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Return to work experiences of persons with cancer

Berry, Donna Lynn, Ph.D.

University of Washington, 1992

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Return to Work Experiences of Persons With Cancer

by Donna Lynn Berry

A dissertation submitted in partial fulfillment
of the requirements for the degree of

Doctor of Philosophy

University of Washington

1992

Approved by Mauri Catanzaro
(Chairperson of the Supervisory Committee)

Program Authorized
to Offer Degree Nursing

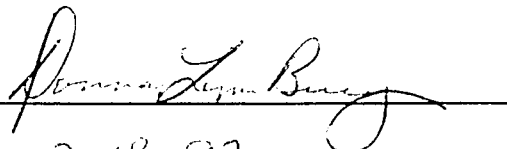
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Abstract

Return-to-Work Experiences Of Persons With Cancer

by Donna Lynn Berry

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Maintaining employment after a diagnosis of cancer and even during therapy is a major challenge for an increasing number of individuals. Although limited, the literature on the return-to-work experience for persons with cancer suggests that they confront a variety of issues and barriers. The individual experience, as understood as meaningful by the worker who has cancer, has been infrequently reported. The purpose of this study was to understand the experience of returning to work after a diagnosis of cancer, discovering the nature and processes of the dimensions. This exploratory, longitudinal study examined and systematically analyzed the dimensions of the return-to-work experience that were evident in data from 19 unstructured interviews. The purposive sample included full time workers who had received surgical treatment or combined modality treatment for a genitourinary cancer. Grounded theory methods of study design and constant comparative analysis guided the interviews and data analysis. Trustworthiness and integrity of the data and the findings were established and confirmed through application of several techniques: triangulation of data sources, peer-debriefing, member checks, maintenance of a field journal, and an audit trail. The core social process suggested by the interview data is one of "*Mobilizing social support*" in the work environment. Critical dimensions of the core process were expressed by the participants: the normalizing effect of re-establishing the worker role, the significant event of sharing the diagnosis with others at work, the use of stories, the social comparisons which enhanced a sense of well-being, and the exploration of priorities. The inceptive theory explains and delineates steps in a process which ultimately facilitates a person's reintegration of

normal activities after a diagnosis of cancer. Further research is now needed to verify these grounded theoretical dimensions of the return-to-work experience, to determine transferability to other samples and then to focus on the critical processes identified here. The added understanding available in these results can guide nurses to focus not only on related dimensions of the return-to-work experience such as time off for treatments, but on central concerns, such as the social benefits of going back to work.

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ACKNOWLEDGEMENTS

Many individuals deserve recognition for the support they provided to me during my doctoral work which has culminated in this dissertation. I will not be able to mention everyone by name, but my most sincere appreciation goes out to all. First, I want to express my gratitude to the members of my supervisory committee: to Marci Catanzaro, whose comprehensive support and scholarly sustenance are unequaled in my experience; to Diane Magyary, whose high standards and guidance enabled me to choose appropriately and go on; to Betty Gallucci, who helped me to focus and clarify my direction; to Tamara Bavendam, who compelled me to justify the significance of the dissertation research and graciously facilitated clinical aspects of the data collection process; and to Kathy Graham and Ed Perrin for all their encouragement and helpful commentary throughout this dissertation process.

I also want to thank the staff at Seattle Urological Associates, particularly Jim Gottesman, and the staff at the Urology Clinic of the University of Washington Medical Center. Their support greatly expedited the implementation of the research. I want to express special thanks to Mary Salazar whose encouragement, support, and leadership promoted the goals of my doctoral program. Also, thank you to Marty DesRosier for her assistance during data collection and analysis.

My family has made many sacrifices in order for me to complete this research endeavor. I cannot adequately express my feelings of appreciation to my very patient husband, Brent Blumenstein, and to my four very lovable daughters: Jessica, Lauren, Jordan, and Cassidy.

Finally, I want to express heartfelt thanks to the participants in the study. Their sharing and insight certainly made this dissertation possible.

I also want to acknowledge the funding sources for this research: Connaught Laboratories, Ltd. and the National Institute for Occupational Health and Safety, Northwest Educational Resource Center Grant, PHS (NIOSH) Grant Number 5 T15 OHO 7087.

DEDICATION

To my mother, Esther Guimarin Berry (1934-1959), who sacrificed her dream of becoming a professional nurse to create the family which would bring me into this world.

CHAPTER I

INTRODUCTION

Statement of the Problem

The majority of the approximately 5 million persons surviving cancer today were diagnosed over five years ago and currently are living without evidence of cellular disease. It is estimated that over one million persons will be newly diagnosed with cancer of some form in 1992. This figure does not include non-melanoma skin cancer which is expected to occur in over 600,000 cases (Boring, Squires, & Tong, 1992). The incidence of almost all cancers increases with age. The United States Census Bureau predicts the current population shift toward the decades beyond age 60 and away from the decades of youth to continue well into the next century (Pope, 1986). The increase in longevity will increase liability to cancer along with other chronic diseases (Hickey, 1987).

Although survival rates are arbitrarily set at 5 or 10 years and vary greatly by site, it is informative to note that greater than half of all persons with cancer diagnosed in 1992 will be living in 1997 (Boring, Squires, & Tong, 1992).

Multimodal treatment and developments in therapeutics and supportive care have lengthened survival (Boring, Squires, & Tong, 1992; Loehrer, Williams & Einhorn, 1988; Thiel, Fietkau & Sauer, 1988; Vanchieri, 1988). Clinical efforts by both nurses and other disciplines, aimed at problems for the person with cancer secondary to the tumor and its treatment, have often ameliorated the impact of cancer on their lives (Groenwald, 1987; Lindsey, 1985a, 1985b; Wiernik, 1983).

Maintaining employment after a diagnosis of cancer and even during therapy is a major challenge for an increasing number of individuals. The majority of pre-retirement persons with cancer have attempted a return to the workplace (Mor, 1987; Stone, 1975). Although limited, literature on the return-to-work experience for persons with cancer suggests that they confront a variety of issues and barriers. Social scientists and legal and health care professionals have attempted to identify particular practices and issues that have affected the return to work experiences of those with a diagnosis of cancer. Mellette (1985) summarizing the literature, explicitly described the two domains of problems encountered by persons with cancer: those relevant to the environment of the workplace and those problems of the individual as he or she adapts and responds to the illness experience itself.

The individual experience of the employed person who has, or had, cancer has been infrequently reported. Little is known about the dimensions of the experience as understood as meaningful by the worker. Although Feldman (1987) and Houts, et al. (1988) analyzed interview data which was derived from the actual words of the workers with a cancer history, there was a significant amount of structure already present in the interview, guiding the responses. Watson (1990) conducted unstructured interviews with cancer survivors to explore the details of and understand the return-to-work experience. While many important problems and issues were raised by the participants, the data were not systematically analyzed. Wellisch (1984) referred to the

problem of assessment of lived experiences such as returning to the workplace after a cancer diagnosis:

...the gap in the world view between the patient and the researcher may be enormous. The result may be a measurement of the quality of life of the cancer patient's life only in terms of the researcher's world view which tells us nothing of what the patient really sees or feels (p. 2290).

Understanding the return-to-work experience is an essential prerequisite to planning both intervention research and clinical nursing therapeutics for persons with cancer who consider maintaining their worker role.

Purpose of the Study

The purpose of the study was to understand the experience of returning to work after a diagnosis of cancer, discovering the nature and processes of the dimensions. This exploratory, longitudinal study examined and dynamically analyzed the dimensions of the return-to-work experience that were evident in data which originated within the world view of the study participants who had genitourinary cancer.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter includes a review and critique of literature relevant to the return-to-work experience for a person with a cancer diagnosis. The framework for investigation and understanding of the return-to-work experience is based on a synthesis of the theoretical and empirical literature.

Human Response Framework

Heitkemper and Shaver (1989) reported the development of the human response framework as a heuristic model for examination within nursing science of the human responses to enteral nutrition and the clinical therapeutics aimed at modifying those responses. The framework is useful in this research as an organizing heuristic tool. Application of the framework enables one to identify gaps in the literature relevant to the return-to-work experience of an individual with cancer and identify what components of that experience have been previously described. The human response framework is based on earlier work by Shaver (1985) which presented a "human ecological model," describing "integrated function of the whole individual from a bio-psychosocial view" (p. 188). The framework is a biopsychosocial view of human health and human responses to environmental and person factors and according to Stevens' (1979) evaluation criteria for nursing frameworks, models, and theories, is a categorical, descriptive theory.

The human response framework includes three constructs that are used to describe human function under the conditions of a particular health care therapy: a) individual adaptations, b) person factors, and c) environmental factors. Person factors

and environmental factors are identified as potential contributors to individual responses. The environmental factors of the human response framework are considered to be either physical or social. Within the external environment the individual is exposed to physical risk factors, for example lack of food availability and/or social risk factors, such as inadequate money to buy food (Heitkemper & Shaver, 1989).

The person factors of the human response framework are considered those that establish a degree of vulnerability for the individual. Disease state is a factor which may or may not be alterable. These factors may predispose the person to the development of untoward responses. Some vulnerability factors such as age are not modifiable. Other factors are modifiable and include knowledge deficits and perceptions (Heitkemper & Shaver, 1989).

Heitkemper and Shaver (1989) describe individual adaptations as human responses manifested along four dimensions: a) physiological, b) pathophysiological, c) experiential, and d) behavioral. In their article, the human responses are said to be in response "to tube feedings" (p. 416). One could interpret this to mean that "enteral tube feedings" represent a unique, complex set of person and environmental factors which affect human responses or a set of problems amenable to nursing diagnosis and treatment. The authors add "clinical therapeutics" to a simplified version of the framework, stating that "clinical nursing therapies can involve changing modifiable vulnerability factors...or reducing environmentally-based risk factors" (p. 417). The research framework illustrating the linkages between the constructs of the human

response framework is presented in Figure 1. Therefore, the framework can be applied to a given health care situation or scenario illustrating the influential factors, particular human responses, and appropriate clinical therapeutics.

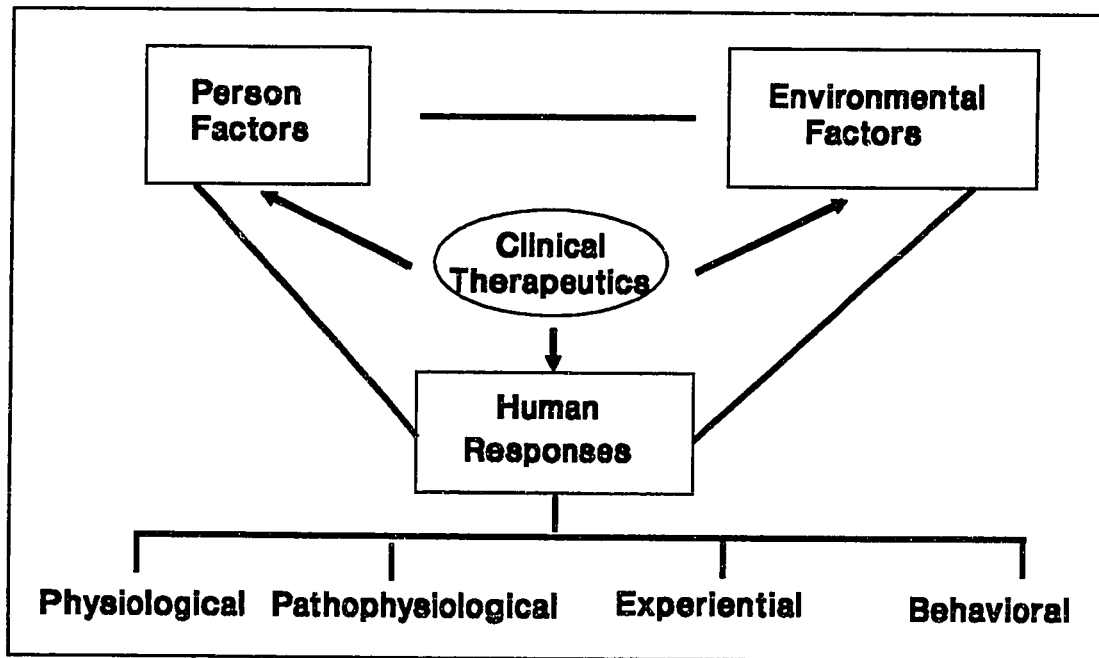


Figure 1. The Human response framework with permission, Heitkemper & Shaver, 1989

Mitchell, Gallucci, and Fought (1991) further illustrated the human response framework by suggesting that specific human responses can be seen as measurable phenomena within each of the four perspectives: physiologic regulatory, pathophysiologic, experiential, and behavioral. These phenomena, together with the environmental and person factors, are central to the practice and science of nursing. Not only do they provide a practical, functional framework, the application of the framework acknowledges the complexities and interactive components of the human experience.

One deficit of the human response framework (Heitkemper & Shaver, 1989) involves the adequacy of the interpretation of person factors in terms of vulnerability and environment factors in terms of risk. The authors omit any discussion of dimensionality for vulnerability and risk. We are told that these risk or vulnerability factors may predispose the patient to the "development of untoward responses" (p. 417). There is only one end of the spectrum for each concept considered. Consider low-risk or no-risk factors, no vulnerability, or hardiness. Could these not be influential factors in the person or the environment? Application of the Heitkemper and Shaver (1989) human response framework in this study also emphasizes the positive dimensions of "risk" and "vulnerability."

In this study, the human response framework is explored as one heuristic model for understanding processes and concepts relevant to the return-to-work for an individual with a cancer diagnosis. The framework is applied to the experience of returning-to-work with a cancer diagnosis as the given health care situation, illustrating the influential environmental and person factors and particular human responses.

Employment

The incidence of cancer increases dramatically with increased age (Boring, Squires, & Tong, 1992). That portion of the population of the United States and the workforce which is most likely to contract cancer is steadily growing (Pope, 1986). The exact number of the over 5 million persons with cancer today who are, have been or will be employed outside of their homes is unknown. Because of the predominance of work as an activity of adult life in the United States, it would be safe to assume

that the majority of pre-retirement persons with, or who have had cancer, will work.

Also, most of those persons will be employees or work for monetary gain.

A population based study completed in the state of Rhode Island (Mor, 1987) indicated that of all newly diagnosed persons with lung, breast and colorectal cancer, about 61% overall were employed at time of diagnosis. Seventy-five percent of those aged 45-54 were employed. Although Rhode Island is not necessarily a microcosm of the United States, the percentages in general are informative.

In 1975, Stone reported a survey completed on all employees of the Bell Telephone Company which were represented in all the 48 continental states. He reported an overall 77% return-to-work rate for 1407 persons with cancer. Site-specific rates ranged from 48% in workers with lung cancer to 88% return in women with "genital" cancer. Subsequent surveys completed with employed persons who have had cancer documented an approximate return-to-work rate of 80%. The studies which have identified work type have documented a differential in return rates for blue and white collar workers. Surveys and studies completed in the last 25 years have shown a greater number of white collar workers do re-enter their former workplace relative to blue collar workers (Feldman, 1976, 1978; Wilson, Richards, & Bercini, 1976; Greenleigh Associates, 1982).

It is important to understand that these reported estimates for return-to-work rates are usually site-nonspecific and the mean of the observed or reported returns. Also, we cannot assume that when 80% of workers return to work that any of them continue working any length of time. One difficulty with the reported studies is that

we do not always know how long after the diagnosis of cancer or the return to work that the count was made. Overall, reports suggest that at least 20% of these workers never return to work and an unknown, but very significant, number make an ultimately unsuccessful return to the workplace. It is for these groups of individuals in particular that an analysis of factors relevant to the return-to-work can ultimately be targeted in an attempt to understand the context of the individual's experience.

Person Factors

The meaning of work is a modifiable person factor in the human response framework. Authors who have written about persons with cancer histories and return-to-work have described work as an extremely important concept, a very meaningful activity. Work has been termed, "the world of the adult, a lifeline ... (Crothers, 1987); "a source of self esteem, an indicator of an individual's ranking in society" (Stagner, 1987); "a vital element in establishing a sense of worth" and "essential for the adequate social functioning" (Feldman, 1987). Social scientists have identified work as a major covariate of general well-being and life satisfaction for the population in general (Bergermaier, 1984, Campbell, 1981, Barofsky, 1989). Little has been done to identify what the meaning of work is from the perspective of the worker. The notable exception is the study reported by Flanagan (1982). Using the critical incident technique, he nationally surveyed 500 men and 500 women with regard to the important components of quality of life. He queried participants as to experiences which were especially satisfying. Through content analysis of the descriptions given by the study participants, the researcher grouped components of quality of life into

various dimensions. One of the five dimensions most frequently described was work; the other four were: health, children, understanding yourself, and spouse.

Unfortunately, the study results were reported as percentages for the list of components without any data presented which might have elaborated on the social experiences of the participants or relationships between components.

Barofsky (1989) discussed the work transitions that may occur after a cancer diagnosis. The impact of the cancer may be related in some way to the changing background of the natural work history which is certainly influenced by the meaning of work to the individual. For example, an individual who has changed jobs every few years will have a different experience during the return-to-work time than someone who has held the same position for 15 years.

The meaning of the work experience from the perspective of the person with cancer has not been reported. Furthermore, there has been no research to determine what modifies the meaning of work. In this particular circumstance, there is a critical need to describe and understand the meaning of work as it relates to returning to the workplace with a cancer diagnosis. Additional study may then be warranted to identify nursing interventions which therapeutically address the issues of the meaning of work.

At least two non-modifiable person factors have been reported in the literature: the type of malignant disease and age. The California Division of the American Cancer Society (ACS) sponsored a large scale study of non-medical needs of 810 persons with cancer. Two years following diagnosis, Greenleigh Associates (1982)

documented higher levels of job loss in the 46-64 year age group and that those with breast and uterine cancer were least affected, while those with leukemia, lymphoma and lung cancer were most affected. In a survey of long-term cancer survivors, van der Wouden and colleagues (1992) discovered similar findings. The 12.5% decline in the number of employed survivors over about ten years was mainly related to an older age. Return to work rates were lower for those individuals with head and neck cancers even though reports of physical problems were similar to those of other tumors. This survey took place in the Netherlands and must be evaluated with such a difference in mind, however relative return-to-work rates for different tumors may be one of the few aspects comparable to the other nationalities.

