach the Committee office between 8:00 am and 5:00 pm, Monday through Friday, by calling 415-476-1814, or by writing to the Committee on Human Research, Suite 11, Laurel Heights Campus, Box 0616, University of California, San Francisco, CA 94143.

I. Consent

I have been given a copy of this consent form to keep.

G. Tape Recording
I consent to tape recording of the interview.
YES__ NO__

H. Follow Up Telephone Calls
I consent to follow up telephone calls from Ms. Kagan should questions about my interview arise.
YES__ NO__

<u>PARTICIPATION IN RESEARCH IS VOLUNTARY</u>. I am free to decline to be in this study, or to withdraw from it at any point in time. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient, student, or employee at the Veterans' Administration Medical Center, Mt. Zion Hospital, or the University of California, San Francisco.

Date:______ Subject's Signature:______________________

Person Obtaining Consent:__________________

UCSF CHR #H6362-07902-01

Deborah Hamolsky
Mount Zion Medical Center
of UCSF
1600 Divisadero St.
San Francisco, Cal 94115

February 20, 1992

To Whom It May Concern:

This letter is written to support the implementation of Sarah Kagan's study entitled "A Grounded Theory Exploration of Symptoms in Elderly Individuals with Solid Tumors." Ms. Kagan has requested that data collection be done at Mount Zion Medical Center of UCSF primarily on the Oncology Care Unit where we care for many elderly patients. Symptom distress in the elderly is not well understood and yet symptom identification and management is an essential part of cancer treatment.

Sarah completed a preceptorship at Mount Zion while in the master's program. She was an asset to oncology practice while she was on the unit and I have respect for her clinical practice and communication skills with patients and staff. I have no reservations about her ability to conduct clinical research while respecting other clinical concerns in elderly patients.

The study has merit; the researcher is ethically and clinically sensitive. I, therefore, recommend that this study be done and I will facilitate whatever internal systems support is required. It is a pleasure to enable this work and Sarah's doctoral research to proceed.

Please contact me if further information is needed.

Sincerely,

Deborah Hamolsky

Deborah Hamolsky, RN, MS
Clinical Nurse Specialist Oncology/HIV

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH AFFAIRS, Box 0962
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

April 10, 1992

Sarah H. Kagan, R.N., M.S.
Department of Social and Behavioral Sciences
1326 17th Ave.
San Francisco, CA 94122

CONTINGENT APPROVAL of: A Grounded Theory Exploration of Symptoms in Elderly Individuals with Solid Tumors

Dear Ms. Kagan:

During the meeting of April 2, 1992, the Committee on Human Research reviewed your and Dr. Wallhagen's new application. *No work should begin on this study until final approval has been issued.* Final approval of this application is contingent upon your response to the following:

First, the members commented that the discussion of the aim and purpose of the study (as described on pages 1 and 2 of the protocol) is too technical and could be presented in a clearer fashion. Terms such as "Grounded Theory" and "Symbolic Interaction" could be more clearly presented by shortening the general discussion of these two theoretical methods and, instead, providing specific examples of how they will be utilized in the particular study at hand. In the future, please edit these sections and eliminate some of the technical terms so that the general purpose of the study is clarified.

Second, the members would like you to clarify the length of time involved for the interview procedure. While the section of the protocol entitled Subject Population (page 2 of the protocol) states that "the subject must feel well enough to be interviewed at least 30 minutes," the Procedures section of both the protocol and the consent form indicate that the interview is expected to last between 1 and 3 hours. Does this mean that the interview may involve several 30 minute sessions with interruptions for breaks? Is the minimum interview length, in fact, between 30 minutes to 1 hour? Has the length of time for this procedure been incorrectly stated in either the protocol or the consent form? Please clarify the total estimated length of time involved for this procedure and make any necessary changes in the Procedures section consent form.

Third, the following additional changes in the consent form were requested:

a) Since the subjects being interviewed are elderly persons diagnosed with cancer, the additional risk of fatigue from participation in the interview procedure should be added to the Risks and Discomforts section of the form.

b) When you have incorporated this change, please place the date in a lower corner of each page of the consent form. This date will make record-keeping easier for both of our offices.

