AD-A239 190

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Form Approved
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ited to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, eviewing the collection of information Send comments regarding this burden estimate or any other aspect of this ourden to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503

2. REPORT DATE

3. REPORT TYPE AND DATES COVERED
THESIS/~~DISSERTATION~~

1

4. TITLE AND SUBTITLE
Navigating Survival: Quality of Life Following Bone Marrow Transplantation

5. FUNDING NUMBERS

6. AUTHOR(S)
Paula A. Peters, Captain

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)
AFIT Student Attending: University of Arizona

8. PERFORMING ORGANIZATION REPORT NUMBER
AFIT/CI/CIA-91-018

9. SPONSORING/MONITORING AGENCY NAME(S) AND ADDRESS(ES)
AFIT/CI
Wright-Patterson AFB OH 45433-6583

10. SPONSORING/MONITORING AGENCY REPORT NUMBER

11. SUPPLEMENTARY NOTES

12a. DISTRIBUTION/AVAILABILITY STATEMENT
Approved for Public Release IAW 190-1
Distributed Unlimited
ERNEST A. HAYGOOD, 1st Lt, USAF
Executive Officer

12b. DISTRIBUTION CODE

13. ABSTRACT *(Maximum 200 words)*

DTIC
S ELECTE D
AUG 09 1991
D

91

91-07315

14. SUBJECT TERMS

15. NUMBER OF PAGES
155

16. PRICE CODE

17. SECURITY CLASSIFICATION OF REPORT

18. SECURITY CLASSIFICATION OF THIS PAGE

19. SECURITY CLASSIFICATION OF ABSTRACT

20. LIMITATION OF ABSTRACT

NSN 7540-01-280-5500

Standard Form 298 (Rev 2-89)
Prescribed by ANSI Std Z39-18
298-102

NAVIGATING SURVIVAL: QUALITY OF LIFE FOLLOWING BONE MARROW TRANSPLANTATION

by

Paula Ann Peters

A Thesis Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements
For the Degree of

MASTER OF SCIENCE

In the Graduate College

THE UNIVERSITY OF ARIZONA

1991

STATEMENT BY AUTHOR

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April 24, 1991

Date

ACKNOWLEDGEMENTS

The completion of this thesis would not have been possible without the generous contributions of many people. To Alice Longman, thesis chairperson, who suggested the idea of quality of life as a focus for this study, and her continual support and enthusiasm was appreciated. To Carrie Jo Braden and Ida M. (Ki) Moore, thesis committee members, for their input in both content and methodology and their astute insight into the cancer experience. To Rannie Fox for her accurate and timely transcriptions.

To the Arizona Cancer Center, Drs. William Dalton and Catherine Azar for their interest and access to patients. A special thank you to Katharine Chavez, my mentor and friend, who introduced me to bone marrow transplantation and assisted me in several steps along the way.

To my family who continue to support any endeavor I undertake, but especially to my father, a cancer survivor, who inspired me to pursue this area of nursing, and to my brother Bob, who taught me that computers are our friends.

Gratitude is extended to the American Cancer Society for funding received to purchase research materials.

To the men and women who so generously discussed their experiences with bone marrow transplantation and cancer survivorship, this thesis is dedicated to you.

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ABSTRACT

This study explored the quality of life of adult Bone Marrow Transplantation (BMT) survivors and processes involved in maintaining or enhancing life quality were identified. Grounded theory methodology was used to explore quality of life from the survivor's perspective. Five adults, 87 to 578 days post BMT, were selected using theoretical sampling and interviewed.

A theory of Navigating Survival emerged from data analysis as a series of coping processes employed by BMT survivors to manage quality of life disruptions. BMT survivors identified disruptions in quality of life during the rapid decision-making period; after discharge when limitations on physical activity must be managed; and as activities resume but fears of recurrence became stronger. Coping mechanisms used varied but were directed toward three areas: adapting to transplant, searching for meaning, and discovering a difference. Identifying unique quality of life aspects will enable oncology nurses to design interventions to enhance life quality of BMT survivors.