Several authors have reported serious discrimination problems for survivors of childhood cancer. Without the seniority or established work history, these young people are particularly vulnerable to discriminatory practices such as job rejection and benefit denial (Fobair et al., 1986; Greenleigh Associates, 1982; Koocher & O'Malley, 1981). Consistent findings were reported by Houts, Schag, and Heinrich (1988) in a study of cancer survivors and their siblings. The younger persons with cancer in the study reported higher socio-emotional problem scores. However when non-working and working persons with cancer were compared by Ganz et al. (1989), significant differences in age were found. For various levels of functional status, the working group on average, was significantly younger.

Environmental Factors

Practically all the published barriers to a successful return-to-work for a person with cancer which have been identified in the current literature can be placed in the Environmental Factors section of the human response framework. Mellette (1985), summarizing the literature, explicitly described the two domains of problems encountered by persons with cancer: those relevant to the environment of the workplace and those problems of the individual as he or she adapts and responds to the illness experience itself. Her examples of environmental problems were "attitudes and actions of the employer and coworkers (p. 363)." Decreases in physical stamina and functional status were examples of problems related to the individual. Interestingly, this categorization is somewhat consistent with the social environmental factors and the human responses of the human response framework. However, Mellette (1985) does not distinguish human responses from other person factors.

It is important to note the shortcomings of the following studies prior to discussing and comparing identified problems met by persons with cancer in the workplace. What constitutes a "problem" has been different in each study, sometimes self-defined by the subjects in the study, at other times defined by the investigators or authors (Hoffman, 1989). The categorization of job problems is not consistent among the reports. No models have been introduced to deal with interaction of various types of problems, for example the interpersonal aspects of discrimination relevant to promotion. Another limitation of reviewing these studies as a group involves the fact that they were completed on different populations, sometimes mixed into the same

sample were factors known to influence problems at work: cancer site, stage at diagnosis, patient age and gender.

Social Environmental Factors

In a now classic trilogy of studies ranging over 5 years in the 1970's, Feldman (1976, 1978, 1980) interviewed 344 cancer patients and 107 employers. Three categories of job problems were identified in 54% of the white collar workers, 84% of the blue collar workers and 25 to 51% of the youth: gross discrimination, workplace attitudes and the person's own attitudes. Gross discrimination included: dismissals, failure to hire, reduction in salary or failure to receive an increase received by all others, changes in hours or work location which isolated the worker with the history of cancer, and reduction or elimination of group health or life insurance coverage. More recently, Feldman (1987) reported the occupational type of the white collar employees as largely nurses and educators. Seventy-two percent of the white collar sample were women as where two thirds of the blue collar sample. The conclusions of the landmark studies regarding the frequency of perceived and documented discriminatory practices have positively influenced workplace environments and certainly impacted subsequent federal and state policies.

Feldman utilized semi-structured individual interviews in both the white collar and blue collar studies and group interviews with 35 self selected white collar workers. The analysis of the interview data was primarily frequency data, for example, number of weeks absent for initial treatment and frequency of reported discrimination problems. Correlations were made with demographic variables to identify

relationships. In addition, Feldman reported some individuals' stories as critical incidents exemplifying certain return-to-work experiences. The researcher labeled the studies as descriptive, combining quantitative and qualitative data (Feldman, 1976, 1978). The exact method for analysis of the qualitative data is unclear and apparently did not utilize a systematic approach to rigorously analyze the experiences of the cancer survivors. Nor has that analysis added to the development a theoretical framework for understanding the return-to-work experiences of persons with cancer.

A second major investigative effort was sponsored by the National Cancer Institute (NCI) in the early 1970's. The "Work-able Project" involved five sites across the country and surveyed both patients and employers. Patients were interviewed by telephone and queried as to their work history since their diagnosis of cancer. Employers from a variety of geographic locations and industries were surveyed with regard to employers' attitudes, policies, and practices relative to the employment of patients with a history of cancer. The results from the study were mixed and serious methodological and analytical problems detracted from their significance (Barofsky, 1989; Crothers, 1987).

Estimates in the literature for the frequency of discriminatory practices probably are underestimated due to the tendency of the samples to include a great majority of white, middle class persons. Another point to be made is that articles and reports of discriminatory practices comprise most of the research literature regarding re-entry to the workplace for people with cancer. Controversy exists in recent literature with regard to the magnitude of the discrimination problem. Mellette and

Franco published a review paper in 1987 postulating that improved survival rates and current publicity and openness about cancer have brought about a decrease in documented cases of discriminatory actions of employers and co-workers. Indeed, recent professional publications indicate a shift of emphasis from proving or seeking discriminatory practices against persons with a cancer diagnosis to identification of employment problems of a broader range, particularly in light of the current workplace environment, interpersonal interactions and social policy (Barofsky, 1989, Watson, 1990). In justifying her unique study of employment experiences of cancer survivors, Watson (1990) stated,

The rationale for this study is not so much that a vast majority of cancer survivors have severe problems, but rather that some proportion of this significant population do experience problems that could and should be avoided for economic as well as humanitarian reasons (p. 26).

Perceptions of workplace discriminatory attitudes and declarations of the existence of discrimination do remain, however, in lay-oriented publications (Mullan & Hoffman, 1990; "Unfair & Illegal," 1992).

Clearly, social policy has been influenced by the elucidation of discriminatory practices in the workplace. The Rehabilitation Act of 1973 (PL 93-112) was passed to prevent discrimination against handicapped individuals by employers who receive federal funding of federal contracts. Unfortunately the legislation has been a limited resource for enabling satisfactory employment for persons with a cancer history. The Act applied only to a portion of the nation's employees, such as those at some hospitals and universities. Only a few states went beyond that federal legislation and

expressly prohibit discrimination based on a cancer history or protect individuals with "real or perceived disabilities" (Hoffman, 1989).

The Americans with Disabilities Act (ADA) (Equal Employment Opportunity Commission & U.S. Department of Justice, 1991) was signed into federal law in July of 1990. Similar to the Rehabilitation Act of 1973, the ADA will prohibit discrimination against a qualified employee because he or she is disabled, has a history of disability, or is regarded as disabled. However, many more employees in America will be protected under the new ADA. By mid-1994, any employer with 15 or more employees must comply with the law (Hoffman, 1990). Although the ADA does not specify cancer as a disability, the courts and agencies are expected to apply the terms of the Act to cancer survivors.

Funding of the comprehensive cancer centers in the United States by the NCI has influenced cancer rehabilitation services. Rehabilitation, including vocational rehabilitation, is considered an objective and goal of such centers. Gunn (1984) described the rehabilitation program at one such center. The central focus emphasized by Gunn is that persons with cancer, as all humans, possess a finite life expectancy and something can be done for anyone to improve the quality of their remaining time. Dietz (1981) discussed the cancer rehabilitation effort, re-terming the concept as readaptation or accommodation to personal needs for physical, psychological, financial and vocational survival. The ultimate goal was stated to be reestablishment of patients as functional individuals in their environments. It was Dietz (1981) who proffered the

maxim that rehabilitation for the cancer patient should begin at the earliest time and continue through recovery until maximum benefit is achieved.

Organizations such as the American Cancer Society and the National Coalition for Cancer Survivorship (NCCS) have met some of the needs created by persons with cancer in relationship to their work. The groups have advocated for survivors and taught survivors of cancer to advocate for themselves publicly and in their specific work and social environments. The NCCS has recently identified employment and insurance as their most pressing concerns (Mullan & Hoffman, 1990).

Interpersonal Environmental Factors

If work occupies an eminent place in a person's life, then the social milieu of the workplace provides the day-to-day relationships critical to a person's job satisfaction. Workers with a cancer history have reported shunning, ridicule and overt hostility from others in the workplace (Houts et al., 1988; Mullan, 1987; Staley, Kagle, & Hatfield, 1987). As explained by Mullan (1987), employment and insurance discrimination is more amenable to prevention by education and to compensation after the fact than the emotional interactions. The phenomenon of shunning, for instance, is difficult, if not impossible, to quantify. In Feldman's blue collar study (1978), 10% of the interviewees reported overt acts of hostility, teasing and mimicry by co-workers. The incidence was most frequent in those treated for head and neck cancer. This incidence can be compared to her white collar study where positive co-worker actions were most frequent, such as voluntarily taking on extra assignments. However it would be a grand mistake to believe that interpersonal conflicts and stresses are

greater for blue collar workers per se. Recall that the white collar sample included nurses and educators, the majority women. One might assume that these groups are highly sensitive to the needs of others.

Staley and colleagues reported on the survey results from 61 working persons with cancer (1987). While a large number of the participants reported a positive experience with their co-workers, the initial return-to-work experience was almost always troublesome, particularly if the person with cancer returned while remaining on continuing treatment for the cancer.

Interpersonal relationships in the workplace for the person with a cancer diagnosis are difficult to study and document. Individuals who survive cancer carry with them the same personal characteristics they had prior to the cancer diagnosis. Detecting the impact of the cancer requires accounting for the background problems in existence prior to diagnosis. This is probably most clear in the findings of the Houts et al. (1988) study of 90 persons with cancer and their same-sex siblings. Of seven problem areas, the three which involved human behavior: employment, social, and family problems, did not show statistically significant increases for the group with cancer. The authors stated that the small difference between job related problems for the persons with cancer and their siblings suggest that problems in the workplace once thought to be cancer-caused were problems which would have occurred in some fashion without a cancer diagnosis. Houts and his colleagues (1988) used telephone interviews of 629 persons with cancer and their sex-matched siblings. The investigators interviewed the participants using an adaptation of Habeck's scale for

assessing psychological, social and economic needs in those with cancer. Additional questions were added based on the literature and on the results of discussions with six focus groups consisting of persons with cancer and their families. The authors reported the lowest reliability score for the content area dealing with employment problems. In contrast to the previous study, Ganz, Schag, and Heinrich (1989) reported that employment related problems were the most enigmatic for the 94 working cancer survivors in their study. Their data were collected through administration of a written questionnaire.

Physical Environmental Factors

The literature which specifically addresses return-to-work for persons with cancer contains very little with regard to physical barriers in the work environment which can cause re-entry difficulties. This may be related to the lack of agreement on what constitutes a disability in, or a barrier for, a person with cancer. There may be some assumption that a person would not return to work until physical needs were normalized. However, authors such as Staley, Kagle, and Hatfield (1987) have described workers' concerns over the understanding of co-workers when physical fatigue had caused them difficulties. Tebbi, Bromberg, and Peidmonte (1989) examined the long-term vocational achievements of 40 survivors of cancer matched with 40 healthy controls. Reporting no significant relationship between health status and employment, the authors stated that 64% of the survivors believed that changes in certain physical features of the workplace were necessary to facilitate readjustment.

Physical problems do exist in the persons with cancer and it can be expected that the worker faces some physical barriers in the work environment. In Feldman's blue collar study (1978), many concerns were voiced about the need for frequent toileting and proximity to bathrooms. Lehmann and colleagues (1978) identified cancer rehabilitation problems in 438 persons with various types of cancer. The authors described the frequent incidence of mobility problems associated with cancer of the nervous system, due to paresis, paralysis and intellectual/perceptual deficits. They reported ambulation, activity-of-daily-living, general weakness, lymphadema and skeletal problems in about a third of the women with breast cancer. Vocational problems were determined to be present in 16% of the same women, although there was no information on the percentage of them who were employed.

Clearly, reintegration to the workplace involves confronting any physical barriers present. Although they did not report a study or evaluation of the implementation of their work re-entry program, Clark and Landis (1989) did imply necessary attention to the physical environment by occupational health nurses. They suggested that the worker with cancer be assessed for physical abilities with respect to rehabilitation services and/or work retraining and reassignment. The emphasis however, remained on identification of possible work limitations caused by the employee's physical problems, not the problems posed by the physical environment.

The issues of integrating activities of cancer therapeutics with one's work life are only beginning to be mentioned as more people receive adjuvant cancer therapy (Clark & Landis, 1989; Meyerowitz, Watkins, & Sparks, 1983). Adjuvant therapy

may continue at intervals up to many months. The person with cancer is presented with the task of integrating episodes of treatment with other life routines. The necessity of going to the therapeutic setting for ongoing treatment presents a different type of physical barrier to a successful return to work, the need to be away from the workplace for significant periods of time. Arranging time for medical treatments was identified by the blue collar workers in Feldman's study (1978) as a "work problem." When comparing working and non-working persons with cancer, Ganz and colleagues (1989) found that only about 10% of the working group reported problems asking for time off for treatments. Yet, of the 222 nonworking survivors, most of them terminated work within six months after the cancer diagnosis. This may represent those who were unable to handle the integration of treatments with their working life.

Meyerowitz and colleagues (1983) reported their study of women having received adjuvant treatment for stage II breast cancer. Thirty-five women were interviewed both during and after therapy. Perceptions of emotional distress and behavioral disruption were rated in five life areas: marital/family relationships; sexual relationships; financial situation; general level of activity; and work-related activity. About 2.5 years after therapy, 35 of an original 50 were interviewed again. A psychologist, using a structured interview format, asked patients to describe "the impact that previous participation in the adjuvant therapy protocol currently had on their lives." For both interviews, responses were rated on 7-point scales, two ratings on each of the life areas. The women were also asked to describe "general reactions" to having received the treatments. Results were presented in terms of score change, gain

or loss from the initial to the second interview. The participants reported significant improvement in four of five life areas: behavioral and emotional sexual relationships, financial situation and work-related activity. Marital/family relationship scores did not show significant change, probably due to the low level of disruption in the initial rating. Overall, 56% of the women who received adjuvant chemotherapy reported continuing physical problems which they believed were related to the treatments.

Human responses

The various responses of a person with cancer, relevant to returning to work, have been addressed in the literature mainly as symptoms and sequelae of the disease and treatment and as survey items addressing employment status. For the most part, the reports of pathophysiological and experiential responses are anecdotal and are not part of the research literature germane to returning to workplace after a cancer diagnosis.

Physiological Responses

Physiologically, tumor growth is arrested and contained as surgery, radiotherapy, antineoplastics and immunotherapeutics aid the body in normalizing cellular response and growth. Time to recurrence is lengthened by various treatment modalities. Normal physiological functioning is the goal and desired outcome.

Pathophysiological Responses

Cancer cells and neoplastic growths are dysfunctional within the tissue of origin and in their metastases. Advancing neoplastic growth is disabling and disfiguring in many instances. Secondary effects, such as the pathophysiological

human response of cachexia, can effect both function and physical form (Wiernik, 1983). In Mellette's review (1985) speech impairment/ability was identified as a predictor of vocational adjustment in persons with cancer of the larynx. Neurosensory deficits, bladder, and bowel dysfunction have also been discussed as examples of pertinent pathophysiological responses (McNally, Stair, & Somerville, 1985).

Experiential Responses

Although there are lengthy lists of disease and treatment toxicities, there is a notable void in the literature of reports of the symptom experiences in the workplace for the person with cancer or a history of cancer. Clearly, the experiential human responses of pain and nausea may broadly influence an individual's life including return-to-work outcomes (Lindsey, 1985a; Padilla, Ferrell, Grant, & Rhiner, 1990). Piper, Lindsey, and Dodd (1987) have discussed and documented the pervasiveness of fatigue in persons with cancer and the implications it has for interference in the person's recovery of meaningful life activity.

Behavioral Responses

Behavioral human responses in the complex scenario of return-to-work include behaviors which will ultimately contribute to success or non-success for the person with cancer. Absences, delayed returns, or quitting work have been addressed in the literature as indicators of the socioeconomic impact of a cancer diagnosis (Mellette, 1985; Meyerowitz, Watkins, & Sparks, 1983; Mullan, 1987; Watson, 1990, Wheatley, Cunnick, Wright, & van Keuren, 1974). Watson (1990) studied over 400 cancer survivors employed by American Telephone and Telegraph (AT&T) who had been

diagnosed with cancer for two years. In addition to an average absentee frequency of 87 days, the findings indicated that women, blue-collar, and non-management employees tended to be out from work a significantly longer period of time. The reasons for these absentee frequencies were speculative. Watson also analyzed variables which influenced another group of employees who never returned to work. Diagnosis and type of treatment were the strongest explanatory variables, while gender and retirement eligibility did not contribute strongly to whether the employee went back to work. Mellette (1985) reported that women with treated breast cancer continue to work, with limited absences, despite "illness from chemotherapy" and metastatic disease while absences were of longer duration in persons with colorectal disease and hematologic malignancies.

It could be implied that the absentee rates also reflect a gross estimate of significant symptomatology. These examples may be indicative of a relationship between an experiential and a behavioral human response, specifically the symptom and the absence.

Clinical Therapeutics

Morbidity issues, including quality of life during and after treatment for cancer have been recently publicized concerns and emphasized by funding priorities of the National Cancer Institute (Greenwald & Cullen, 1985). However, few have evaluated interventions to facilitate a successful return-to-work. Comparative trials of different surgical procedures or different modalities have included return-to-work as an outcome variable. Williams and Johnston (1983) evaluated the percent of their patients

undergoing surgery for rectal cancer who returned to work. Eighty-three percent of those treated by low sphincter saving resection returned to previously held jobs, compared to 40 percent of those treated by abdominoperineal resection. In another comparison of surgical procedures (Schuller, Reiches, Hamaker, & Lingeman, 1983), no significant difference in return to pretreatment employment was discovered for patients treated with variations of neck dissection.

An informational intervention, in the form of a pamphlet, "Getting Back to Work," has been designed by the Illinois Cancer Council (1988). The pamphlet suggest various self-care behaviors to manage problems encountered during the return to the workplace for women with breast cancer. An evaluation of the intervention is in progress (M. List, personal communication, October 16, 1992).

At the 1989 Annual Congress of the Oncology Nursing Society, President Deborah Mayer presented a position paper on rehabilitation of persons with cancer, committing the Society to promote educational and research efforts in the area. After reviewing what literature was available in the area, she claimed that issues of cancer rehabilitation had been neglected, particularly in nursing research.

Oncology nurses in the therapeutic setting have reported interest in the collaboration with rehabilitation specialists in helping with the reintegration of cancer patients to their premorbid lifestyles (Dudas & Carlson, 1988; Romsaas, Juliani, Briggs, Wysocki, & Moorman, 1983). However, return-to-work has been but a small component of these articles. In a review article, Dudas and Carlson (1988) suggested "promotion of successful integration in the workplace" as an objective of nursing

interventions which enhance cancer rehabilitation. Romsaas and colleagues (1983) developed a checklist for use in the oncology clinic that would identify rehabilitation needs of patients with cancer. However, none of the queries regarding activities or participation in various things, such as community activities or social relationships, mentioned work or employment. The one item which addressed work was that of "concerns [regarding your] inability to return to your regular work or school schedule" (p. 18).