Please submit five copies of your response and revised consent form to Box 0962. When these have been received and accepted, final approval will be issued. *Any unaccepted consent forms in your files should be destroyed to prevent their accidental use.* If you have any questions, please call the office of the Committee on Human Research, 476-1814.

Sincerely,

Reese T. Jones, M.D.
Chairman
Committee on Human Research

rlf
cc: Margaret I. Wallhagen, Ph.D.
Department of Physiological Nursing
Box 0610

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH AFFAIRS, Box 0962
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CHR APPROVAL LETTER

TO: Margaret I. Wallhagen, Ph.D.
Box 0610

Sarah H. Kagan, RN, MS
1326 17th Ave.
San Francisco, CA 94122

RE: A Grounded Theory Exploration of Symptoms in Elderly Individuals with Solid Tumors

The Committee on Human Research, the UCSF Institutional Review Board holding Department of Health and Human Services Multiple Assurance #M-1169, has reviewed and approved this application to involve humans as research subjects.

APPROVAL NUMBER: H6362-07902-01. This number is a UCSF CHR number and should be used on all consent forms, correspondence and patient charts.

APPROVAL DATE: May 13, 1992. **Expedited Review**

EXPIRATION DATE: May 15, 1993. If the project is to continue, it must be renewed *by the expiration date*. See reverse side for details.

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within ten working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0962.

Sincerely,

Reese T. Jones, M.D.
Chairman
Committee on Human Research

HEPC Project # 92007902

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH AFFAIRS, Box 0962
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CHR APPROVAL LETTER

TO: Margaret I. Wallhagen, Ph.D.
Box 0610

Sarah H. Kagan, RN, MS
1326 17th Ave.
San Francisco, CA 94122

RE: A Grounded Theory Exploration of Symptoms in Elderly Individuals with Solid Tumors

The Committee on Human Research, the UCSF Institutional Review Board holding Department of Health and Human Services Multiple Assurance #M-1169, has reviewed and approved this application to involve humans as research subjects.

APPROVAL NUMBER: H6362-07902-01A. This number is a UCSF CHR number and should be used on all consent forms, correspondence and patient charts.

APPROVAL DATE: July 30, 1992. **Expedited Review**

EXPIRATION DATE: May 15, 1993. If the project is to continue, it must be renewed *by the expiration date*. See reverse side for details.

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within ten working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0962.

Sincerely,

James Kahn

James O. Kahn, M.D.
Vice Chairman
Committee on Human Research

HEPC Project # 92007902

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH AFFAIRS, Box 0962
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CHR APPROVAL LETTER

TO: Margaret I. Wallhagen, Ph.D.
Box 0610

Sarah H. Kagan, RN, MS
1326 17th Ave.
San Francisco, CA 94122

RE: A Grounded Theory Exploration of Symptoms in Elderly Individuals with Solid Tumors

The Committee on Human Research, the UCSF Institutional Review Board holding Department of Health and Human Services Multiple Assurance #M-1169, has reviewed and approved this application to involve humans as research subjects.

APPROVAL NUMBER: H6362-07902-02. This number is a UCSF CHR number and should be used on all consent forms, correspondence and patient charts.

APPROVAL DATE: May 27, 1993. **Expedited Review**

EXPIRATION DATE: May 15, 1994. If the project is to continue, it must be renewed *by the expiration date*. See reverse side for details.

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within ten working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0962.

Sincerely,

Reese T. Jones, M.D.
Chairman
Committee on Human Research

HEPC Project # 92007902

APPENDIX FOUR

A Grounded Theory Exploration of Symptoms in Elderly Individuals with Cancer

This is a nursing research study.It looks at what it is like for older adults with cancer to have symptoms. Symptoms are problems such as pain, tiredness, mouth sores, and nausea. The experience of symptoms, both positive and negative, will be explored through confidential interviews with older adults who are being treated or have been treated for cancer. The interviews will include questions like:

1) What symptoms bother you most?
2) What did you do to control a particular symptom?

The goal of this study is to document and analyze the information older adults with cancer give about their symptoms. The information will include which symptoms they find most bothersome and the general processes they use to control symptoms. The research findings may then help nurses and other health care providers better understand the experience of people like those who participate in the study.