CHAPTER ONE

INTRODUCTION

Bone Marrow Transplantation (BMT) has evolved from an experimental treatment into a therapeutic modality for many hematologic, immunologic, and neoplastic disorders. Transplantation in many instances offers the only hope for cure. Over 4,000 patients per year receive bone marrow transplants at more than 250 centers worldwide including every continent except Antarctica (Bortin & Rimm, 1989). The advancement of BMT and the larger numbers of people receiving this treatment have led to a significant number of long-term disease free survivors. Rates of survival vary according to diagnosis, age, stage of remission, and type of transplant done, but on the average bone marrow transplantation offers a 50% survival rate (Freedman, 1988).

Long-term survival following bone marrow transplantation has been described as the absence of disease, and only recently has the quality of that life been addressed. The first 100 days represent short term or acute survival, as the recipient of a transplant confronts the side effects of the conditioning treatment such as neutropenia, acute graft-versus-host disease (GVHD), or graft rejection. Long-term survival from BMT (absence of original disease more than 100 days after transplant) involves facing new challenges such as chronic GVHD and waiting for the transplanted immune system to become competent (Corcoran-Buchsel, 1986). Marrow rejection, pancytopenia, infections, financial burdens, role changes within the family, employment difficulties, and fear of recurrence are among the long-term sequelae facing BMT survivors (Corcoran-Buchsel & Kelleher, 1989). The treatment itself can be carcinogenic, putting the patient at risk for a second malignancy.

Statement of the Problem

The interest of oncology nurses in the description and measurement of life quality of cancer patients is well documented in the literature (Dirksen, 1989; Graham & Longman, 1987; Padilla, Ferrell, Grant, & Rhiner, 1990). The increase in overall long-term survival from cancer has directed nursing research to address what improves life quality in these patients and how nurses can impact the quality of the cancer patient's life (Carter, 1989; Gambosi & Ulreich, 1990; Hoffman, 1989; Loescher, Clark, Atwood, Leigh, & Lamb, 1990). Nursing research addressing the perceived quality of life of bone marrow transplant patients is especially pertinent, as nurses provide the acute care during the transplant, and many oncology nurses are involved in the lengthy follow-up care required by these patients. The knowledge base on quality of life of cancer patients has grown tremendously over the last 10 years, and research on specific patient populations is now needed to add dimension to this knowledge. The research question addressed in this study was: what processes are involved in maintaining or enhancing quality of life following BMT?

Purpose

The purpose of this study was to explore the quality of life of persons surviving bone marrow transplantation. Quality of life was defined as the degree of satisfaction with present life circumstances as perceived by the person (Young & Longman, 1983). Quality of life of cancer patients is found in the literature however, the experience of the BMT survivor is sparsely researched in regards to quality of life.

Significance

Cancer survivors have changed the way in which medicine and nursing views cancer. Rapid advances in technology have enabled patients to live longer following the diagnosis of cancer and many of these survivors are disease free. Early work in cancer treatment promoted treatment of disease regardless of cost, promoting quantity of life without consideration of the quality of that life. Cancer treatment comes with a high morbidity, and long term complications are a reality.

Nurses have responded to the quality of life concerns of cancer patients and through research, have developed tools to measure quality of life (Curtis & Fernsler, 1989; Ferrans, 1990; Lough, 1988; Monahan, 1988). Pediatric cancer survivors initially studied were found to be at risk for developing many long term physical treatment related complications including learning disabilities from radiation to the brain, multiple organ system damage from chemotherapeutic agents, and growth retardation from ionizing radiation to the growth plates of long bones (Meadows, Massari, Fergusson, Gordon, Littman, & Moss, 1981; Pratt, Ransom, & Evans, 1978; Sanders, Pritchard, Mahoney, et al., 1986). An increasing risk for a secondary malignancy was also found (Deeg, Sanders, Martin, et al., 1984). These findings provided nurses and physicians with a clear picture of physical and psychological problems facing cancer survivors, which may directly influence quality of life.