Within nursing, the care of inpatients, outpatients and long-term patients has often been fragmented within institutional and divisional boundaries. Control of treatment toxicities and pain have frequently been priorities of cancer nursing practice and research (Donovan & Girton, 1988; Lindsey, 1985a, 1985b). Occupational health nurses, such as Clark and Landis (1989), have identified the need to attend to the reintegration of the employee with a cancer history into the work setting. The authors suggested that the occupational health nurse be involved in rehabilitation counseling, referrals, and cooperate with the therapeutic health care provider to schedule treatments which interfere the least with work schedules. Expansion of employee health programs with policies and strategies for working with employees with chronic diseases has been proposed as means to control health care costs, decrease absenteeism and maintain active, valuable employees (Moore & Childre, 1990). Employee Assistance Programs (EAP) have evolved from early efforts to control corporate financial losses caused by alcoholism into comprehensive counseling and referral programs for employees with a wide range of personal or job-related problems (Brody,

1988; Thompson, 1988). Although persons with cancer have not been an identified target group for EAP's, it is feasible that occupational health nurses could support such workers with a cancer diagnosis through the services of an EAP.

Given the paucity of clinical trials with return-to-work outcomes in persons with cancer, it is instructive to briefly consider how return-to-work has been studied in conditions and chronic illness experiences other than cancer. Cardiac rehabilitation is often found as an established program in the inpatient and outpatient setting both in the United States and abroad. Also noteworthy, is the fact that the rehabilitation effort begins very early in the inpatient course of treatment. Clearly, return-to-work is an outcome measure utilized in reporting success of the cardiac rehabilitation program (Blessing, Jakeman, Mathews, & Tankersly, 1988). Most often a percentage is given of those patients in the program who have returned to work. Kavanaugh and Matosevic (1988) analyzed 1150 post-infarct and post-bypass graft patients, and reported 10 % had not returned to work six months after the acute event. The white-collar workers were more successful than blue-collar in returning to the workplace as were the medically versus surgically treated.

Cay and Walker (1988) discussed the many factors, especially psychological factors, which influence the return. They cautioned against merely using the return to the workplace as a single outcome criteria due to the frequent mismatch between the job and the capabilities of the patient. These authors cited studies, mainly applying regression statistical analyses, which reported the great significance of the patient's pre-operative expectations of return-to-work in prediction of the actual post-operative

employment status. Erroneous beliefs regarding behaviors during rehabilitation are associated with negative expectations and subsequently, with failure to resume gainful employment. Additionally the anxiety of physicians, unwarranted medical restrictions and the complexity of multiple physicians from various services can negatively influence the return to the workplace.

Persons with renal disease who are chronic dialysis patients have been studied in terms of quality of life and various aspects of adaptation. "Vocationally active" is considered a criteria for positive adaptation. Again, frequency data is reported for those working or not (Bremer, McCauley, Wrona, & Johnson, 1989; Wolcott, Nissenson, & Landsverk, 1988). In a cross-sectional quality of life study of 66 chronic dialysis patients, Wolcott, Nissenson, & Landsverk (1988) reported that those vocationally active participants as compared to vocationally inactive had superior medical, psychological and social adaptation. Male gender, age greater than 51 and vocational inactivity were all associated with poorer dialysis adaptation. Bremer et al. (1989) reported objective losses of life quality in all end stage renal disease patients in their study, particularly loss of employment. However, the successful transplant and home hemodialysis patients fared better on both subjective and objective measures.

Causal modeling has been a method used to explain employment outcomes in persons with multiple sclerosis (MS). Kornblith, La Rocca and Baum (1986) used many demographic and disease status variables to build a predictive model of the factors of work status. Of 949 persons with MS, 65.2% had worked at the time of the first symptom and only 27.2% were still employed at the time of the study, an average

of 17 years later. Path analysis revealed the significance of mobility dysfunction in predicting employment, particularly for men.

Haffey and Lewis (1989) reported on programming for occupational outcomes in persons with traumatic brain injury. Their program included precise identification of barriers to employment and systematic planning for skill generalization and maintenance. The authors also described an interesting program component termed "supported work" which involves a "job coach" who facilitates the entry to the workplace and the actual day-to-day work. This coach would intervene only as necessary both prior to returning to the workplace and after the return. While the role was not explicated further, the report implied that the coach was not another worker, but an external party. The report did not include an evaluation of the program.

Summary

The synthesis of the human response framework and findings of the literature review identified current literary directions and revealed many gaps in our knowledge about the experience of return-to-work for the person with cancer. As seen in Figure 2, the majority of variables identified thus far are environmental factors.

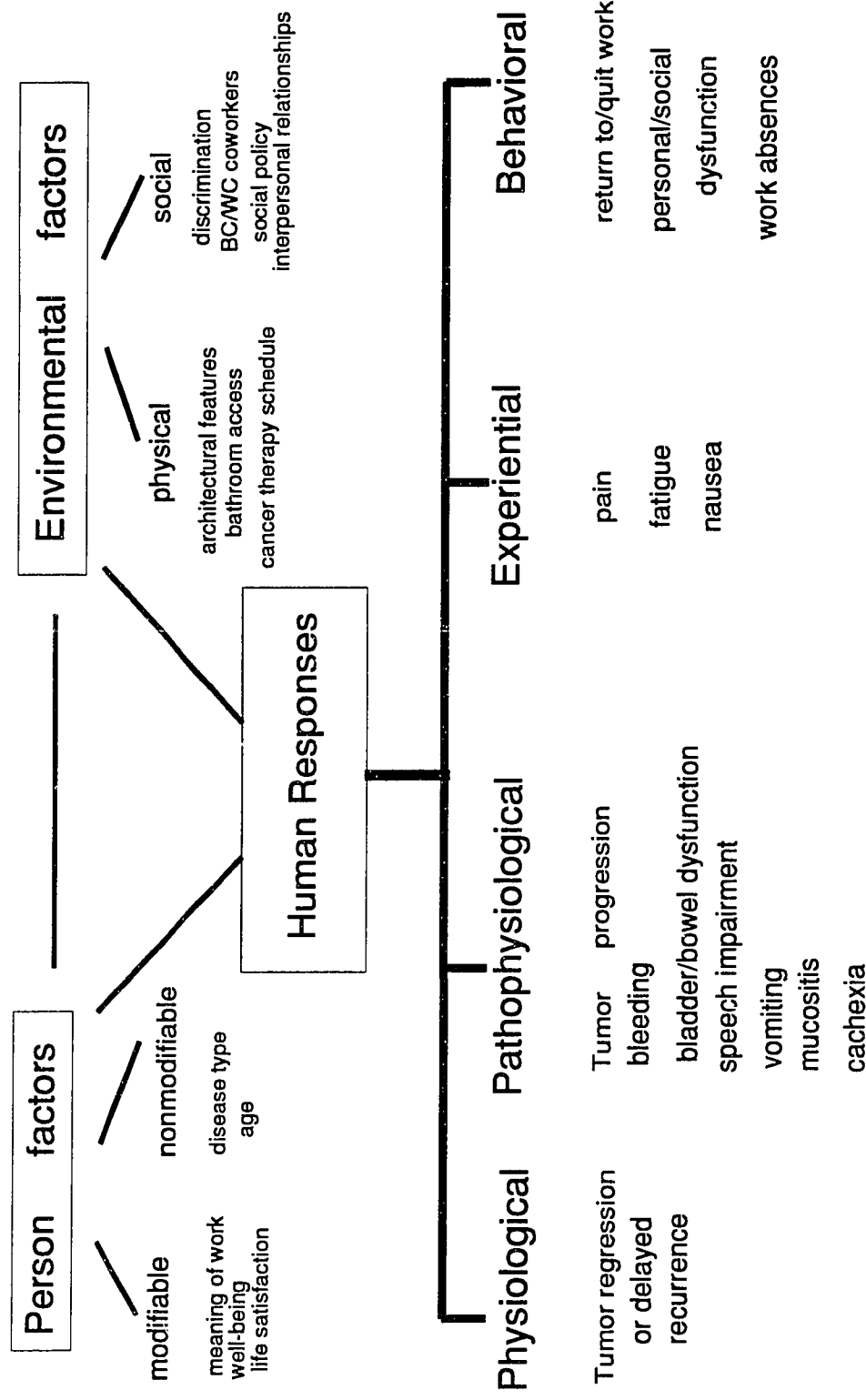


Figure 2. Returning to the workplace with a diagnosis of cancer
adapted from Heitkemper & Shaver, 1989

The human responses, or individual adaptations, to circumstances of living with cancer are fairly well represented in the literature. However, these responses have been evaluated infrequently in relation to return-to-work outcomes. Table 1 lists the person and environmental factors, human responses and clinical therapeutics which have been researched and the designs utilized.

Table 1

Return-to-Work Research

	QUANTITATIVE DESCRIPTIVE STUDY DESIGN	EXPERIMENTAL STUDY DESIGN
ENVIRONMENT	Architectural features Bathroom access Cancer treatment schedule Discrimination BC/WC coworkers Interpersonal relationships	
PERSON	Meaning of work Disease type Age	
HUMAN RESPONSE	Return to/quit work Work absences Personal/social dysfunction	Tumor regression versus tumor progression Return to/quit work
CLINICAL THERAPEUTICS		Cancer therapy Modified surgery

Quantitative, descriptive study reports, often focusing on discrimination issues, are the most frequently cited literature related to return-to-work for patients with cancer. The next most common is the article published as a consciousness-raising or professional education piece. The comparative research report is rarely seen in this literature. This pattern in the literature is not surprising however, when the history of cancer survivorship is considered. Persons with cancer have not always been a significant percentage of applicants nor have they been the employees returning in great numbers to reclaim their former jobs. The changes discussed in the earlier section of this chapter have created unique scenarios, experiences and work environments for the person who has survived cancer.

The individual experience of the employed person who has, or had, cancer has been infrequently reported. Surveys have identified bits and pieces of data relevant to the individual's experience. Little is known about the complete set of dimensions experienced by the worker. The complex process of returning to work after a diagnosis of cancer has not been documented. Not only do practicing nurses lack research-based interventions to facilitate a successful return-to-work, they lack an understanding of the individual's experiences and the relationships between influential variables and factors within that experience.

This study, designed to explore the dimensions and process of the experience of returning to work after a diagnosis of cancer, will add to the research base. The resulting theory, grounded in data derived from the experiences and worldviews of the participants, can be used to test relationships between influential factors and ultimately

test nursing interventions. Clinical trials can be implemented applying various study designs appropriate to the intervention and outcome measure.

CHAPTER III

DESIGN AND METHODS

Study Design

This chapter will explain the study design and methods used to collect and analyze the research data. Brief narratives will highlight specific references relevant to the design and methods implemented.

This exploratory, longitudinal design was implemented to document the process and dimensions of an individual's experience in returning to work with cancer. The naturalistic paradigm and qualitative research methods, particularly those of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990), informed all aspects of the study design. A substantive theory has been generated which explicates the experiences of the participants and provides clinicians and researchers an enhanced understanding of the process of returning to work after a diagnosis of cancer.

The multiple realities of the participants' experiences were best investigated in a "naturalistic context" (Lincoln & Guba, 1985), that is, with the very persons having the particular experience at the very time of the experience. The use of a human instrument for data collection and the application of the qualitative methods described below provided a method which was sufficiently adaptable to encompass and accommodate the variety of experiences encountered in the research (Lincoln & Guba, 1985). The theory-generating methods of grounded theory (Strauss & Corbin, 1990) enabled discovery of dimensions and processes of a return to the workplace with cancer, an experience for which no *a priori* theory existed. Hutchinson (1986) suggested that generation of grounded theory in clinical nursing situations often is

inherently more relevant to the clinical environment than verificational research which attempts to find data to fit an *a priori* theory transferred from another discipline or clinical situation.

The Sample

Twelve participants were recruited from one of two urban, Pacific Northwest study sites: a private urological group practice or the urology clinic at a large university medical center. All potential participants who were contacted agreed to participate in the study. The following eligibility criteria were met by all participants: a) aged 18 years or older, b) able to read and speak English, c) diagnosed with a genitourinary cancer, and d) employed full time at time of study entry.

Initial accrual of participants to the study began with purposive sampling. The urologists at the study sites assisted in identifying eligible patients from recent surgeries and sent letters to each participant inviting them to participate in this study. Efforts were made to enhance variability in the sample for certain demographic and individual factors. After accrual of several men with prostate cancer, participants of other diagnoses were purposively selected for study entry. Sampling on variations on age, gender and length of time since diagnosis was conducted to uncover a full array of return-to-work experiences. Theoretical sampling guided the latter participant accruals. Age and gender variations were sought to further explore partially discovered dimensions of the return-to-work social process. These sampling techniques increased the scope of the data collected, encouraging not only patterns and commonalities to develop, but elucidated the deviant, unique experiences. Lincoln and

Guba (1985) wrote that purposive sampling will maximize an investigator's ability to construct the grounded theory.

Sampling was conducted from December, 1991 through June, 1992. With the completion of the initial interview with participant TWELVE, much of the data analyzed was redundant with what had been collected and analyzed over the previous six months. This is consistent with the point in a research study which Glaser and Strauss (1967) called "theoretical saturation." An effort was made to identify and invite another younger man to participate, however none were available at that time. Given the near theoretical saturation, study accrual was halted. Table 2 lists the participants' numbers, gender, and occupations.

Table 2

Participant Gender, Age and Occupation

NUMBER	GENDER	AGE	OCCUPATION
01A	woman	39	personal care assistant
01	man	55	cook
02	man	58	engineer
03	man	59	school district administrator
04	man	43	public school teacher
05	man	69	financial planner
06	man	57	business owner
07	man	54	manager for airline
08	woman	58	legal secretary
09	woman	49	registered nurse
10	woman	46	technical writer
11	man	32	forest ranger

Protection of Human Subjects

This study was approved by the University of Washington Human Subjects Review Committee on July 16, 1991 and renewed on July 7, 1992. All data is held in anonymity. Only the investigator has access to the data form code list. Informed consent was obtained from all participants prior to any interview. Each participant was given a copy of the consent form. The consent form for the study can be found in Appendix A.

Data Collection Procedures

Data were gathered through unstructured interviews and completion of a demographic/medical history case report form (Appendix B). Participants were not asked to fill out any forms. The medical record of the participant was reviewed for some information gathered on the demographic/medical history case report form. Other information collected on the case report form was obtained during the interview.

The Interviews

Six of the 12 initial interviews were conducted in the urology clinic just after or during a previously scheduled appointment. These took place in a private room without interruptions. Another 5 initial interviews were conducted in a public place, a small delicatessen close to the urology clinic. Although public, the layout of the delicatessen afforded privacy to all interviews. Participant FIVE was initially interviewed in his private office.

The investigator placed telephone calls to all participants from 6 to 16 weeks after the initial interview. To those participants whom the investigator was able to speak with in person, the question was posed, "Have there been any changes in your return-to-work situation since our interview?" For those whose answer was clearly negative, no follow-up interview was scheduled. Second interviews were conducted with seven of the participants. Table 3 lists the participants and the interviews conducted with each.

Table 3

Interview Locations and Time Between Interviews

PARTICIPANT	INITIAL INTERVIEW	TIME BETWEEN INTERVIEWS	SECOND INTERVIEW
01A	Urology clinic	13 Weeks	Delicatessen
01	Urology clinic	8 Weeks	Telephone
02	Urology clinic		None
03	Urology clinic	12 Weeks	Telephone
04	Delicatessen	12 Weeks	Delicatessen
05	Private office		None
06	Urology clinic	12 Weeks	Private office
07	Urology clinic		None
08	Private office		None
09	Delicatessen	16 Weeks	Telephone
10	Delicatessen		None
11	Delicatessen	12 Weeks	Telephone

Many of the participants homes were several hours away from the urology clinic. In fact, 2 participants live over 1000 miles away. Thus, telephone interviews were used for several second interviews.

All but one of the interviews were audiotaped and transcribed verbatim by a skilled transcriptionist. One of the second interviews was documented by concurrent note-taking and post-interview field notes. The transcripts were entered into a software program, The Ethnograph, (Seidel, 1988) for analysis.

The initial interviews were conducted in an unstructured format. Lincoln and Guba (1985) wrote that the unstructured format is the mode of choice when the interviewer "does not know what he or she does not know" (p. 269). Such was the case in this naturalistic study where no *a priori* theory was available to generate and guide the interview questions. The unstructured interview format provides the greatest opportunity for the interaction between the participant and the investigator to flow, creatively discovering aspects of the germane experience in the words and perspective of the participant.

Each initial interview was opened by the statement, "Tell me about your return-to-work experience after your diagnosis of cancer." Although all participants knew the research topic as described in the informed consent process, this statement re-introduced the relevant experience to the participant. Spradley (1980) termed this the "grand tour question." The direction and content of each initial interview was then led by the participant.

Second interviews and initial interviews with participants EIGHT through ELEVEN contained some specific questions from the investigator only after the participant had elaborated on the direction of his or her choice. The narrowing in scope, or specificity, introduced at these points of data collection is useful for triangulation or member-checking (Lincoln & Guba, 1985) and for completion of conceptual dimensions (Spradley, 1980). This data collection strategy will be discussed in further detail below.

Data Analytic Procedures

Techniques of constant comparative analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1990) directed the data analysis of this study. Although the steps in the data analysis will be described sequentially, the iterative nature of the analysis must be emphasized. Some steps occurred simultaneously and the direction reversed at times. Strauss and Corbin (1990) explained that although there are distinct strategies for data analysis, the investigator often alternates between the strategies.

Open coding of the transcripts began the analysis procedure. Through close examination of the data, open coding identifies and conceptualizes the less abstract phenomena presented in the data (Strauss & Corbin, 1990). In this study, for example, the data from the early interviews presented many concepts relevant to *Telling others*¹ at work about the *Detection* and diagnosis of their cancer. As each phenomenon or incident is coded, the "comparative" aspect of this method comes into play. Glaser and Strauss (1967) describe this as the "basic, defining rule for the constant comparative method" (p. 106). Each incident or concept is compared to previously coded incidents for similarity and differences. Some codes are repeated frequently and others are found only once or twice in all of the data.

Grouping concepts or incidents revealed the categories of data evident in the transcripts. For example, *Comparisons* was identified as a category which included comparisons of *Age*, and downward and upward social *Comparisons*. During the

¹Concepts, constructs and categories coded during data analysis are italicized and capitalized (first word) throughout the text of this document.

process of categorization, the investigator asks questions of the data, building the dimensions of each category identified (Strauss & Corbin, 1990). For example, while examining the category, *Telling others*, the question was asked, 'why did the participants tell anyone in the workplace?'