Please call me, Sarah Kagan RN at 415-731-3908, if you think you might like to participate in the study by talking about your experience with symptoms and cancer. In order to meet the study requirements, you must:

A) be a patient at Mt. Zion or the VA Hospital.
B) have any type of cancer.
C) be in the older age range (65 years and older).

The interview is <u>confidential</u> and would likely take no more than 2-3 hours at most. Most people spend 45 minutes to one hour in the interview.

Thank you very much for your time and attention.
UCSF CHR#H6362-07902-02A

APPENDIX FIVE

FIGURE 2:a
INTEGRATING CANCER INTO A LIFE MOSTLY LIVED

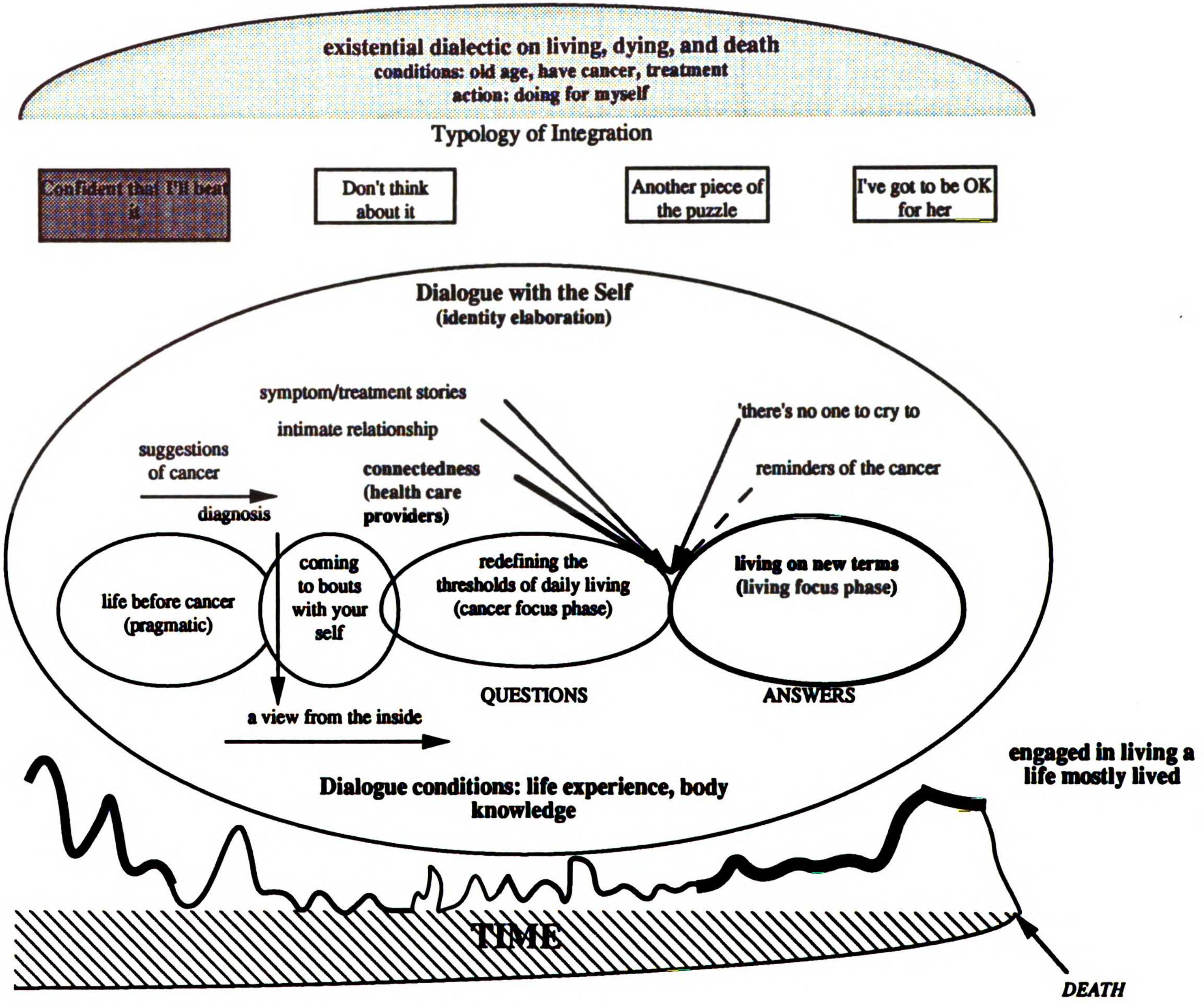

FIGURE 2:b
INTEGRATING CANCER INTO A LIFE MOSTLY LIVED

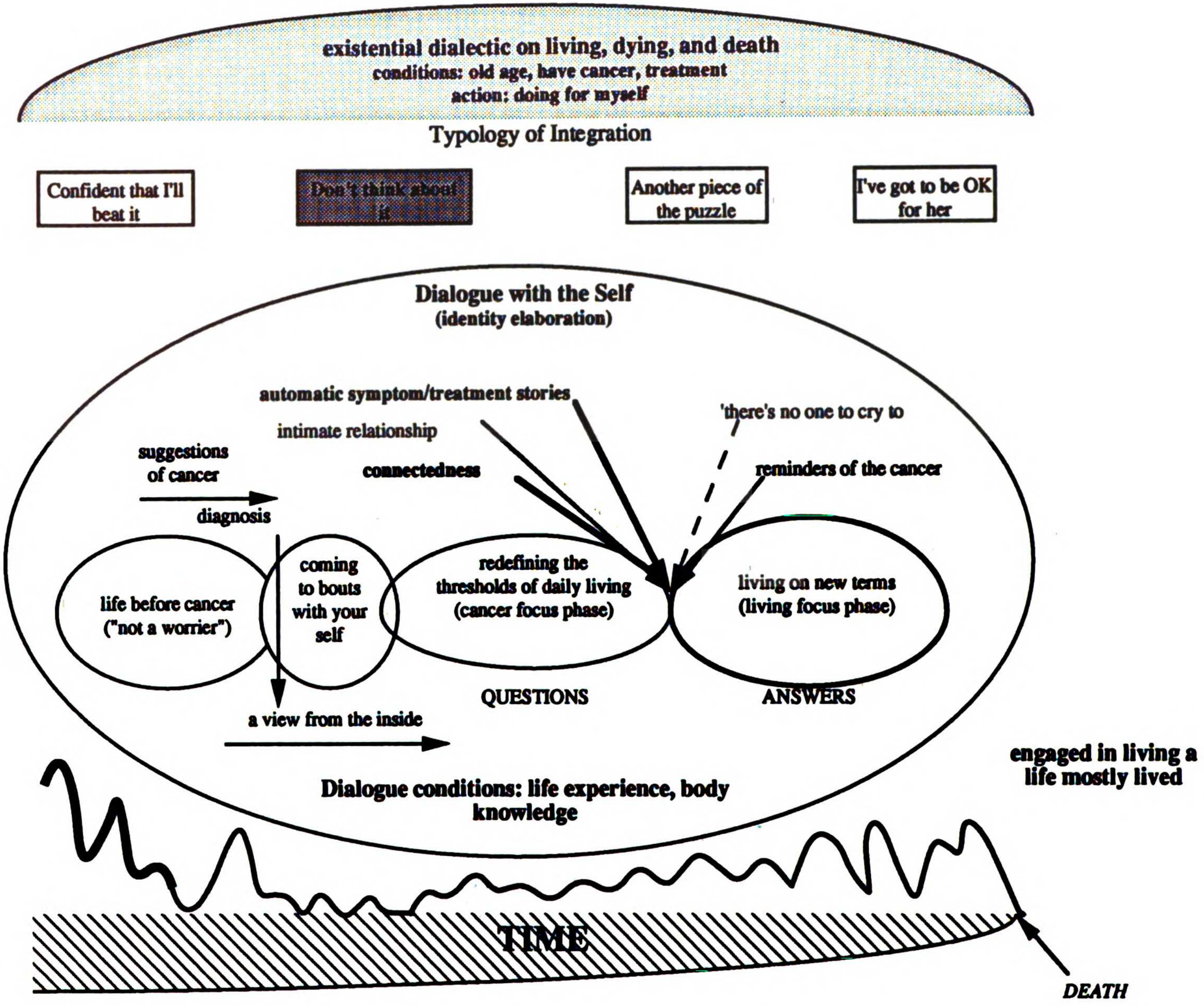

FIGURE 2:c
INTEGRATING CANCER INTO A LIFE MOSTLY LIVED

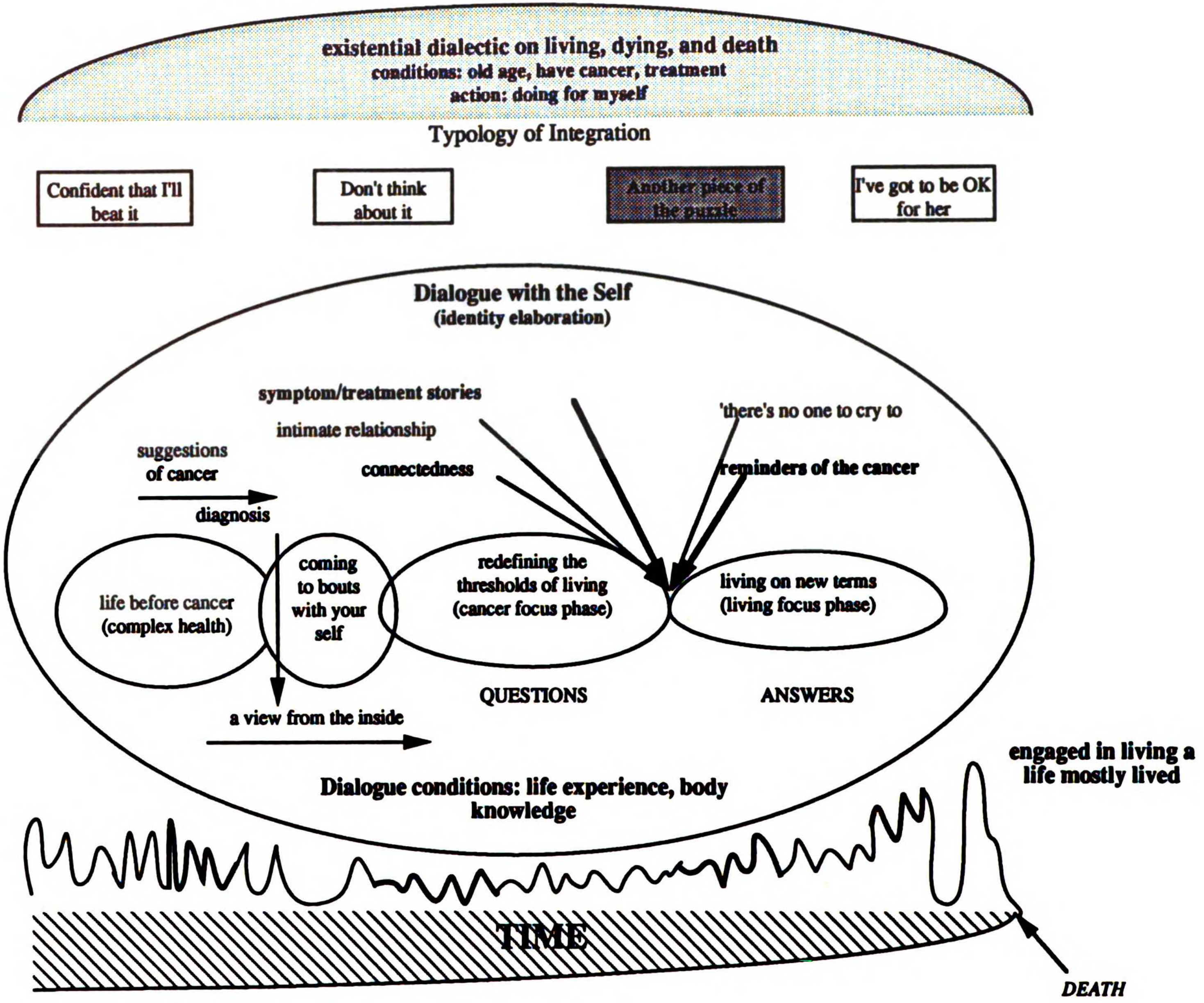

FIGURE 2:d
INTEGRATING CANCER INTO A LIFE MOSTLY LIVED