While the numbers of BMT survivors have increased, relatively little is known about that survival. Quality of life has importance for this group of cancer survivors (Androwski, Altmaier, Barnett, Otis, Gingrich, & Henslee-Downey, 1990). Research on adult BMT survivors suggests that cure of underlying disease may produce significant long-term complications affecting general physical health and psychosocial well-being, impacting their quality of life (Andrykowski, Henslee, & Farrall, 1989). Knowledge of long-term functioning and adaptation of BMT survivors is important for several reasons. First, identification and description of quality of life outcomes enable patients to provide informed consent for this procedure. Second, a more complete analysis of costs and benefits of BMT can be accomplished when quality of life is considered rather than survival rates alone. Third, identification of the physical and psychosocial complications experienced by BMT survivors can provide important information that will assist in modifying the BMT procedure to produce less morbidity and improve quality of life (Andrykowski, Henslee, & Farrall, 1989; Haberman, 1988; Quigley, 1989).

Summary

The purpose and significance of studying the quality of life of adult bone marrow transplantation survivors have been introduced. Quality of life is a high priority nursing concern as patients are treated for and surviving from malignancies. Cancer treatment modalities may produce significant long term complications that impact the life quality of survivors. Identification of factors which detract from survivors quality of life can enable nurses to modify or prevent morbidity to improve the outcomes for these cancer patients. Quality of life is an individual perception, and dealing with processes people go through enables detailed personal descriptions of the bone marrow transplant experience and its impact on quality of life.

CHAPTER TWO

REVIEW OF THE LITERATURE

Information regarding the bone marrow transplantation process is presented in this chapter. Literature review is organized arount the concepts of quality of life, long-term survival, and late effects of cancer treatment.

Bone Marrow Transplantation

Although early attempts to use bone marrow therapeutically resulted in failure, the discovery of atomic energy in the 1940s brought renewed interest in bone marrow transplantation through increased understanding of marrow failure caused by radiation injuries (Santos, 1983). Grafts were attempted on humans in the late 1950s but lethal immunologic reaction of the graft against the host, and lethal viral and fungal infections resulted (Champlin, 1990a). The discovery of human histocompatibility typing in the late 1960s made it possible to match the recipient's tissue type with the donor's bone marrow leading to a decrease in the incidence of acute host rejection. Attempts to prevent infections have focused on using various forms of protective isolation, and prophylactic antibiotic therapy. These advances have increased the survival from bone marrow transplantation; however infections and graft-versus-host disease still remain a problem for these patients.

Bone marrow transplantation is used to treat a variety of disorders, and is continually finding new applications in the treatment of malignancies and immunologic disorders. It gained notoriety as a treatment for leukemia and lymphoma, and has been used to treat acute and chronic leukemia, hairy cell leukemia, preleukemic states, Hodgkin's and non-Hodgkin's lymphoma, multiple myeloma, and some solid tumors (Champlin, 1990a). Non-malignant disorders that are successfully treated with BMT include disorders of the bone marrow stem cells. Patient's with aplastic anemia, Falconi's anemia, thalassemia, and sickle cell anemia have also benefitted from transplanted marrow.

There are three types of BMT, based on the source of the donated marrow (Champlin, 1990a; Corcoran-Buchsel & Kelleher, 1989). Allogeneic marrow is donated by an individual who is genetically matched to the recipient. This type of transplant is used when the stem cells contain disease as in hematologic malignancies and anemias. Autologous marrow is the patient's own marrow which is donated and then administered after treatment for cancer to build up the marrow damaged by treatment. Patients with solid tumors (breast, colon) benefit from this type of transplant. Syngeneic marrow is a rare transplant as the donor is the identical twin of the recipient, providing an identical genetically matched bone marrow. When the marrow is from an outside source, the patient is at greater risk for rejection or the onset of GVHD, both an acute and chronic complication of this therapy (Freedman, 1988).