The documentation of steps such as asking questions of the data occurred in the form of code notes and memos. Early notes were made directly on each transcript. As these accumulated, additional code notes and theoretical memos were typed. The "second rule of the constant comparative method" (Glaser & Strauss, 1967, p. 107) is to stop coding at certain points during data analysis and record memos on ideas.

The next coding strategy which was used to analyze the data was axial coding. Strauss and Corbin (1990) discussed axial coding as a process of reconstructing the various categories and concepts identified in open coding to make connections and relationships between categories or between a category and its sub-categories. In this study, axial coding of the category, *Telling others*, revealed the consequences of *Telling others* in the workplace about the diagnosis of cancer (eg. Receiving *Information, Identifying personally, Caring, and Reassignment of duties.*)

Selective coding is the third and final type of coding to which the data were subjected in this study. It is at this time in the analysis that the "story line" is explicated, the "core category" is identified and other categories are described in relationship to the core category (Strauss & Corbin, 1990). Theoretical notes, memos, and diagrams are drafted to explore the core category and the patterns of social process demonstrated in the data. *Mobilizing support* was identified in this study as

the core category or social process which theoretically encompasses the experience of returning to work with a diagnosis of cancer. A revisiting of the literature was necessary, providing a secondary source of data which enhanced the completion of the story line and the core process. Strauss and Corbin (1990) stated that using the literature in tandem with primary data increases the theoretical sensitivity of the investigator and enhances the conceptual richness of the theory.

Field notes were also maintained during the data collection period of this study and often transcribed on to the end of the participants' interview as a post-script note. Nonverbal behavior of the participants, interactions with staff and other details were included in the field journal. A methodological log was maintained separately recording the investigator's thoughts and feelings about procedures for data collection and analysis.

Trustworthiness of the Data

From the beginning of applied grounded theory and qualitative methods, there has been controversy regarding issues of rigor. Glaser and Strauss wrote in 1967 about their doubts regarding the applicability of conventional canons of rigor in research such as reliability, validity, and hypothesis construction to judge the credibility of grounded theory.

Lincoln and Guba (1985) claimed that direct application of concepts of reliability and validity from the traditional empirical analytic mode to an inquiry made from a naturalistic paradigm is inappropriate. They offered credibility, transferability, dependability and confirmability as relevant "trustworthiness criterion."

Credibility

A credible report of a naturalistic inquiry using grounded theory generating methods will have demonstrated "truth value," and has adequately represented multiple constructions of reality. Certain field activities can increase the probability of high credibility: a) prolonged engagement, b) persistent observation, and c) triangulation of data, methods and/or investigators (Lincoln & Guba, 1985). In this research, the investigator attained prolonged engagement over the six months of data collection in the clinical sites, being present up to three days per week. Triangulation of data was accomplished through comparison of medical records and interview data.

Peer debriefing is another strategy to assure credibility discussed by Lincoln and Guba (1985) and implemented in this study. The investigator contracted with a peer researcher, a doctoral candidate without an oncology background, to debrief at two specific points in data collection and analysis. The peer debriefer had access to sample transcripts. Coding completed by both the investigator and the peer debriefer was consistent and often used the very same terms. The debriefer also inquired as to directions within the interviews and methodological moves. The investigator responded and implemented at least one change based on these debriefing conversations. Debriefing also occurred with the investigator's supervisory committee chairperson on a regular basis. The sessions were instrumental in the development of the method application and the illumination of critical categories.

Member checks have been identified by Lincoln and Guba (1985) as the most crucial of all the techniques for establishing credibility. This research implemented

both "in process" and "terminal" member checks (p. 328). For instance, beginning with Participant SEVEN, after the direction of the interview had been set and exhausted by the participant, the investigator inquired regarding the category, *Telling others*. A brief description was given to the participant of the findings regarding the category and then the participant was asked to comment on those findings.

Supplementary components of the dimensions for that category were revealed as different participants provided additional data. A terminal member check was conducted after the storyline had been developed. A summary of the major study results, the core process and a version of Figure 3 (see Chapter 4) were sent to five participants along with a letter requesting any written or telephone feedback. In keeping with the style of the study, participants were free to write anywhere on a copy of the summary or graphic. The question was posed for their consideration, "Does this reflect my experience somewhat?" The investigator received responses from three participants. Participants SEVEN and ELEVEN agreed that the summary reflected their experience practically in total. They added some interesting comments, however the comments did not reflect a contradiction with the data. Participant SIX agreed with the summary for the most part, but qualified one aspect of his own experience. Given the responses, the credibility of the findings is enhanced and strengthened.

Transferability

Transferability is the term applied by Lincoln and Guba (1985) to address the traditional issue of generalizability. They contended the investigator in a naturalistic inquiry cannot specify the external validity of an inquiry, but can provide the "thick

description" necessary for another to transfer the results to another context. Strauss and Corbin (1990) wrote that the more systematic and widespread the theoretical sampling in a study, the more conditions and variations will be built into theory, enhancing generalizability. During data collection for this study, the investigator sought to collect detailed description as much as possible through member checking and sampling techniques. Theoretical sampling pursued leads in the data such as gender and age differences that were presented in *Telling others* of the cancer diagnosis.

Dependability and Confirmability

The human instrument is in question when issues of dependability and confirmability are addressed. Lincoln and Guba (1985) have fully described a technique which can provide evidence for dependability and confirmability. An "audit trail" can be established. In the case of the naturalistic study, the audit trail should be available for any inquiry. From the raw data to the findings and interpretations to the recommendations, the audit trail documents the analysis and establishes the confirmability of the results. An audit trail was developed and maintained in this study beginning with the coding, both paper and pen codes and codes entered directly into The Ethnograph (Seidel, 1988) software program. Data analytic tools such as memos, diagrams and theoretical notes are all documented on paper and on computer hard and floppy disks.

Although a comprehensive or formal audit was not made of the study materials, the chairperson of the investigator's supervisory committee has had input to the

analysis. Raw data in the form of transcripts, both on paper and on disk were made available to the chairperson early in data collection and throughout the study with the addition of draft analysis notes and diagrams. Discussions between the investigator and the chairperson covered issues of method, specific participant experiences and personal concerns of the investigator. The chairperson was able to confirm directions suggested by the investigator and make suggestions as to how to proceed in data collection and analysis.

As described above, both the field journal and methodological log documented not only some data but specific aspects of the process of data generation, collection, and analysis. Lincoln and Guba (1985) suggested the use of journals and logs as strategies which support and establish all four aspects of trustworthiness discussed above.

Summary

Rigor has been applied to the conduct of this naturalistic inquiry in the forms of Lincoln & Guba's trustworthiness criteria (1985) and their suggested strategies. A core category was identified as the central social process present in the experiences of the study participants. Most of the theoretical categories were saturated, while others were near saturation. A substantive theory was constructed to explain the dimensions and processes of the experience of returning to work with a diagnosis of cancer.

CHAPTER IV

FINDINGS AND DISCUSSION

The findings of this study and the discussion of the findings are integrated in this chapter. The core process identified in the analysis of the data, *Mobilizing social support*, will be presented and discussed first. Theoretical and empirical reports in the social support literature corroborate the findings of this study. References from this literature will be strategically placed in the following discussion as secondary sources of data. Additional categories will then be considered relevant to the core process. Finally, categories and concepts which were identified as peripheral to the core process and the return-to-work experience will be reviewed.

The Core Process

Given the unstructured format of the interviews, the participants had the opportunity to address topics and issues with the frequency and urgency of their own choices, relevant to their personal return-to-work experiences. The theory which has been generated from the data of the 19 interviews is grounded on a foundation of concepts and categories which presented themselves early and throughout the data collection process. Figure 3 graphically introduces the core process story line for *Mobilizing social support*.

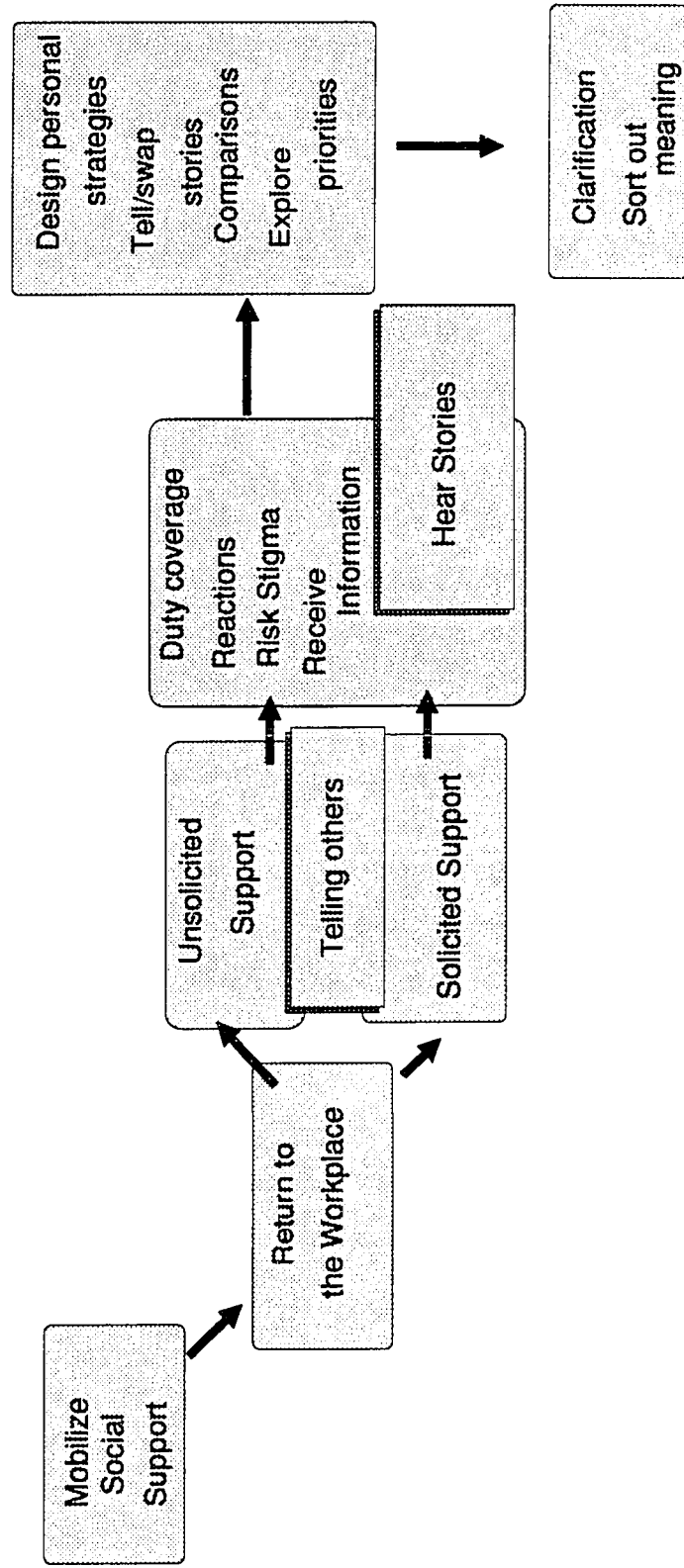


Figure 3. Story line - Mobilizing social support

The description of the *Return-to-work (RTW)* event, *Telling others*, and the *Detection experience* were concepts in the data that appeared early in virtually all the initial interviews. Of these three categories, the *RTW* event and *Telling others* were analyzed as central to the core process. The *Detection* experience was found to be peripheral and will be discussed later in this chapter. Table 4 lists the initial experience categories described in the first five to ten minutes of the interview by each participant.

Table 4

Categories Identified Early in Each Initial Interview

NUMBER	CATEGORY LABEL
01	<i>RTW, Detection</i>
01A	<i>other persons with cancer, RTW</i>
02	<i>Telling others, Detection</i>
03	<i>Telling others, RTW</i>
04	<i>Treatment choices, RTW</i>
05	<i>RTW, Detection</i>
06	<i>Telling others, RTW</i>
07	<i>Detection, Treatment choices</i>
08	<i>RTW, Detection</i>
09	<i>RTW, Detection</i>
10	<i>Detection, Telling others</i>
11	<i>Support, RTW</i>

Return to Work Event (RTW)

The majority of the participants offered a brief description of the event of actually returning for that first week or so to the workplace. Although the experiences differed, the content was consistent. The participants shared how long they had been away from the workplace and that they were anxious to be back at work. There was an emphasis on getting back quickly. Participant SIX responded,

I tried to get out of the hospital quick, and get my catheter out quick, and resume my normal activities as quick as possible.

Two participants told a *Story*, about another person with cancer who had returned to work, as a preamble to their own experience. Being back at work was analogous to being "fine," it meant getting on with one's life and getting past a significant part of the cancer experience. For example, Participant TWO reported strongly,

My attitude of going back to work will be, 'To hell with all this crap; forget it. I have to get on with my life and my business.'

The workplace constitutes one component of an individual's social network. This network is a web of various relationships and affiliations. The social network defines the boundaries of supports upon which one can draw when necessary (Pearlin, 1985).

Certainly the workplace is only one of several environments and sources of support into which the social network extends. The health care environment, family members, and friends all may be available for *Mobilizing social support*. Figure 4

depicts the social networks and environments relative to an employed person with cancer.

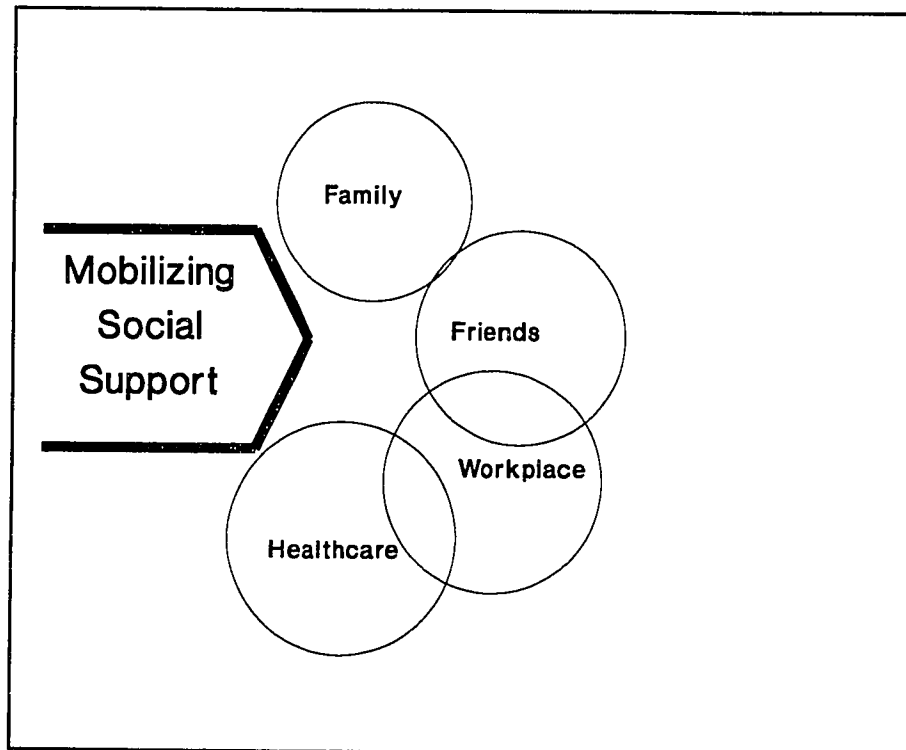


Figure 4. Social networks in which support can be mobilized

It was with the initial act of the *RTW event*, that the workplace became a source of social support. In fact, even the planning for, and anticipation of, returning to the workplace was a source of potential support. Eckenrode and Wethington (1990) defined the construct of social support mobilization as follows:

Support mobilization is the process of marshalling social support resources in anticipation of or in response to a perceived threat (p. 82).

Returning to work was a way to normalize things, a return to a "precancer" role, to be "just the way I was before I left" (Participant ONE). Participation in certain formal social relationships, such as those in the workplace, demonstrates that

an individual is capable of fulfilling associated normative role obligations (Pearlin, 1985). This type of "status support" was found by the participants simply by going to work. Pearlin (1985) wrote that the relational rewards, which are derived merely from the existence of the relationship, may be correlated with psychological well-being.

The social companionship afforded by returning to the workplace was a factor in the motivation to return to work and to stay there. Participant ONE-A stated her job was "great," that she enjoyed her clients so much..."It's just a wonderful feeling." Participant TEN mentioned that he had had lunch with his business partner everyday for 35 years. Social relationships can be supportive by furnishing the social environment with much potential for companionship during both leisurely and work-related events (Pearlin, 1985).

Both status support and social companionship are aspects of social support available to an individual with cancer as they re-enter their workplace. These types of support can be described as unsolicited support. They can happen by virtue of being physically present in the workplace. Other forms of social support are solicited and usually necessitate social interaction specific to the cancer experience. A distinction should be made between unsolicited and solicited support because of the following factors: a) they are likely to occur through different processes with different sets of contingencies, b) unsolicited support may not involve verbal self disclosure, and c) solicited support carries different implications for issues of self-esteem (Eckenrode & Wethington, 1990).

Self-disclosure can occur when unsolicited support is mobilized. However in that case, the supporter has usually been cued by signs of, or inferred, distress and not by explicit requests for help (Eckenrode & Wethington, 1990). Probably this is what happened for most of the participants in this study. Most participants were able to *Tell others* about their diagnosis, yet did not request specific support or assistance from their *Coworkers*, *Supervisors* or employees. This action may have been less threatening in terms of self esteem. Seeking help from others can carry psychological costs of vulnerability, weakness, and failure and be more threatening than accepting support that is offered without having to ask for it (Gross et al., 1979; Nadler, 1983). Additional details of aspects of self-disclosure will be discussed later in this chapter.

During the early descriptions of the *RTW event*, only three of the participants discussed specific problems with their return to the workplace. Table 5 lists the participants and those with identified problems.

Table 5

Problems Identified during the Return-to-Work Event

PARTICIPANT	TREATMENT	PROBLEMS
01A	intravesical immunotherapy	fatigue, viral infection decreased work hours
04	systemic chemotherapy, surgery	emotional problems, fatigue
10	surgery, adjuvant immunotherapy	fatigue
01	surgery	
02	surgery	
03	surgery	
05	surgery	
06	surgery	
07	surgery	
08	surgery	
09	surgery	
11	systemic chemotherapy	

Clearly, the commonality for the three with specified problems demonstrated in the table involves the nature of the treatment. With the exception of participant ELEVEN, the participants who described their initial RTW event as problematic had received immunotherapy or chemotherapy. Another notable commonality for these three participants is that they also described experiencing *Changes* in their jobs or positions upon returning to work. Work hours were cut by participant ONE-A's

Supervisor during her intravesical therapy; participant FOUR quit one job and took a new job during his course of chemotherapy and then after surgery felt that the direction of his work had taken on a new direction set by his substitute; and participant TEN found that a significant portion of her work had been reassigned to her coworkers.

It is instructive to note that both participant ONE-A and FOUR were experiencing recurrences at the time of the interviews. Only participant TEN said she returned to work before she was ready, due to benefit constraints and her desire to save her vacation time for taking care of her ill mother. Contrast the following quotes:

No, there really hasn't been any serious problems at all. I was able to come back to work and do everything I could before, with the exception of [heavy lifting]. (Participant FIVE)

I am absolutely supported at work. They said, 'Come back when you feel like it, and if you can't be here, you can't be here.' (Participant SEVEN)

So I wasn't feeling particularly good about having major portions of my work delegated out to other people... So I was not in a good position ... [particularly regarding] how I felt about my relationship with my coworkers ... I came back before I was physically ready, but I would not have been eligible for any kind of benefit, because the statistics say you can go back to work after six weeks. (Participant TEN)

The interplay of all these factors can explain the problematic *RTW event* for the three participants, yet no causality can be distinguished. The role of fatigue as a side effect of chemotherapy and immunotherapy has been described in the cancer nursing literature (Piper, Lindsey & Dodd, 1987). This study may be one of the first to document some relationships between fatigue and the success of the return-to-work

experience. Not only have descriptive studies barely touched on this phenomenon as related to working, intervention studies addressing fatigue are practically absent from the literature. Winningham's program of research (1991) involving exercise training as an intervention has addressed fatigue, but as a secondary outcome. There is no scientific, empiric basis for nursing therapeutics designed to alleviate fatigue problems in the workplace.

The *Changes* which were evident in the workplace during the RTW event were those out of the control of the participant. They should be distinguished here from the many *Changes* that some participants chose to make in their lives after their diagnosis and treatment. The participants described these later in the interviews and often when addressing the *Future*. These *Changes* will be presented later in this chapter.

Telling others

Telling the news of their cancer diagnosis to others in the workplace was a priority issue for the majority of the participants. The experience of telling or not telling others was the first or second topic offered by four participants in their initial interviews. Recall that the interviews were unstructured and the investigator did not query any particular information in the early parts of the interviews.

Sharing the diagnosis with others in the workplace was a significant issue for five of the men and one woman. They disclosed a limited amount of information about their cancer and therapy and with a very limited number of individuals within the first few weeks after the diagnosis. Interestingly, all but one of these six provided

spontaneous description of their struggle with disclosure of the diagnosis in either the initial or follow up interview. Conversely, those for whom telling others was not limited and not an issue they struggled with, only described such experiences when queried.

Self-disclosure is a social behavior which is a component of support mobilization, occurring after the problem is defined and resources appraised (Eckenrode & Wethington, 1990). Cozby (1973) reviewed and discussed the variables which influence self-disclosure. Some racial differences reported include a lower disclosure level by people of color, however, social class may be the more influential variable. For the most part, women are reported to disclose more information and more intimate information than men. While examining comforting as a socially supportive behavior, Burleson (1990) summarized that although women place a greater emphasis on the emotional support function of friends than men, most men will look to their friends as sources of support during troubled times. More often than not, the friends of men are probably in the workplace.

The results of this study indicate a continuum of how much was disclosed in the workplace. There were the extremes, from one man who purposefully hid his diagnosis and surgery from all but his 'next-in-line,' to three women who freely discussed their experience at appropriate times with everyone. Participant THREE stated:

It was never a secret with my deputy, because he needs to know what's going on; it was never...And the whole point behind it, because of my position, I didn't want anyone else to know.

The other extreme, from participant NINE can be contrasted:

I'll talk to anybody about it (laughing). I mean, I have not a problem with talking about it.

The participants gave examples of the dimensions of *Telling others*. They described why one would tell others, reasons not to tell others, who was told, who had to be told, when to tell and how to tell others of their diagnosis and oftentimes of their treatment and recovery experiences. Table 6 lists various examples of these dimensions.

Table 6

Dimensions of *Telling Others* in the Workplace

DIMENSION	EXAMPLES
Why tell	cover work duties, emotional support, get information, avoid rumors
Why not tell	it distracts from work, position & status, others are ignorant of illness, avoid "stigma," illness seen as a "weakness," "vulnerability," shame, fear of recurrence, others uncomfortable
Who was told	immediate supervisor, immediate subordinate, peer coworkers, clients,
Who had to know	immediate supervisor, immediate subordinate,
When to tell	during & after diagnosis, after recuperation from surgery, at recurrence, only if someone inquires
How to tell	have coworker do it, in person, metaphorically, while "swapping stories"

One pragmatic reason to tell others was described by several participants as the need to cover work duties during the actual absence from work or to prepare for an actual or potential absence. The supervisors and subordinates who were told were those who "had to know." Participant SEVEN said, "I wanted to tell people, rather than have other people tell them." To the contrary, participant SIX described, "I have a business associate - a partner - and when I was in the hospital, then he told the

employees, 'J. is gone, he's having a small operation, he'll be back in three or four weeks.'" This same participant, while stating several times that he did not want to talk about it much at all, said he confided in a salesman (his subordinate), "I confided in him because I wanted to find out about his dad." The salesman's father had had the same operation for prostate cancer as the participant. Although not an issue for participant FIVE, he stated that the results of telling others, including those at work, contributed to "the proper mental attitude." He had felt emotionally supported and encouraged by those he had told. While gaining information or social support was not identified by all the participants as a reason to tell others of their cancer diagnosis, there were additional references to increased social support as an outcome of coworkers knowing about the diagnosis and treatment. Participant TEN remembered the concern her peer coworkers had shown,

They were very [concerned]...Saying encouraging things like, 'take time in the middle of the day - go over to the other building and lay down' ... So my first two weeks back were hard, and the people were very concerned and generous.

Receiving Information

The *Information* received by participants in the study was a consequence of *Telling others* the diagnosis of cancer. Informational support is one of several categories in classifications of what kinds of social support are available in social networks such as the workplace. Components of social support have been aggregated and classified in several different ways (e.g. Cutrona, Suhr & MacFarlane, 1990; Vaux, 1988; Wills, 1985). Common categories of social support include emotional support, instrumental support, and informational support.

Practically all of the information received from others in the workplace took the form of *Stories* told to the participants. In turn, the participants relayed information during the interview about *Other persons with cancer* through similar stories.

Here are some examples of how *Stories* initially were addressed by some of the participants.

I confided in him because I wanted to find out about his dad...'how's your dad, how's the operation'...He says, 'It was horrible, it was excruciating.'
(Participant SIX)

Or they'll [coworkers] say, 'I knew so-and-so...' And maybe they're looking for somebody, or a doctor or something... (Participant EIGHT)

They [coworkers] told me that there were people that they had known who ... when I first came to work in this particular group - a fellow with whom I'd worked - had just come back like a week before I showed up. (Participant TEN)

The category, *Stories*, appeared multiple times in the initial interviews, often coded as *Information*. The investigator subsequently inquired about further dimensions of the concept at the end of some later initial interviews and follow-up interviews. The application of *Stories* in receiving *Information* occurs in either a solicited form or an unsolicited form. Eckenrode and Wethington (1990) discussed story-telling as a mechanism of help and information seeking. Some individuals, they contended, make "disguised attempts at help seeking whereby help is sought by indirect means..."(p. 92). This method of gaining unsolicited support can be less threatening than the potential loss of self esteem which can coincide with admitting the diagnosis of cancer and perhaps acknowledging vulnerability and weakness (Eckenrode & Wethington,

1990). Indeed, only participant SIX reported asking to hear a specific story about another person with cancer. As presented earlier, disclosure of their cancer was uncomfortable for many of the participants, particularly in the beginning of the return-to-work process. Participant FOUR reported these feelings succinctly,

There is a vulnerability associated with telling about it, showing weakness, reminds one of being in the hospital, totally out of control...

This same participant described a scenario of "story-swapping," having taken place several times in the lunchroom at work. Whenever health difficulties come up as a topic, he and his coworkers play 'top this story.' When questioned as to why this interaction takes place, participant FOUR responded with an analogy. During the time the participant was active in the Air Force, he and other Vietnam pilots often told *Stories* of their escapades to each other. Remembering these stories helped the participant the next time he was faced with a similar situation. Wrapped up in the story was a strategy to deal with the situation. He wondered if this could be a way of learning in an informal conversation. Participant FOUR is a public school teacher whose experience is appropriately corroborated with Glidewell's (1983) description of "experience swapping" by school teachers as an informal means of obtaining advice and information without explicitly asking for such support.

Many of the participants were approached by coworkers with *Stories of Other persons with cancer* that were apparently for the benefit of the *Coworkers'* comfort level in discussing the participants' illnesses. Participant ELEVEN called the use of *Stories* an "ice breaker," an acceptable way to enter a conversation about experiences with cancer. It was his experience that sometimes the *Coworker* needed information

from him, as a reliable informant, about the experience with cancer. This information could then be applied to the *Coworker's* other acquaintance or family member with cancer. Other times, the *Coworker* simply used the *Story* as a way to "share compassion;" to say they "know the pain, they know what it's like."

Participant ELEVEN reported some additional interesting points when queried about storytelling. He said that others were often very interested in knowing why he had gotten cancer, the etiology of his disease. The *Coworker* might share a story about a family member who smoked for many years and "of course" got lung cancer. Then the coworker would ask questions of participant ELEVEN about his own disease origin. The participant summarized, speaking about the cancer experience relayed through *Stories*,

There's got to be some sense and order to it...It's [the story] got to have a reason for it [the cancer], and it's got to have a little 'how you dealt with it,' and then a close [an end] to it.

Participant NINE moved from a large urban locale to a remote Alaskan island between the first and second interviews. She was able to provide some insight into the use of *Stories* among two sets of *Coworkers*. In the first workplace, she reported, *Stories* were a way to discuss mutual experiences and fears with *Coworkers*. She said,

I think it's a definite part of the healing process, sharing your story with someone. It does ...it kind of reinforces your sort of humanness...there's a common thread.

Participant NINE also stated that older women were more compassionate, better listeners and story sharers than the younger women in the second workplace. She explained this by the difference between herself and the young women. They were

virtually all young wives and mothers, intent on their family activities. The participant is a single, middle-aged woman without any family close by. Not surprisingly, participant NINE had not told her new peer *Coworkers* about her cancer experience.

Participant SIX also discussed the feeling of hearing that there are others in your own situation.

It's sort of comforting to know you're not alone - you hear that all these guys had prostate cancer. 'Oh, God, he's got it; everybody's got it.' It's nothing; they can feel more secure ...it's sort of commonplace - 'Oh yeah, prostate cancer, what the hell?'

Cutrona, Sur, and MacFarlane (1990) identified story-telling as a strategy in their study of interpersonal transactions and social psychological support behaviors. While the researchers used a sample of healthy married couples and undergraduate college students, the reasons for telling stories as supportive behaviors are comparable to reasons discussed above in this study of persons with cancer. *Stories* were told by their subjects in order to: a) convey that the individual is not alone in the stress experience, b) convey a sense of understanding, and c) indirectly offer suggestions and advice.

The results of this study would add an additional reason for story-telling. *Information* can be gained by the story-teller for their own personal use. Other examples of this reverse role, the participant as supporter to a coworker, were reported in the data. Upon hearing the news of the cancer diagnosis in the participants, several coworkers of both participants TWO and EIGHT were motivated to seek health care for themselves.

It was very surprising, because in my workplace there are a number of men that are over 50...when you bring up the subject of prostate cancer, they immediately get - they take it personal...Suddenly the focus is away from you and on them...[they were] relating it to themselves - and they get frightened. (Participant TWO)

The evidence in the data for an exchange of "giver" and "getter" roles in social support suggests that supportive behaviors are interactive in nature. Dynamic exchange of roles can occur between colleagues and coworkers much more quickly than one might expect. Pearlin (1985) wrote that socially supportive behaviors occur primarily in continuing relationships in which there are no rigid expectations of giver and getter functions and these may be reciprocally exchanged. The norms of helping each other clearly are dependent on the nature of the social network in any particular environment. The type of supportive behavior can differ based on the social network. Supports can be specialized, that is, support can be drawn from different sources for different problems or threats (Pearlin, 1985). For serious life problems, all available systems of support may be mobilized, but specialized along the lines of types of supportive behaviors. In this return-to-work study, the participants mobilized mainly informational support. Perhaps it was their family or friends outside of work who provided the bulk of tangible aid, or instrumental support.

Based on structured interviews with 79 patients, Dunkel-Schetter (1984) identified self-reported supportive behaviors experienced by the cancer patients. While informational support was identified as the second most helpful behavior, it was experienced as helpful when received from health professionals. When received from friends and family members, information and advice was more often identified as

unhelpful. While these results initially appear contradictory to the results of this return-to-work study, participant THREE cited some of these very feelings when explaining why he chose not to tell anyone in the workplace, except his immediate subordinate, about his cancer. He also disguised the absence for his radical prostatectomy by having the procedure completed the day before Thanksgiving day and returning to work the following Monday morning.

That's another thing - people think, 'Cancer - oh...[you're going to die]...yeah, well that's the thought; right away, that's the immediate kind of thoughts. But the point is that people - there's just such an ignorance...about the different kinds and treatments. (Participant THREE)

The difference in the results of the two studies may lie in the different emphases in the nature of the *Information* provided. In the Dunkel-Schatter (1984) study, information and advice seemed to be instructional in nature and was not described as taking the form of story-telling. For the participants in this study, the predominant use of *Stories* to provide *Information* as a supportive behavior indicates a more appropriate type of social support behavior in the workplace.

But what of participant THREE? What individual differences or characteristics did he possess to create such a different experience for him compared to the others in this sample? The answer is beyond the scope of this study. However, some work has been done to identify specific correlates of receiving social support. After a study of 75 married couples, Dunkel-Schatter, Folkman, and Lazarus (1987) concluded that the way in which an individual copes with stressful encounters may provide cues to members of his or her social network regarding the person's need and desire for support. The individual that distances himself from the problem, similar to participant

THREE's actions, may signal that the person does not want information or advice. The psychological costs of self-disclosure perceived by participant THREE may have been too high, and the levels of intimacy with others in his workplace too low, to permit *Telling others*.

Having one's duties at work covered by coworkers and receiving *Information* were, for the most part, positive outcomes of *Telling others* for the participants in this study. Negative or neutral outcomes were reported, although to a lesser extent.

The stigma of having cancer was an issue verbalized by several participants. One might expect that current beliefs about cancer would no longer contain myths such as cancer as punishment or cancer as a death sentence. These study results indicate that some myths are present yet today. Participants THREE, SEVEN and TEN spoke of their feelings of the stigma of having cancer.

I didn't tell everybody. I didn't want the feeling, the karma, that raised consciousness to be, 'Oh, he has cancer - he's going to die.' (Participant SEVEN)

I didn't talk a whole lot in the workplace - about being diagnosed as having cancer. It's a shameful thing, you know? We still have this pagan approach to being pointed at by the gods - we have this thing about, 'If you have cancer, it's your fault - you did something wrong, you're being punished - you deserve it.' (Participant TEN)

Both of the participants quoted above blamed their cancers of their own lifestyle behaviors, and for participant SEVEN, also on his mental/emotional attitude. Although both participants were perhaps embarrassed by their diagnoses, they eventually were much freer in *Telling others* about their cancers. Both had positive experiences of support from coworkers upon their return to the workplace.

Recall that participant ELEVEN described sharing the estimated etiology or cause as part of one's cancer story. Although he did not ascribe a cause to his own testicular cancer, others with whom he swapped *Stories* practically insisted hearing his appraisal of the cause. This piece of information, relevant to the cause of the cancer or even where the fault lies for the cancer, may be crucial to sorting out the meaning of the cancer for certain individuals. The other participants in the study did not address stigma or blame for their cancers per se. However, a review of Table 6 provides much opportunity to identify reasons of *Why not tell* as indicators of feelings relevant to the stigma or blame. Certainly there is a relationship between feelings of stigma and self-disclosure in the workplace.

The *Reactions* of those in the workplace to the news of the participants' cancer diagnosis and treatment were overwhelmingly positive. The majority of *Reactions* were described as supportive, generous, and caring. Only one instance of negative *Reaction* was reported.

One guy at work jokes around, keeps making inappropriate comments about me since the surgery. That makes me pretty angry (Participant FOUR).

The low incidence of such *Coworker Reactions* is consistent with the literature reviewed in Chapter II. The highest incidence of negative coworker reactions was reported in Feldman's (1978) blue collar worker study. Participant FOUR was in a white collar position as were the majority of study participants.

Comparisons

Hearing *Stories* about *Other persons with cancer* enabled the participants to take certain actions. Not only were they able to design personal strategies for dealing

with their own situation and swap *Stories* as discussed above, the participants were given a rich matrix of examples in which to make social *Comparisons*.

Social comparison is a method through which individuals engage in self-evaluation. Festinger (1954) proposed that people need to evaluate, for themselves, their opinions and abilities and they often do so by comparing themselves with others. The theory has since been extended and tested in several settings (Wheeler, 1991). Both upward comparison (i.e., comparing with a person who is better off than oneself) and downward comparison (i.e., comparing with a person who is worse off than oneself) have been described as major constructs in the theory (Wills, 1991). Downward comparison has been demonstrated to predominate in field studies involving persons with cancer (Wills, 1991; Wood, Taylor & Lichtman, 1985). Wills (1991) stated, "The basic principle of downward comparison posits that subjective well-being will be enhanced through comparison with a less fortunate other" (p. 65). It is under the perception of stress or threat that the use of downward comparison overshadows that of upward comparisons.

Perhaps the most direct downward comparison was expressed by participant ONE-A.

You know, there's other people out there that have terminal cancer and everything - I think I have it pretty darn good.

Often the comparison was implied in the recounting of some details from the *Story* of another person with cancer.

I believe it was last year...one of the employees was diagnosed with cancer...but he died very quickly and that was sad. And at the time that I got my diagnosis was when Michael Landon got his...(Participant SEVEN)

...I think his whole thing was more severe than mine - his whole surgery was more severe. He was in the hospital more...I remember he said, 'J. it was rough.' Oh God, I heard that! But, he had it much rougher than I did.
(Participant SIX)

Participant ONE expressed a comparison that was neither upward or downward but "lateral." While discussing his own incontinence, the participant made the comparison as if to demonstrate equivalence.

...there was one of the guys that I sail with [coworker on a ship], had the same operation...he says he still has a little bit of leakage - not a big amount, you know.