Pretransplant Conditioning

When a donor or a source of marrow has been identified, the recipient is admitted to the hospital for pretransplant preparation. The conditioning regimen is administered prior to transplant and serves the following functions: (1) it destroys the patient's own immune system and therefore decreases the risk of graft rejection; (2) it removes malignant cells; and (3) it prepares space in the bone marrow for engraftment of the new marrow (Freedman, 1988). For nonmalignant conditions, the preconditioning treatment is aimed at eradication of the host's immune system while in malignant disorders therapy must also eradicate malignant cells. Preconditioning treatment varies according to type of disease and consists of either high-dose chemotherapy alone, or in combination with total body irradiation. High dose chemotherapy with such agents as Cyclophosphamide (Cytoxan), an alkylating agent, and Busulfan are frequently used to provide tumor kill and produce immunosuppression (Champlin, 1990a); they are most effective on rapidly dividing cells of the bone marrow. Total body irradiation is used in leukemia to penetrate the central nervous system to destroy malignant cells sequestered there (Freedman, 1988). Both chemotherapy and radiotherapy are at much higher doses than those given for conventional treatment producing severe side effects which include nausea, vomiting, diarrhea, stomatitis, skin reactions, and alopecia. Parotid gland tenderness and swelling as well as low grade fever are frequently seen following total body irradiation.

Bone marrow donation is done in the operating room under general anesthesia. Multiple bone marrow aspirations are made from both iliac crests to collect from 400 to 800 ml of marrow (Champlin, 1990a; Santos, 1983). The bone marrow is filtered to remove fat and bone chips, mixed with heparinized saline to prevent clotting, and transferred to a blood transfusion bag. The actual transfusion of marrow is a simple procedure, much like receiving a blood transfusion.

Early Complications

The period following the infusion of marrow is a waiting game for the patient which can be punctuated by many serious and life-threatening problems (Champlin & Gale, 1984). Immediate problems confronting the patient include infection, bleeding, acute GVHD, interstitial pneumonia, veno-occlusive disease of the liver, and graft rejection (Champlin & Gale, 1984; Ford & Ballard, 1988).

Neutropenia (WBC count less than 1.0 mm3) occurs following the conditioning and prior to engraftment, leaving the patient at high risk for developing bacterial, fungal, or viral infections, and unable to mount an effective response. Pathogens most problematic include those which colonize the skin, upper airway, and gastrointestinal tract, as the integrity of these areas are altered by the conditioning regimen (Schryber, LaCasse, & Borton-Burke, 1987). Neutropenia not only hastens the clinical course of infection but also hides markers of infection such as elevated WBC count or local inflammation at infected sites, therefore aggressive searching for the source of infection and immediate treatment are essential. Infection is problematic to some degree in every transplant patient, and a major contributor to most post-transplant deaths (Champlin & Gale, 1984). Measures taken against infection include protective isolation, laminar air flow rooms, prophylactic systemic antibiotics, acyclovir, passive immunity with intravenous immunoglobulin, blood product screening for Cytomegalovirus (CMV), low bacterial/sterile diet, and aggressive mouth care.

Hemorrhage can occur at any time during the transplant process but the highest incidence occurs during the first four weeks (Ford & Ballard, 1988). Platelets are not being produced during this time and platelet counts are maintained through transfusions. Clinical manifestations of bleeding can be seen when platelet counts fall below 15,000 microns/liter and include nose bleeds, mouth or gum bleeding, presence of blood in urine, feces, or emesis, and bleeding from old injection sites.

Graft-versus-host disease is unique to allogeneic transplant patients. In BMT, it is the immune system which has been transplanted, and this competent immune system (graft) recognizes the body tissues of the recipient (host) as foreign and mounts an attack against them. The T-lymphocytes specifically identify foreign proteins and respond in GVHD (Champlin & Gale, 1984). Graft-versus-host disease occurs in 40% to 50% of all allogeneic transplants and those at highest risk include persons who are over age 30, have an opposite sex donor, or are not perfectly matched with their donors (Champlin & Gale, 1984; Ford & Ballard, 1988). Incidence increases with age ranging from approximately 10% in patients under 10, and as much as 70% in patients over the age of 40.

Acute GVHD occurs around 25 days after transplant and primarily affects the skin, liver, and gastrointestinal tract. Treatment is aimed at suppressing the response and is an area of BMT that is much investigated today (Gratama, Jansen, Lopovich, Tanke, Goldstein, & Zwaan, 1984; Storb, et al., 1986). The goal of therapy is to remove or inactivate the T-lymphocytes that are responsible for the attack, and to reduce the number of microorganisms that may aggravate the response (Champlin, 1990b; Deeg & Henslee-Downey, 1990). Although removal of T-cells prior to transplant decreases the incidence and severity of GVHD, there is a significant increase in failure of engraftment which often results in the death of the patient (Thomas, 1988).