A final method of comparison evidenced in the data was an inferred comparison to a well-known public figure.

Prostate cancer...I read this morning's [paper]...someone in Bush's cabinet. The guy was seventy one...but its a headline; he's not going to let this prostate cancer beat him. Jeez - the headline, just this morning...I don't want to read that. (Participant SIX)

While exploring the experiences of women with breast cancer, Wood, Taylor, and Lichtman (1985) described comparisons made to "supercopers," those public figures highlighted in the media who do very well with the challenge of cancer. Feelings of well-being are not enhanced, they suggested, when an ordinary individual with cancer compares herself with a supercoper. The quote from participant SIX above certainly illustrates similar sentiments.

Table 7 lists the different types of comparison made by each participant while illustrating the ubiquitous nature of this phenomenon.

Table 7

Use of Social Comparison

PARTICIPANT	DOWNWARD COMPARISON	LATERAL COMPARISON	SUPERCOPER COMPARISON
01A	X		X
01		X	
02	X	X	
03			
04	X		
05	X	X	
06	X		X
07	X		
08	X		
09	X		
10	X		
11	X		

The use of social *Comparison* was absent in only one individual in the sample. Recall that participant THREE was adamant about disguising his *Absence* for *Surgery* and reported not telling anyone in the workplace except his immediate subordinate. If social *Comparisons* are enhanced by hearing *Stories* about *Other persons with cancer* from one's *Coworkers*, then it is no surprise that this man did not report or imply *Comparison* activities.

The great majority of all the *Comparisons* made were to *Other persons with cancer* whom the participant had heard about and did not know personally. Or, in the case of participant ONE, to an anonymous group of unfortunate others. A similar finding was reported by Wood, Taylor, and Lichtman (1985). From an analysis of responses to open-ended queries, the investigators concluded that many women with breast cancer downwardly compare themselves more often to "normative standards" than to individuals known to them. This type of "target-free" *Comparison* allows an individual more flexibility in *Comparison* making. The investigators also emphasized the value of using naturalistic methods for studying *Comparisons* and discovering such *Comparison* characteristics as discussed above.

Everyday conversation abounds with social *Comparison*. Although a common phenomenon, the cognitive process can be complex. Wood, Taylor, and Lichtman (1985) and Wills (1991) reported shifts in foci of the social *Comparison* that individuals in threatening situations made in order to construct the *Comparison* of most benefit to them. In this study, the use of an *Age* dimension for *Comparison* was frequently applied by the men in the sample.

Pearlin (1985) suggested that a support system is a potential source of appropriate models on which people pattern their actions. These "reference figures" are sought by individuals requiring social support (p. 51-2). The social network available to the participants in the workplace afforded much opportunity for social *Comparison* material. Even for participant SIX who "didn't enjoy talking to other cancer patients at all," and often did anyway, downward social *Comparison* was

pervasive in data from his interview. Given the *Stories* they heard, the participants were free to construct the *Comparison* that suited their own needs.

It is possible that social *Comparison* facilitated the appraisal of the participant's situation and how well he or she were coping with the cancer experience. Through downward *Comparison*, the participant could conclude, 'I'm doing as well or better than others in my situation.' Vaux (1988) suggested that certain forms of advice and guidance, as supportive behaviors, during such times of appraisal could ultimately positively effect the receiver sense of well-being by buffering the impact of the threat. The data from this return-to-work study lends evidence for his suggestions.

Exploring Priorities

Several of the participants in this study reported feelings of indecision and ambivalence about continuing as a full time workers and/or in the present position now that their cancer treatment was over or near completion. The majority, however, was determined to remain gainfully employed. It is no surprise that those with the ambivalence were also those with serious concerns about *Recurrence* of their tumors. Participants FOUR, SIX, and TEN had either been treated already for two separate occurrences of cancer or were high risk for recurrence. The following quotes illustrate some of their turmoil.

I have to look around with reality and say, 'What profession...or, can I consider changing professions again with my health history?' I've had a small business on the side in the past, and the consideration of taking it full time... it's the reality of I can't afford to. So, it limits your options. (Participant FOUR)

When I get really upset...I'll blurt out that it bothers me that something could come back. I sit right here at this goddamn desk when I could be out traveling

and enjoying myself...I always thought that if I was diagnosed with cancer, that I would take off - however, I did just the opposite. I am working harder now. (Participant SIX)

...here I am pacing back and forth in the doctor's office, 'I've never been to Mexico, I haven't even been to Hawaii - I never even been to ... Disneyland!' I've got to do these things, I don't have time now. So my attitude about my job has changed a whole lot...One of things that's important for me now is to fill up my memory bank. I need more memories, I don't have enough memories. (Participant TEN)

While these are poignant examples of the dilemmas faced by individuals with uncertain futures, consideration of the sample as a whole gives an impression of surprisingly little uncertainty. Wortman and Dunkel-Schetter reviewed the literature in 1979 and found many references to the feelings of uncertainty associated with a cancer diagnosis. Indeed, a theory of uncertainty has been developed through work with persons with cancer (Mishel, Padilla, Grant, & Sorenson, 1984). After arguing that there are discrepancies in the documentation of psychological distress and mood disturbance in cancer research and that an individual's place on the disease trajectory may explain differences in levels of emotional disturbance, Munkres, Oberst, and Hughes (1992) tested such psychological measures in 60 persons treated for either initial or recurrent cancers. They concluded that neither group in their sample were experiencing marked mood disturbances as measured by the Profile of Mood States-S.

Holahan and Moos (1981) reported the use of the Work Relationships Index to measure the quality of social relationships in the workplace. Their results indicated that decreases in work environment social support were significantly related to increased psychological maladjustment. Direct beneficial and buffering effects of social support have been studied frequently in the last decade and have guided the

majority of research on social support (Vaux, 1988). Although it seems clear that social support can have beneficial effects on well-being, summarized Vaux (1988), the processes and specifics remain indistinct. Supportive aspects of the workplace environment may have been factors in the sense of well-being expressed by many of the participants in this study.

Seven of the 12 participants in this study had received curative cancer surgery. In addition, they had successfully returned to their full time work, to a socially supportive environment, at the time of the interviews. The reported lack of uncertainty is consistent with theoretical and clinical suspicions that many patients with cancer are in fact, quite optimistic and certain about their future.

Participant TWO provided an archetypical response relevant to uncertainty.

But I have no concern at all about this cancer - it's gone, and let's get on with my life.

Summary

The constant comparative method of data analysis for this naturalistic study of return-to-work experiences in persons with genitourinary cancer has led to the generation of a theoretical process. The core social process suggested by the interview data is one of *Mobilizing social support* in the work environment. In a review of literature pertinent to support mobilization, Eckenrode and Wethington (1990) identified research of the process of mobilizing social support as a missing segment in social support research. The authors offered a model depicting support mobilization as a mid-level construct and a component of coping. Help-seeking actions were described as aspects of support mobilization. Cognitive processes such as social

Comparison and appraisal were suggested as important earlier in the process of support mobilization and were followed later by an emphasis on social behaviors such as self-disclosure. They summarized, the steps, mediating variables, and influential factors of the support mobilization process require further explication (Eckenrode & Wethington, 1990).

The social network of the workplace in this study provided practically all the participants with some amount of social support. For those participants who told their *Coworkers* about their cancer experiences, the *Reactions* and responses were for the most part, positive and supportive. Many participants chose not to *Tell others* immediately and simply let the news spread through *Supervisors* and *Coworkers*. These same participants found themselves discussing their cancer diagnosis more freely as time went on.

The participants were often told *Stories* about *Other persons with cancer* by their *Coworkers*. Given such information, along with the participants personal knowledge and experience, social *Comparisons* were made and *Priorities* explored. These finding suggest that steps within the process of *Mobilizing social support* may be recursive. Full appraisal of the threat of their cancer to their lives could not be made until the participants had more "material" to work with, more examples of *Other persons with cancer* with which to make *Comparisons*. One way to get these examples was to swap *Stories* with coworkers. Self-disclosure had to occur at some level in order to get such *Information*. The participants were then able to *Sort out* and clarify the meaning of this cancer experience for themselves.

For most of the participants, the return to the workplace was a small challenge, managing fatigue and treatment schedules. However, getting back to work was beneficial and facilitated the participants' adjustment to living with a cancer diagnosis.

Additional Categories

Four additional major categories in the data were related to the core process, but were not critical components of *Mobilizing social support*: a) *Absences*, b) *Benefits*, c) *Supervisor*, and d) *Change*. If one was to prepare a survey of issues related to a return-to-work after a cancer diagnosis based on the literature reviewed in Chapter II, it would likely have emphasized some of these categories along with discriminatory practices. Of course, this is exactly what has been done in the past (e.g., Feldman, 1987; Mellette, 1985; Watson, 1990). Surveys have not captured significant, central dimensions of the experience of many of the individuals who have returned to the social network of the workplace. For the participants in this study, the following concepts were represented only as related issues to the central process of *Mobilizing social support*.

Absences

There was great variability in the amount of time that the participants were absent from their work for the cancer diagnosis and treatment occurring at the time of the study interviews. Most of the difference can be explained by the nature of the treatments and by the work tasks completed on the job by the participants. For example, participant FIVE said he had no problems coming back to work at 5 weeks

because he basically sits at a desk most of the day. This can be contrasted to participant ONE's statement.

I'd go back tomorrow if I didn't have to do all that lifting...it wouldn't be fair for me to slough and people under me doing my work.

Watson (1990) found that diagnosis and type of treatment were strong explanatory variables in predicting any return to the workplace for persons with cancer. The average absentee frequency in her study of 400 cancer survivors was 87 days, not dissimilar to several participants in this study. Watson also found that blue collar workers had significantly longer absences than white collar or management.

This naturalistic study was able to identify details and contrasts between the absence patterns of white collar workers and the two blue collar workers. Of the five men who had a radical prostatectomy, the one blue collar worker, participant ONE was off work the longest time (see Table 8). Participant THREE is the obvious outlier on the other extreme. He chose to disguise his absence for surgery during the Thanksgiving holidays. Participant ONE-A was being treated with a modality different from any other participant. She was required to spend up to 2 hours in the urology clinic once a week for six weekly treatments. Neither the nature of the treatment nor the side effects she experienced would have precluded her working any other time. Once she had begun her treatments, her hours at work decreased and stayed at the lower level until several weeks after her treatment. The participant was an hourly employee and was losing income due to the decrease. She recounted a conversation with her supervisor.

Let's see - I told my supervisor...I mentioned that I would like to work in the afternoon [of my treatment day]. She said, 'That won't be a problem?' and I said, 'No, I don't think so.' But she says, 'Will you please let me know if it is? We may just have you not work on Thursdays.' (Participant ONE-A)

The apparent unilateral decision for the participant not to work on Thursday afternoons soon included another full day each week. This may be a subtle form of discrimination in the workplace. It is unclear how assertive the participant may have been in requesting a return of her hours.

The flexibility and nature of *Work Tasks* for the participants in white collar occupations clearly influenced the length of absence. The following table lists the occupation, specific treatment and time absent for the treatment.

Table 8

Occupations, Treatments and Absences

PARTICIPANT	OCCUPATION	TREATMENT	ABSENCE
01A	personal care assistant	intravesical immunotherapy	2 days per week for 6 weeks
01	cook	radical prostatectomy	2 months
02	engineer	radical prostatectomy	1 month
03	school district administrator	radical prostatectomy	5 days
04	public school teacher	abdominal surgery	2 months
05	financial planner	prostatectomy	5 weeks
06	business owner	radical prostatectomy	1 month
07	airline manager	radical prostatectomy	several weeks
08	legal secretary	nephrectomy	4 months
09	registered nurse	nephrectomy	3 months
10	technical writer	surgery, adjuvant immunotherapy	6 weeks
11	forest ranger	systemic chemotherapy	3 months

While participants ONE-A, ONE, and TEN had either limited or no sick leave benefits, they were not necessarily the individuals with the shortest absences.

Participants ONE and TEN were able to use vacation time as needed for medical leave. Both participants ONE and ONE-A were in blue collar occupations.

Once the participants had returned to work, additional absences were rare. This experience is consistent with the findings in women with breast cancer reviewed by Mellette (1985). Participant ELEVEN did not return to work full time for 3 months, however he would go in for several days in between chemotherapy cycles. He wrote of the positive benefit of those few days.

It was always refreshing and revitalizing to be able to work a few days in between chemotherapy treatments. (Participant ELEVEN - member check written response)

Again, the flexibility afforded this participant enabled a very positive experience of integrating treatments with his work. "Early return to work" programs and other new worker health policies have been described in the occupational health literature (Moore & Childre, 1990). By virtue of the goals of such programs, employees are given the opportunity to return to work on a limited basis or with appropriate modifications to their responsibilities. Moore and Childre (1990) summarized the benefits of these creative programs, particularly citing decreased absenteeism and fewer resignations. Although none of the participants in this study were part of a special return-to-work program, the positive effect of workplace accommodation and flexibility is apparent.

Benefits

The relationship between sick leave *Benefits* and *Absences* has been discussed above. Several participants addressed their concerns about *Benefits* when addressing

the *Future* and re-assessing their *Priorities* in life. Participant ONE even deliberated about his need for sexual activity at his age of 55 years versus the burden of an uninsured procedure such as placement of an inflatable penile prosthesis.

...I've heard the cost, and I don't think our insurance pays for it, and that's a lot of money for me to try and think about, especially at my age - ten or five years from now I might not care, or five months from now. You know, I'm getting up there in age; it's not like I'm a 20 year old kid.

Some of the dilemma of whether to remain employed has been discussed earlier in this chapter. Participants SIX and TEN reported that quitting their current job was not possible because they believed they would lose their health insurance benefits for themselves and their families. Participant SIX had the option of remaining as a consultant and retaining his benefits but had not decided to make any *Changes*.

Returning to previous full time employment after cancer treatment can be motivated by the reality of maintaining health benefits. Undoubtedly, health benefits are important considerations for an individual with a cancer diagnosis when comparing the pro's and con's of continuing employment.

Supervisor

While the vast majority of interpersonal interactions in the workplace after the diagnosis of cancer were reported to be with *Coworkers*, a few salient and significant interactions with the participants' *Supervisors* were presented. For the most part, *Supervisors* reacted to the news of the participant's cancer with understanding and concern. Participant TWO's boss became "frightened," expressing concern that he too

might have a malignant prostate problem associated with some previous pain he had experienced.

The *Supervisors* were constrained at various levels by institutional policy regarding sick leave and time off. Some, however, appeared to have flexibility in the way they planned for the participant's absence. For those who had flexibility, different tactics were used. The participants reported the varying supportiveness of the different tactics. Participant TEN was disappointed and angry at the reassignment her *Supervisor* had implemented in her absence and then maintained upon her return.

[I heard] that my supervisor had gone through a reactive panic mode, and had done some redistribution of the workload...a significant portion of my work had been doled out to 1) people who didn't want to do it, and 2) people who didn't know how to do it.

Participant ELEVEN's *Supervisor* was married to a registered nurse who intervened during the initial disclosure of the participant's diagnosis, telling the participant not to be concerned at all about his job or the absence, only to do whatever was needed for himself. His *Supervisor*, along with the state office for the parks department, continued to provide this unconditional support throughout his treatments.

There are clear differences in *Supervisor* reactions to these participants' cancer experiences. It is beyond the scope of this study to explain the differences. The Americans With Disabilities Act of 1990 may have a much greater influence in the future on the dimension in a worker's experience relevant to *Supervisor* reactions and actions.

Changes

A concept which was found and coded in many of the interviews was that of *Changes*. Initially, the *Changes* reported fell into one of two groups, those which were due to the cancer experience and out of the participant's control and those *Changes* which were initiated by the participant. With further analysis and axial coding, it was clear that *Changes* made by the participant were part of a process to *Regain control* of aspects of their lives, balancing out the loss of *Control* which had occurred previously. Participant FOUR described the key sentiments in the process of *Regaining control*.

The cancer itself, to me, took my power - taking decisions or control over my life away from me. So, I spent a lot of time thinking, 'How can I get control of my life back? How can I change things? Where am I going? What makes me happy? So, I went eventually for the big career change...got my teaching degree and ended up teaching.

The aspects identified as *Changes* which were out of the control of the participants were cited as: a) control taken from the participant by the cancer, b) treatment plans, and c) work assignments, directions and responsibilities. The participants reported using or planning self-initiated *Changes* which, either directly or through implication, enabled the process of *Regaining control*: a) remarriage, b) lifestyle/health behavior changes, c) attitude changes, d) job changes or transfers, and e) retirement. These *Changes* also helped to delineate or mark a point in time or in the process of *Getting past* the unpleasant cancer experience. Participant ELEVEN metaphorically described this process after he had transferred to a new job location.

So it was in part, feeling good enough and confident enough, that I didn't have to have that proximity to [city] and the doctors...Things were looking good and looking on the up and up - I think we *Closed that chapter*.

Their employment status and the workplace provided the participants with another source of potential for change. Some of the participants utilized the opportunity, others avoided *Changes* in their work and sought other mechanisms to *Regain control*. Participant SEVEN's interview was replete with references to *Changes* he had made in himself. The following is an example of cognitive *Changes* described by participant SEVEN.

I think I found some things which I believe might have been causing a negative approach to life, in my life, that I can end...[I am more] insightful and understanding and try to appreciate that all that's good everywhere is in you, as it is in me. [I] look for that, instead of the bad things.

In a naturalistic study of bone marrow transplant patients, Ersek (1992) discovered a process by which the participants in her study kept the disease in its place while "sustaining hope" through the active treatment phase of their disease. One strategy used by those participants to do this was "managing the sense of control." Similar to the findings in this return-to-work study, Ersek described attitudes, thoughts, and actions taken by the bone marrow transplant patients to maintain control. However, for the working participants in this study, the outcome of *Regaining control* was the ability to *Get past* the cancer, to *Go on* with normal activities and *Close that chapter* of their lives. The emphasis in the Ersek study was on keeping the disease in its place in order to maintain hope. There is a profound difference in disease trajectory and treatment modality for the two study samples which certainly can

explain the difference in outcome emphasis for an apparently similar process of *Regaining control*.

Peripheral Concepts

A set of concepts and categories were presented in the data which were not integrally related to the core process of mobilizing the social support of the workplace. These peripheral concepts, however, were often major components of what was reported by the participant in his or her interview. For example, a full recounting the *Detection* experience was included in the first five to ten minutes of most interviews. Remember, given the unstructured format, the participants were able to guide the direction and content of their interviews. The peripheral concepts are briefly reviewed below in order to address the comprehensive nature of the interview data.