Pneumonia is the single greatest cause of death during the first 100 days after transplant, occurring in 35% of the patient population, and responsible for death in 23% of patients transplanted for hematologic malignancy (Champlin & Gale, 1984). Interstitial pneumonia has a rapid onset and the patient deteriorates rapidly. Symptoms include dry cough, dyspnea, tachypnea, and rales. Diagnosis of the cause of pneumonia is often difficult, yet essential for treatment. Fifty percent of pneumonias in transplant patients are caused by CMV, while other causes include viruses such as herpes simplex and varicella zoster, bacteria and fungi (Ford & Ballard, 1988).

Veno-occlusive disease is a hepatic complication secondary to the pretransplant conditioning therapy which causes fibrous material to deposit and plug small venules in the liver (Schryber, LaCasse & Bortin-Burke, 1987). This occlusion results in blood flow backup, causing sodium and albumin to leave the vascular space and enter the peritoneal cavity. Blood flow backup also causes a decrease in renal blood flow causing further water and sodium retention (Ford & Ballard, 1988). Weight gain, ascites, and elevated liver function tests are seen. Shunting of blood away from the liver decreases liver metabolism resulting in increased serum bilirubin. Veno-occlusive disease occurs soon after transplant in the first two weeks, with resolution occurring in half the cases. Treatment is aimed at maintaining intravascular volume and renal perfusion, and minimizing accumulation of extravascular fluid.

For the transplant to be successful, the donor marrow cells must engraft, reestablish a normal hematopoietic and immune system in the recipient, and become immunologically tolerant of the host (Champlin & Gale, 1984). Graft rejection is usually due to an immune-mediated rejection of the transplanted bone marrow cells. Factors influencing graft rejection include (1) the degree of genetic disparity between the donor and recipient; (2) the cellular composition of the graft; (3) the number of transplanted bone marrow (stem) cells; (4) the immunocompetence of the recipient; (5) the type and intensity of pre- and posttransplant immunosuppressive treatment; and (6) whether or not the recipient has been sensitized to donor transplantation antigens by prior blood transfusions or pregnancy.

Late Complications

The first 100 days mark the acute phase in BMT and while the patient has survived many actual and potential crises, long-term complications of BMT may still occur. The immune system takes nearly a year to become fully competent. Most long-term complications are caused by high-dose chemotherapy and/or radiation, chronic GVHD, and problems arising from the original disease (Nims & Strom, 1988).

Sequelae of the conditioning regimen include gonadal dysfunction, growth retardation in children, and secondary malignancies (Corcoran-Buchsel, 1986). Gonadal dysfunction is a complication of high-dose chemotherapy alone or when combined with total body irradiation. Age at time of transplant determines the extent of dysfunction when chemotherapy alone is used. Sanders, Buckner, Leonard, and Sullivan (1983), found no dysfunction in prepubertal transplant recipients but both males (33%) and females (66%) over age 26 experienced sterility and premature menopause respectively. When total body irradiation and chemotherapy are combined in the conditioning regimen, 95% of transplant patients were found to be sterile (Sanders, et al., 1983). Secondary malignancies are a rare occurrence following BMT, and are primarily treatment related.

Chronic GVHD affects 25% to 50% of patients living longer than 100 days after BMT (Corcoran-Buchsel, 1986; Nims & Strom, 1988). This disease occurs either as an extension of acute GVHD, after resolution of acute GVHD, or in the absence of acute GVHD. Chronic GVHD is a multisystem disorder affecting the skin, musculoskeletal system, eyes, mouth, esophagus, gastrointestinal tract, lungs and liver. Early detection and treatment of chronic GVHD prevents long-term complications. Screening studies done around day 100 can detect clinical or subclinical disease (Corcoran-Buchsel & Parchem, 1988). Successful treatment requires immunosuppression and antibiotics to fight infection. Immunotherapy includes prednisone taken alone or in combination with procarbazine, cyclosphosphomide, or azathioprine given for one year or more (Nims & Strom, 1988). Bactrim is given to prevent secondary infections during treatment.