Another major category found in the data is that of the participants' experiences with *Doctors*. Both feelings of frustration and those of appreciation were reported in the *Stories* the participants told. Interestingly, although only five references were made to *Nurses*, all were laudatory and positive.

Brief descriptions of the treatment modality with which the participant was treated were offered by almost all the individuals in the sample. Along with the *Detection* experience and their experiences with *Doctors*, references to the treatment modality seemed to be critical preliminary components of each participant's *Story* about themselves. These were included even when the opening statement clearly queried the return-to-work experience. The preliminary components were used by the participants as an orientation, setting the scene and context of their *Story*.

Several participants (all men) recounted the difficulty they had with "*Hearing*" what the doctor had said to them. This occurred mainly during the discussions when the diagnosis was revealed, when the treatment plan was presented, and when the results of the surgery were revealed. The participant would describe how he could not recall all the information given by the doctor. Often, the participant would say how fortunate it was to have his spouse available. One participant reported that the surgeon would not have discussed treatments with him unless his wife was present.

The following list specifies other peripheral concepts which were reported and coded 10 or more times in the data and the ways in which the participants used the concept.

CONCEPT	APPLICATION
<i>Cancer</i>	what the cancer does or is; the outcomes of having cancer
<i>Catheter</i>	references to having a urinary catheter and leg bag after prostate surgery
<i>Choice</i>	mainly treatment choices
<i>Fear</i>	the feelings of fear; being scared and frightened by the diagnosis; fear of recurrence
<i>Friends</i>	references to friends mainly outside of the workplace
<i>Kids</i>	references to children of the participants
<i>Recurrence</i>	concerns related to existing and possible recurrences of their cancer
<i>Sex</i>	issues related to sexual activities

<i>Spouse</i>	references to the participant's spouse
<i>Surgery</i>	aspects of the surgery itself including the hospitalization

Summary

The core social process suggested by the interview data is one of *Mobilizing social support* in the work environment. Although problems such as treatment schedules and work hours, fatigue, and changes in the workplace had to be managed, the overall experience of returning to work was beneficial to the participants in this study. Four additional major categories in the data were related to the core process, but were not critical components of *Mobilizing social support*: a) *Absences*, b) *Benefits*, c) *Supervisor*, and d) *Changes*. Concepts peripheral to the core process, illustrated experiences of the participants which were quite significant and meaningful to their general cancer experience.

CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

This chapter summarizes the study of return-to-work experiences of persons with genitourinary cancer. The human response framework (Heitkemper & Shaver, 1989) will be evaluated as a conceptual framework in light of the findings. Study limitations will then be examined. Recommendations for future research will be made and contributions of the study to nursing science and practice will be discussed.

Summary

Although limited, the literature on the return-to-work experience for persons with cancer suggests that they confront a variety of issues and barriers. The individual experience of the employed person who has, or had, cancer has been infrequently reported and data from such experiences has not been systematically analyzed for theory development. This exploratory, longitudinal study examined and analyzed the dimensions of the return-to-work experience that were evident in the data from 19 interviews conducted with 12 participants with genitourinary cancer. Four women and 8 men who were full time workers and had received surgical or combined modality treatment for either bladder, prostate, renal or testicular cancer participated in unstructured interviews at various points in their disease trajectories.

The constant comparative method of data analysis for this naturalistic study of return-to-work experiences in persons with genitourinary cancer has led to the generation of a theoretical process. The core social process suggested by the interview data is one of *Mobilizing social support* in the work environment. The social network

of the workplace provided practically all the participants with some amount of social support. For those participants who told their *Coworkers* about their cancer experiences, the *Reactions* and responses were for the most part, positive and supportive. The participants were often told *Stories* about *Other persons with cancer*. Given such information, along with the participant's personal knowledge and experience, social *Comparisons* were made and *Priorities* explored. The participants were able to *Sort out* and clarify the meaning of this cancer experience for themselves. For most of the participants, the return to the workplace was in a small way, a challenge. However, getting back to work was beneficial and facilitated the participants' adjustment to living with a cancer diagnosis. The findings from this study corroborate and extend much of the theoretical summary by Eckenrode and Wethington (1990) regarding the process of social support mobilization.

Four additional major categories discovered in the data were related to the core process, but were not critical components of *Mobilizing social support*: a) *Absences*, b) *Benefits*, c) *Supervisor*, and d) *Change*. There was great variability in the amount of time that the participants were absent from their work for the cancer diagnosis and treatment occurring at the time of the study interviews. The flexibility in rescheduling and differences in work tasks afforded the participants in white collar occupations more alternatives for when they did choose to return to the workplace. *Benefits* were an issue relevant most often to *Plans* for the *Future* and to an appraisal of *Priorities* in the participants' lives. The majority of the participants' *Supervisors* reacted to the news of the cancer diagnosis with *Support* and concern. The one example of what

may have been discrimination against a participant in the study was when a *Supervisor* made a unilateral decision to cut the work hours of the participant while she was on immunotherapy. The dimension of the participants' experiences that reportedly involved *Change* was very complex and a dimension in which the workplace was only one of many components. Some changes were out of the participant's *Control*, leading to feelings of loss of *Control* and *Power*. Other changes were initiated by the participants in efforts to *Regain control* and *Get Past* the cancer experience. *Change*, relevant to the workplace, was a part of these strategies implemented by the participants.

Concepts and categories which were peripheral to the core process were coded, portraying other dimensions of the participants' experiences. Participant references to, and discussion of, their experiences with *Doctors*, their *Detection* experiences and the treatments they received were so commonly shared during each interview that these dimensions developed as critical, preliminary elements of the participants' *Stories* about themselves.

Evaluation of the Human Response Framework

The human response framework (Heitkemper & Shaver, 1989) was used in Chapter II as a heuristic model to identify gaps in the literature related to returning to work with a cancer diagnosis. The application of the framework also organized the significant factors which potentially influence human responses in the return-to-work experience. Revisitation of the applied framework reveals confirmation of some factors, addition of others, and challenge to the appropriateness of other factors.

Figure 5 illustrates a newly modified version of the adapted human response framework. The following factors have been added given the results of this study: a) meaning of illness, b) level of control, c) *Supervisor*, d) interpersonal interaction, e) social network, f) *Mobilizing social support*, g) reciprocal social support, and h) *Change*. Those factors not corroborated by the findings in this specific study have been removed: a) life satisfaction, b) bathroom access, c) bleeding, d) speech impairment, e) vomiting, f) mucositis, g) cachexia, h) nausea, and i) personal/social dysfunction.

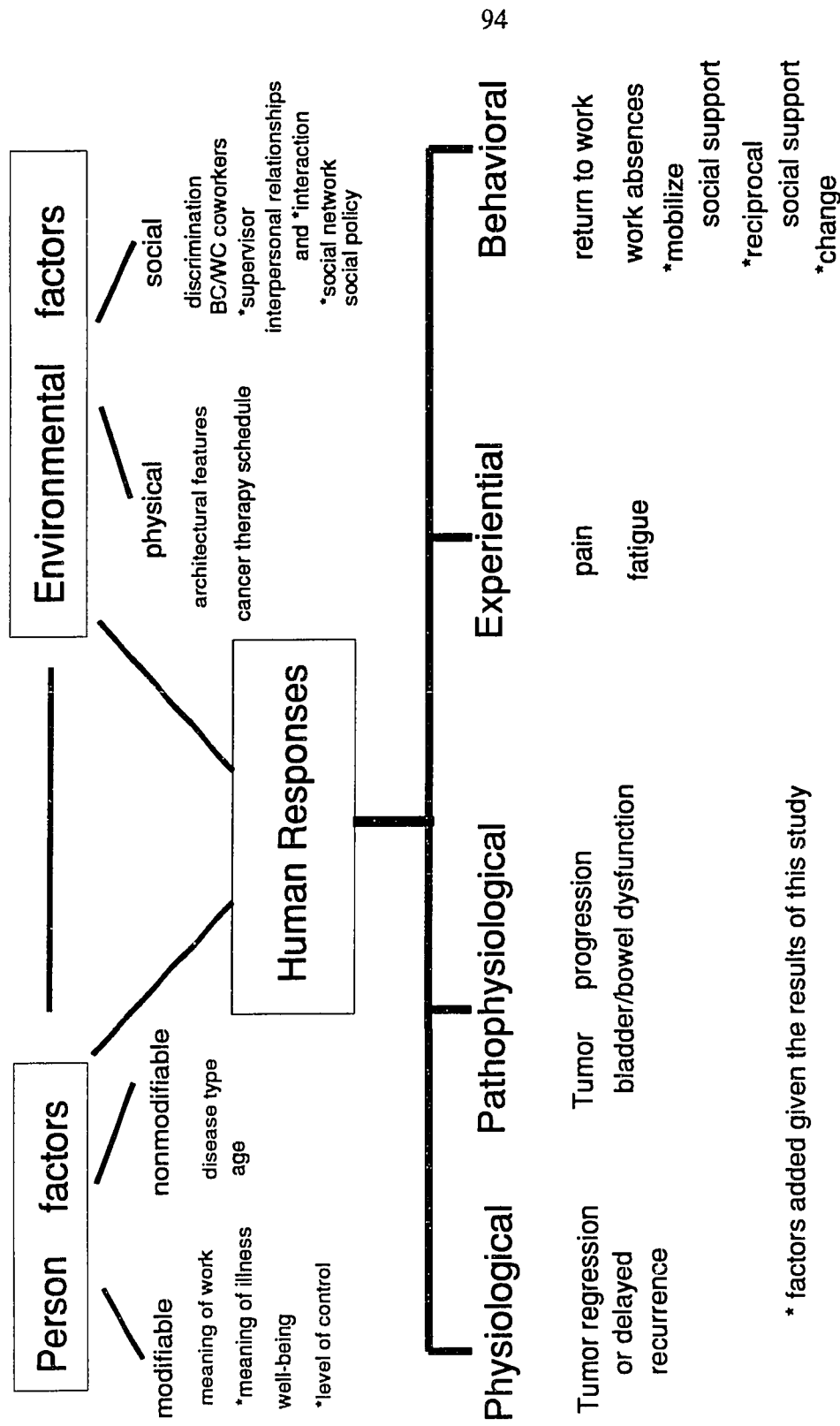


Figure 5. Returning to the workplace with a diagnosis of cancer - modified for study results adapted from Heitkemper and Shaver, 1989

In Chapter II, the human response framework was criticized for only addressing the negative dimensions of environmental and person factors, specifically risk and vulnerability. The results of this study suggest a bi-dimensional aspect to both environment and person factors. Positive factors were identified in the data. For example, the social network and accompanying social interactions were not only low risk for the participants, those factors were beneficial to the social support mobilization process. Further work with the human response framework should consider the dimensionality of environmental risk and personal vulnerability allowing for both positive and negative dimensions.

Integration of the findings of this study with the human response framework illustrates the limits of such a framework. While an excellent tool for organizing related concepts, the framework is static and does not demonstrate process. One can view some of the relationships between factors, such as the presence of the influence of the cancer therapy schedule on *Absences*. However, one cannot understand when or how the influence takes place in the return-to-work process. The pairing of the human response framework with a process diagram or illustration could provide a comprehensive and powerful graphic display of key components and issues for a given experience. Nurses could utilize such a paired graphic to identify areas for clinical therapeutics and research priorities.

Study Limitations

Critical review of the sample and the findings of this study identifies several limitations of the study. In general, it is possible that certain aspects of the return-to-

work experience were not captured or reported in the analyzed data from the 12 participant interviews. As discussed in Chapter 3, however, the data input to the various categories began to be redundant in the latter interviews.

The study was conducted with individuals who had a diagnosis of one of four types of genitourinary cancer. Can the results transfer to people with other cancers? The theory generated from analysis of the data focused on the social processes of interpersonal interactions in the workplace, an emphasis that is not specific to the nature of the tumor tissue. A concept such as the Catheter, worn for about two weeks by the men in the sample after prostate surgery, was not part of the central dimension or core process. This pattern of peripheral status for tumor-specific concepts was consistent. Due to this pattern of centrality and marginality, the investigator has concluded that the threat to transferability based on tumor type is minimal.

The ethnic homogeneity of the participants limits the transferability of the results. All the participants were Caucasian and had been residents of the Pacific Northwest for many years. Although a wide range of occupations and incomes were represented in the sample, people of color were not frequent clients of the study sites.

Even with implementation of purposive sampling, only two of the participants were employed in blue collar occupations. There was, however, a wide range of white collar occupations: technical, professional and management positions.

All but 2 of the participants were over 40 years of age. Participants ONE-A and ELEVEN were 39 and 32, respectively. This is not unexpected given the incidence rates of cancer in these age groups. The majority of individuals with cancer

who return to work will be over 40 years of age. Major differences may exist in the experiences of younger workers (or students) with cancer diagnoses.

A final qualifier regarding the characteristics of the sample is that of disease trajectory. Every participant was stable and well enough to be seen as an outpatient. Although some participants had metastatic disease, no participant was considered terminally ill or was in their final days of life. If an individual with cancer continued to work during the final days or weeks of their life, then the return-to-work experience could be very different than that presented in this study.

Self-disclosure was an issue at some level of discomfort in the workplace for six of the participants. In another naturalistic study, self-disclosure was problematic for some participants as they shared certain aspects of their experiences (Ersek, 1992). There was no indication that the participants in this study had difficulty expressing themselves during the interview about even the most typically sensitive topics. In fact, there were several indications that the participants shared as much or more with the investigator as with anyone. Participant ONE discussed his post-surgical impotence.

Well, you know, it's hard for me to talk to people, but to help you out on your research, or whatever, I might as well tell you...I don't even know how to phrase it...Um...yeah, the erection part. They say, yeah it's going to come back and everything, but it's...that eats on you quite a bit.

The unstructured format of the interviews facilitated comfort with discussing sensitive topics. Participants were free to begin the interview with less sensitive topics and as rapport was established during the interview, the participant was free to choose when to interject the more troublesome topics. Yet, those participants for whom

Telling others in the workplace about their cancer diagnosis was an uncomfortable issue, addressed that topic within the first ten minutes of the interviews.

In summary, the most significant limitation to the transferability of this study is the lack of ethnic heterogeneity in the sample. There is certainly a large proportion of workers with cancer who are also of different cultural and ethnic backgrounds in the United States. The theory generated in this study of return-to-work experiences may not apply, in part or in total, to those workers.

Recommendations for Future Research

Extension of this study, or others of similar focus and methods, to include people of color, participants in blue collar occupations and those younger workers with cancer would strengthen the transferability potential of the theory of *Mobilizing social support*. Although there are few workers who remain on the job in their final weeks of life, exploration of their workplace experience would be a fascinating extension of this study. In fact, two *Stories* about *Other persons with cancer*, recounted by participants in this study, were about *Coworkers* who worked "up until the end."

Future research should pursue clarification of relationships between certain concepts and categories demonstrated in the data: a) *Regaining control* and *Change*, b) individual differences and self-disclosure, and c) story telling/story swapping and social *Comparison*. Additional supportive behaviors could be identified, both in and outside of the workplace. While clarifying relationships such as those above, research related to working persons with cancer should integrate and explore the

appropriateness of the Eckenrode and Wethington (1990) model of mobilizing support in response to stressors.

Investigation of linkages between *Mobilization of social support* and outcomes of cancer treatment should be pursued. A broad range of outcomes could be included, psychological and experiential as well as tumor response outcomes. For example, a comprehensive quality of life assessment study in men treated for prostate cancer could be examined retrospectively and prospectively for return-to-work status.

Given an improved understanding of the return-to-work experience of an individual with cancer, nurses can design and test interventions to facilitate the processes of that experience. Aspects of the support mobilization process which might inform intervention research include: comfort with self-disclosure, the use of *Stories* and social *Comparison*, *Coworker/Supervisor Reactions*, and *Regaining control*.

Contributions to Nursing Science and Practice

Nursing Science

The complex process of returning to work with a diagnosis of cancer has now been documented, in part, with the generation of this inceptive theory, *Mobilizing social support* in the workplace. Dimensions of the experience which had previously been identified in survey research have been theoretically placed as central to the core process or peripheral to the process of returning to the workplace. A significant contribution may be the elucidation of where the emphasis lies within the worker's experience. For the participants in this study, it was not struggle of the return to work, but the social benefits of the return to work.

Much of the empiric evidence in the data from this naturalistic study informs the support mobilization model suggested by Eckenrode and Wethington (1990). It may be that for a person with cancer, a return to the workplace is essentially a step in the overall support mobilization process as described by Eckenrode and Wethington (1990). The specific nature of the cancer experience may or may not qualify the theorized process.

Nursing Practice

The findings of this study provide nurses in clinical practice with an explication of an experience which many of their clients will have. The added understanding available in these results can guide nurses to focus not only on related dimensions of the return-to-work experience such as time off for treatments, but on central concerns, such as the social benefits of going back to work. Story telling may be not only be a strategy for individuals with cancer and their *Coworkers*, but also for nurses to use as an educational or supportive intervention.

Occupational health nurses may be in a key position to facilitate the process of support mobilization in the workplace. Understanding the process and timing of self-disclosure and the use of *Stories* can enhance the professional nursing services provided to employees with cancer and their *Coworkers*. A nurse in the workplace could, for example, assist in creating an environment where reciprocal social support is mobilized.

Conclusion

The results of this naturalistic study characterize and describe the experience of returning to work with a diagnosis of genitourinary cancer. A theory of *Mobilizing social support* in the workplace was constructed using constant comparative analysis of data which was grounded in the perspectives of the study participants. The inceptive theory explains and delineates steps in a process which ultimately benefits a person's reintegration of normal activities after a diagnosis of cancer.