Relapse following BMT is usually from a failure of the conditioning treatment to eradicate all residual leukemic cells (Corcoran-Buchsel, 1986). Patients may present with similar signs and symptoms to those noted at time of original diagnosis. A second BMT is a rare treatment option for these patients.

Psychosocial Problems

Patients with BMT face a myriad of life-threatening crises throughout the acute and long-term recovery from treatment. The goal is cure of the malignancy, however, the physical cost can be tremendous. In addition to enduring many physical challenges, the BMT patient also experiences frequent psychosocial distress. Haberman (1988) identified six stages that BMT patients go through that parallel the transplant process. Stage 1 involves making the decision to undergo a transplant, which marks a major turning point in the life of the patient. During this time Haberman (1987) found that adult leukemia patients tended to minimize the significance of the clinical estimates of survival, especially when those estimates are grim. Patients tend to redefine the statistics in their own favor. Brown and Kelly (1976) found that patients protected themselves from the helplessness and anxiety caused by the transplant with defense mechanisms such as denial, to maintain a sense of being less vulnerable. Uncertainty after the decision has been made can linger as the patient realizes the acute complications, long-term complications, and possible reduced quality of life surrounding the transplant process.

Stage 2 is preadmission and is accompanied by anxiety and anticipation (Haberman, 1988). Organization of personal affairs and saying goodbye to relatives and friends can be difficult at this time. Mental preparation involves supporting a positive attitude and will to live. This stage is marked by two feelings; a sense of urgency to get started now that the decision is made and frustration over waiting for test results or bed space on the transplant unit. The patient's way of coping with illness stems from the particular meaning the illness and treatment has for the individual (Brown & Kelly, 1976).

The pretransplant conditioning regimen constitutes stage 3 and according to Haberman (1988), total body irradiation has been identified by patients as a major stressor. Patients strive to derive meaning and purpose to the aggressive conditioning treatment, feel exposed and defenseless, and often refer to this time as the "point of no return" (Brown & Kelly, 1976). The realities of nausea and vomiting may resurface doubts about the initial decision to undertake the transplant. Patients talk more about their own death or speak in a displaced way about friends and family.

Stage 4 involves immunosuppression and a lengthy period of germ-free isolation. Some patients experience a heightened sense of worry over physical symptoms (Haberman, 1988). Adjustment to isolation is a stressor of this stage. There is a concern on the part of patients and families about barriers to touching and patients feel more alone at this time. Passive-oriented individuals tend to adjust to isolation better than active individuals.

Stage 5 is marked by the transplantation itself and the wait for engraftment (Haberman, 1988). The day of the transplant can be filled with emotion, even considered a second birthday by some patients. Progress toward engraftment is keenly monitored by the patients and their families, examining blood counts daily, and monitoring for GVHD or infection. The presence of GVHD usually results in anger or depression and is viewed as a major setback, as the patient feels unfairly trapped by the situation (Brown & Kelly, 1976). Uncertainty pervades this period, as well as a struggle for personal control. Patients during this stage experience tremendous anxiety if another patient on the unit dies, especially if they have the same primary disease in common (Patenaude & Rappeport, 1982). Discharge from the hospital marks stage 6 and patients may experience separation anxiety. Depression may occur as patients grieve the loss of relationships with staff. Returning home can produce anxiety and uncertainty, as the patient recognizes that long-term problems may develop and immunosuppression persists for up to one year.

Quality of Life

The question of what constitutes quality of life has been the focus of sociological (Campbell, Converse, & Rogers, 1976), psychological (Schipper, 1990), medical (de Haes & van Knippenberg, 1987), gerontological (Palmore & Kivett, 1977), and nursing research (Graham & Longman, 1987; Padilla, Present, Grant, Metter, Lipsett, & Heide, 1983; Presant, Klahr, & Hogan, 1981; Young & Longman, 1983). Investigators have associated quality of life with concepts such as hardiness (Lee, 1983), self-esteem (Taft, 1985), life satisfaction (Laborde & Powers, 1980), and well-being (Dirksen, 1989).