REFERENCES

- Barofsky, I. (1989). Work and Illness - the Cancer Patient. New York: Praeger.
- Bergermaier, R., Borg, I., & Champoux, J.E. (1984). Structural relationships among facets of work, non-work and general well-being. Work and Occupation, 11, 163-181.
- Blessing, D.L., Jakeman, C., Mathews, C., & Tankersly, D. (1988). Success of a cardiac rehabilitation program in returning patients to work. Critical Care Nursing Quarterly, 1, 81-85.
- Boring, C., Squires, T., & Tong, T. (1992). Cancer statistics. CA - A Journal for Clinicians, 42, 19-38.
- Bremer, B.A., McCauley, C.R., Wrona, R.M., & Johnson, J.P. (1989). Quality of life in end-stage renal disease: a reexamination. American Journal of Kidney Disease, 13, 200-9.
- Brody, B.E. (1988, Winter). Employee assistance programs: an historical and literature review. American Journal of Health Promotion, 13-18.
- Burleson, B.R. (1990). Comforting as social support: relational consequences of supportive behaviors. In S. Duck, (Ed.). Personal Relationships and Social Support (pp. 66-82). London: Sage Publications.
- Campbell, A. (1981). The Sense of Well-being in America: Recent Patterns and Trends. New York: McGraw-Hill.
- Cay, E.L., & Walker, D.D. (1988). Psychological factors and return to work. European Heart Journal, 9, suppl., 74-81.
- Clark, J.C., & Landis, L.L. (1989). Reintegration and maintenance of employees with breast cancer in the workplace. AAOHN Journal, 37, 186-93.
- Cozby, P.C. (1973). Self-disclosure: a literature review. Psychological Bulletin, 79, 73-91.
- Crothers, H.M. (1987). Employment problems of cancer survivors: local problems and local solutions. In American Cancer Society. Proceedings of the Workshop on Employment, Insurance and the Patient with Cancer (pp. 51-57).
- Cutrona, E., Suhr, J.A., & MacFarlane, R. (1990). Interpersonal transactions and the psychological sense of support. In S. Duck, (Ed.). Personal Relationships and Social Support (pp. 31-45). London: Sage Publications.

- Dietz, J.H. (1981). Rehabilitation Oncology. New York: John Wiley and Sons.
- Donovan, M., & Girton, S. (1988). Cancer Care Nursing, (2nd ed). Connecticut: Appleton-Century-Crofts.
- Dudas, S., & Carlson, C.E. (1988). Cancer rehabilitation. Oncology Nursing Forum, 15, 183-88.
- Dunkel-Schetter, C., Folkman, S., & Lazarus, R. (1987). Correlates of social support receipt. Journal of Personality and Social Psychology, 53, 71-80.
- Dunkel-Schetter, C. (1984). Social support and cancer: findings based on patient interviews and their implications. Journal of Social Issues, 40, 77-98.
- Eckenrode, J., & Wethington, E. (1990). The process and outcome of mobilizing social support. In S. Duck, (Ed.). Personal Relationships and Social Support (pp. 83-103). London: Sage Publications.
- Equal Employment Opportunity Commission & U.S. Department of Justice (1991). Americans with Disabilities Act Handbook. Washington, D.C.
- Ersek, M. (1992). The process of maintaining hope in adults undergoing bone marrow transplantation for leukemia. Oncology Nursing Forum, 19, 883-889.
- Feldman, F.L. (1978). Work and Cancer Health Histories: A Study of Recovered Blue-Collar Workers. American Cancer Society, California Division, San Francisco.
- Feldman, F.L. (1980). Work and Cancer Health Histories: Work Expectations and Experiences of Youth (Ages 13-23) With Cancer Histories. American Cancer Society, California Division, San Francisco.
- Feldman, F.L. (1976). Work and Cancer Health Histories: A Study of the Experiences of Recovered Patients. American Cancer Society, California Division, San Francisco.
- Feldman, F.L. (1987). The return to work: the question of workability. In American Cancer Society. Proceedings of the Workshop on Employment, Insurance and The Patient with Cancer (pp. 27-35).
- Festinger, L. (1954). A theory of social comparison processes. Human Relations, 7, 117-140.
- Flanagan J. (1982). Measurement of quality of life: current state of the art. Archives of Physical Medicine and Rehabilitation, 63, 56-9.

- Fobair, P., Hopp, R.T., Bloom, J., Cox, R., Varghese, A., & Spiegel, D. (1986). Psychosocial problems among survivors of Hodgkin's disease. Journal of Clinical Oncology, 4, 805-814.
- Ganz, P.A., Schag, C.C., & Heinrich, R.L. (1989). Information about work from studies with the Cancer Inventory of Problem Situations (CIPS). In Barofsky, I. (Ed.). Work and Illness: the Cancer Patient (pp. 117-132). New York: Praeger.
- Glaser, B.G., & Strauss, A.L. (1967). The Discovery of Grounded Theory. New York: Aldine Publishing.
- Glidewell, J.C., Tucker, S., Todt, M., & Cox, S. (1983). In A. Nadler, J.D. Fisher, & B.M. DePaulo (Eds.), New Directions in Helping Vol. 3: Applied Research in Help Seeking and Reactions to Aid (chpt. 4). New York: Academic Press.
- Greenleigh Associates, Inc. (1982). Report on the social, economic, and psychological needs of cancer patients in California (Summary). Proceedings of Western States Conference on Cancer Rehabilitation. Palo Alto, California.
- Greenwald, P., & Cullen, J. (1985). The new emphasis in cancer control. Journal of the National Cancer Institute, 74, 543-551.
- Groenwald, S. (Ed.) (1987). Cancer Nursing Practice. Monterey: Jones and Bartlett Publishers, Inc.
- Gross, A.E., Wallston, B.S., & Piliavin, I. (1979). Reactance, attribution, equity, and the help recipient. Journal of Applied Social Psychology, 9, 297-313.
- Gunn, A.E. (1984). Cancer Rehabilitation. New York: Raven Press.
- Haffey, W.J., & Lewis, F.D. (1989). Programming for occupational outcomes following traumatic brain injury. Rehabilitation Psychology, 34, 147-58.
- Heitkemper, M., & Shaver, J. (1989). Nursing research opportunities in enteral nutrition. Nursing Clinics of North America, 24, 415-26.
- Hickey, R.C. (1987). Cancer rehabilitation as a pattern of health care. In American Cancer Society. Proceedings of the Workshop on Employment, Insurance and the Patient with Cancer (pp. 41-44).
- Hoffman, B. (1989). Cancer survivors at work: job problems and illegal discrimination. Oncology Nursing Forum, 16, 39-43, 1989.

- Hoffman, B. (1990). Taking care of business. In Mullan, F. and Hoffman, B. (Eds.). Charting the Journey (pp. 97-142). Mount Vernon, New York: National Coalition for Cancer Survivorship and Consumers Union.
- Holahan, C.J. & Moos, R.H. (1981). Social support and psychological distress: a longitudinal analysis. Journal of Abnormal Psychology, 90, 365-370.
- Houts, P.S., Yasko, J.M., Simmonds, M.A., Kahn, S. B., Schelzel, G.W., Marconi, K.M., & Bartholomew, M.J. (1988). A comparison of problems reported by persons with cancer and their same sex siblings. Journal of Clinical Epidemiology, 41, 875-81.
- Hutchinson, S. (1986). Grounded Theory: The Method. In P. Munhall & C. Oiler, (Eds.), Nursing Research - A Qualitative Perspective. Norwalk, CT: Appleton-Century-Crofts (pp. 111-130).
- Illinois Cancer Council. (1988). Getting Back to Work. Chicago, Illinois.
- Kavanaugh, T., & Matosevic, V. (1988). Assessment of work capacity in patients with ischaemic heart disease: methods and practices. European Heart Journal, Nov, 9, suppl., 67-73.
- Koocher, G.P., & O'Malley, J.E. (1981). The Damocles Syndrome: Psychological Consequences of Surviving Childhood Cancer. New York: McGraw Hill.
- Kornblith, A.B., LaRocca, N.G., & Baum, H.M. (1986). Employment in individuals with multiple sclerosis. International Journal of Rehabilitation Research, 9, 155-65.
- Lehmann, J.F., DeLisa, J.A., Warren, C.G., deLateur. B.J., Bryant, P.S., & Nicholson, C.G. (1978). Cancer rehabilitation: assessment of need, development and evaluation of a model of care. Archives of Physical Medicine and Rehabilitation, 59, 410-19.
- Lincoln, Y.S. & Guba, E.G. (1985). Naturalistic Inquiry. Beverly Hills: Sage Publications.
- Lindsey, A. (1985). Building the knowledge base for practice - part I: Nausea and Vomiting. Oncology Nursing Forum, 12, No. 1, 49.
- Lindsey, A. (1985). Building the knowledge base for practice - part II: Alopecia, breast self-exam and other human responses. Oncology Nursing Forum, 12, No.2, 27.

- Loehrer, P., Williams, S., & Einhorn, L. (1988). Testicular cancer, the quest continues. Journal of the National Cancer Institute, 80, 1373-82.
- McNally, J., Stair, J., & Somerville, E. (Eds.). (1985). Guidelines for Cancer Nursing Practice. Orlando: Grune & Stratton.
- Mellette, S.J. & Franco, P.C. (1987, Winter) Psychosocial barriers to employment of the cancer survivor. Journal of Psychosocial Oncology, 5, 97-115.
- Mellette, S.J. (1985). The cancer patient at work. CA - A Journal for Clinicians, 35, No. 6, 360-73.
- Meyerowitz, B.E., Watkins, I.K., & Sparks, F.C. (1983). Psychosocial implications of adjuvant chemotherapy. Cancer, 52, 1541-45.
- Mishel, M.H., Padilla, G., Grant, M., & Sorenson, D.S. (1991). Uncertainty in illness theory: a replication of the mediating effects of mastery and coping. Nursing Research, 40, 266-40.
- Mitchell, P.H., Gallucci, B., & Fought, S.G. (1991). Perspectives on human response to health and illness. Nursing Outlook, 39, 154-157.
- Moore, P.V., & Childre, F. (1990). Creative policy-making - strategies for working with the healthy chronically diseased employee. AAOHN Journal, 38, 284-88.
- Mor, V. (1987) Work loss, insurance coverage, and financial burden among cancer patients. In American Cancer Society. Proceedings of the Workshop on Employment, Insurance and the Patient with Cancer (pp. 5-10).
- Mullan, F. (1987). Re-entry: the educational needs of the cancer survivor. Health Education Quarterly, 10 (suppl.), 88-94.
- Mullan, F. & Hoffman, B. (Eds.). (1990). Charting the Journey. Mount Vernon, New York: National Coalition for Cancer Survivorship and Consumers Union.
- Munkres, A., Oberst, M., & Hughes, S. (1992). Appraisal of Illness, Symptom distress, self-care burden, and mood states in patients receiving chemotherapy for initial and recurrent breast cancer. Oncology Nursing Forum, 19, 1201-1209.
- Nadler, A. (1983). Personal characteristics and help-seeking. In, DePaulo, B.M., Nadler, A., & Fisher (Eds.). New Directions in Helping, Vol. 2, New York: Academic Press.

- Padilla G., Ferrell B., Grant M., & Rhiner M. (1990). Defining the context domain of quality of life for cancer patients with pain. Cancer Nursing, 13, 108-15.
- Pearlin, L.I. (1985). Social structure and processes of social support. In S. Cohen & S.L. Syme. Social Support and Health. (pp. 43-59). Orlando, FL: Academic Press.
- Piper, B.F., Lindsey, A.M., & Dodd, M.J. (1987). Fatigue mechanisms in cancer patients: developing nursing theory. Oncology Nursing Forum, 14, No. 6, 17-23.
- Pope, A.M. (1986). Aging and the environment. Newsletter of the Commission on Life Sciences, National Research Council, 12, 2, Spring.
- Romsaas, E.P., Juliani, L.M., Briggs, A.L., Wysocki, G., & Moorman, J. (1983). A method for assessing the rehabilitation needs of oncology outpatients. Oncology Nursing Forum, 10, No. 3, 17-21.
- Schuller, D., Reiches, N., Hamaker, R., & Lingeman, R. (1983). Analysis of disability resulting from treatment including radical neck dissection or modified neck dissection. Head and Neck Surgery, 6, 551-8.
- Seidel, J.V. (1988). The Ethnograph version 3.0, [computer program]. Corvallis, OR: Qualis Research Associates.
- Shaver J. (1985). A Biopsychosocial View of Human Health. Nursing Outlook, 33, 186-91.
- Spradley, J.P. (1980). Participant Observation. New York: Holt, Rinehart & Winston, Inc.
- Stagner, S. (1987) The role of education in the employability of persons with a history of cancer. In American Cancer Society. Proceedings of the Workshop on Employment, Insurance and the Patient with Cancer (pp. 58-61).
- Staley, J.C., Kagle, J.D., & Hatfield, A.K. (1987). Cancer patients and their coworkers: a study. Social Work in Health Care, 13, 101-12.
- Stevens, B. (1979). Nursing Theory - Analysis, Application, Evaluation. Boston: Little, Brown and Company.
- Stone, R.W. (1975). Employing the recovered cancer patient. Cancer, 36, July suppl., 285-6.

- Strauss, A., & Corbin, J. (1990). Basics of Qualitative Research - Grounded Theory Procedures and Techniques. Newbury Park, CA: Sage Publications.
- Tebbi, C.K., Bromberg, C., & Piedmonte, M. (1989). Long-term vocational adjustment of cancer patients diagnosed during adolescence. Cancer, 63, 213-8.
- Thiel, H., Fietkau, R., & Sauer, R. (1988). Malnutrition and the role of nutritional support for radiation therapy patients. Recent Results Cancer Research, 108, 205.
- Thompson, L. (1989). The occupational health nurse as an employee assistance program provider. AAOHN Journal, 37, 501-07.
- Unfair & illegal. (1992, Fall). Coping, 6, p.11.
- van der Wouden, J.C., Greaves-Otte, J.G., Greaves, J., Kruyt, Ph. M., van Leeuwen, O., & van der Does, E. (1992). Occupational Reintegration of long-term cancer survivors. Journal of Occupational Medicine, 34, 1084-1089.
- Vanchieri, C. (1988). News - Clinical alert stimulates changes in practice. Journal of the National Cancer Institute, 80, 1185-86.
- Vaux, A. (1988). Social Support: Theory, Research, and Intervention. New York: Praeger.
- Watson S. (1990). Saving money and helping people: a multi-method analysis of the employment experiences of cancer survivors. Unpublished manuscript. Washington Business Group on Health.
- Wellisch, D.K. (1984). Work, social, recreation, family and physical status. Cancer, 53, May 15 suppl., 2290-302.
- Wheatley, G.M., Cunnick, W.R., Wright, B.P., & van Keuren, D. (1974). The employment of persons with a history of treatment for cancer. Cancer, 33, 441-5.
- Wheeler, L. (1991). A brief history of social comparison theory. In J. Suls & T.A. Wills, Social Comparison - Contemporary Theory and Research. (pp. 3-22). Hillsdale, New Jersey: Lawrence Erlbaum Associates.
- Wiernik, P. (Ed.). (1983). Supportive Care of the Cancer Patient. New York: Futura.
- Williams, N., & Johnston, D. (1983). The quality of life after rectal excision for low rectal cancer. British Journal of Surgery, 70, 460-2.

- Wills, T.A. (1991). Similarity and self-esteem in downward comparison. In J. Suls & T.A. Wills, Social Comparison - Contemporary Theory and Research. (pp. 51-78). Hillsdale, New Jersey: Lawrence Erlbaum Associates.
- Wills, T.A. (1985). Supportive functions of interpersonal relationships. In S. Cohen & S.L. Syme, (Eds.). Social Support and Health. (pp. 61-82). Orlando, FL: Academic Press.
- Wilson, T.R., Richards, J.A., & Bercini, D.H. (1976). A Study of the Employment of Workable Cancer Patients: Survey of Employer Attitudes and Practices. Report prepared for the National Cancer Institute. Alexandria, Virginia: Human Resources Research Organization.
- Winningham, M.L. (1991). Walking program for people with cancer. Cancer Nursing, 14, 270-276.
- Wolcott, D.L., Nissenson, A.R., & Landsverk, J. (1988). Quality of life in chronic dialysis patients. General Hospital Psychiatry, 10, 267-77.
- Wood, J.V., Taylor, S.E., & Lichtman, R.R. (1985). Social comparison in adjustment to breast cancer. Journal of Personality and Social Psychology, 49, 1169-1183.
- Wortman, C.B. & Dunkel-Schetter, C. (1979). Interpersonal relationships and cancer: a theoretical analysis. Journal of Social Issues, 35, 120-155.

APPENDIX A

UNIVERSITY OF WASHINGTON CONSENT FORM RETURN TO WORK EXPERIENCES IN PERSONS WITH CANCER (B)

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PURPOSE AND BENEFITS

You have been asked to participate in a research study. We want to understand more about the experience of going back to work as told from the perspective of the person with a cancer diagnosis. There are no direct benefits to participants in the study. Future patients may benefit from our increased understanding and knowledge about important factors which affect going back to work after a diagnosis of cancer.

PROCEDURES

If you decide to take part in this study, the investigator listed above, Donna Berry, will have two interviews with you, each may last up to an hour. These interviews, approximately six to eight weeks apart, can be scheduled along with your other appointments so you will not have to make extra visits to the clinic. The interviews will be audiotaped. The exact questions for the interviews are not decided before the interview takes place. It will begin with, "Tell me about going back to work after this diagnosis of cancer." Further questions will be decided depending on what you and the other study participants have to say about the return to work experience. This is called an "unstructured interview." You may refuse to answer any question and are free to end the interview at any time.

RISKS OR STRESS

Invasion of privacy is a risk of the study if you describe personal information during the study.

OTHER INFORMATION

Your name will not be used on any data form in order to assure confidentiality. Only the investigator, Donna Berry, will have access to the list of names and codes. The interview data will be evaluated for common themes. The audiotapes will be erased immediately after analysis, however the written data will be kept by the investigator indefinitely. The results of the study will be written in a dissertation document and shelved at the University of Washington Health Sciences Library. The results of the

study will be presented at professional meetings and published in professional journals, however your identity will not be revealed.

You may refuse to participate or you may withdraw from the study at any time without penalty or loss of benefits to which you are otherwise entitled.

Signature of investigator Date

Participant's statement:

The study described above has been explained to me. I voluntarily consent to participate in this activity. I have had an opportunity to ask questions. I understand that future questions I have about the research or about my rights as a participant will be answered by one of the investigators listed above.

Signature of participant Date

Copies to: Participant
 Investigator's file

APPENDIX B

CODE _____

RETURN TO WORK
STUDY ENTRY FORM 01

DATE _____

Birthdate _____ Age _____ Marital status _____

Household members:

relationship _____

CANCER HISTORY

Diagnosis _____ Date of initial diagnosis _____

Urologist _____

Number of recurrent episodes including this one _____

Previous treatment:

where _____

prior modalities/agents _____

if bladder carcinoma, previous intravesical retention method

Current symptoms

Grade 0-4

OTHER HEALTH CONCERNS

WORK

Usual transportation: to work _____ to office _____

Occupation _____

How long in current position _____

How long in this type of work _____

Hours usually worked: per day _____ per week _____

Salaried or hourly _____ Income _____ per _____

Benefits: health insurance HMO plan sick time accrual _____

BIOGRAPHICAL NOTE

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