Definitions of quality of life within the literature include a purpose in life, and adequate self esteem (Lewis, 1982), and a complex of physical function, personal attitudes, perceived well-being and support (Padilla & Grant, 1985). Dirksen (1989) defined well-being as the subjective perception of current life quality, and Laborde and Powers (1980) equated quality of life with material possessions that add to the enjoyment of life.

From the definitions available in the literature, clearly quality of life means different things to different people, reflecting their own point of view. The concept can be described and measured only in individual terms, and it depends on past experiences and future hopes, dreams, and ambitions (Calman, 1987). Quality of life must include all areas of life and take into account the impact of illness and treatment. Quality of life changes over time and under normal circumstances can vary greatly (Donovan, Sanson-Fisher & Redman, 1989). Quality of life measures the difference, at a particular point in time, between the hopes and expectations of the individual and the individual's present experience (Calman, 1987).

Quality of life is conceptualized as having domains or aspects of life that are affected by illness. Schipper (1990) identifies four such domains: physical and occupational function, psychological function, social interaction, and somatic sensation. These domains are predominantly found within the literature on quality of life (Calman, 1987; Campbell, Converse, & Rogers, 1976; de Haes & van Knippenberg, 1987; Gotay, 1984; Padilla, et al., 1990). Physical and occupational function represent physical and intellectual effort needed to get things done. Psychological function describes overall mental state and its influence on quality of life. Anxiety, fear, depression, sense of well-being, hope, denial, and coping can impact in this area (Ferrans, 1990; Schipper, 1990). Social interaction describes societal functioning, i.e., an individual's desire for and ability to make contact with others and be part of a community. Somatic sensation or symptom distress provides a sense of how pain, nausea, and other sensations are part of day to day existence and the effect these sensations have on quality of life (Germino, 1987; Schipper, 1990). Somatic sensations may result from aggressive therapy or be the consequence of disease trajectory.

Many other domains of quality of life have been identified more recently including happiness and spiritual domains (Calman, 1987; Ferrans, 1990; Packa, 1989a). Happiness is the way in which a good quality of life is recognized, and spirituality reflects a strong personal belief system. Financial domains that can impact quality of life include cost of treatments and loss of earnings. Calman (1987) identified wider dimensions of the concept including the individual dimension (ambitions, priorities, hobbies, accomplishments and past experiences), cultural dimension (cultural values), political dimension (political philosophy of a country or government determines a major part of quality of life, and standard of living), philosophical dimension (meaning of life and its purpose), and time dimension (time changes many things and with that the quality of life).

Quality of Life Instruments

Medical and nursing researchers have developed many objective instruments to tap the domains of quality of life. Instruments which measure quality of life focus on specific domains of quality of life such as physical, psychological, and social functioning (Ferrans & Powers, 1985; Spitzer et al., 1981; Young & Longman, 1983), while other tools cover a wide range of aspects including financial and spiritual issues (Bernheim & Buyse, 1984; Gough, Furnival, Schilder, & Grove, 1983). Donovan, Sanson-Fisher, and Redman (1989) reviewed 17 quality of life instruments against specific criteria and found that no one instrument met all the criteria. According to the authors, characteristics of an adequate measure include: (1) an appropriate underlying conceptualization of quality of life; (2) testing for psychometric properties; (3) responsive to changes in quality of life; (4) based on patient generated data; and (5) acceptable to patients, health providers, and researchers.

Quality of life is an important outcome variable for cancer patients undergoing aggressive treatment and surviving many years following diagnosis. Tools designed to measure physical functioning only, often miss important life domains that can dramatically impact on quality of life. Instruments designed to measure physical, psychological, social, and spiritual domains achieve a more complete measure of quality of life especially if changes in the domains can be detected. For example, there is evidence that as the physical condition deteriorates, spiritual issues commonly gain in importance as determinants of quality of life (Donovan, Sanson-Fisher, & Redman, 1989). Tools devoid of spiritual measures may not be effective when measuring the quality of life of endstage cancer patients (Gotay, 1984). Another discrepancy within the literature is whether one tool can adequately measure quality of life or if multiple measures are needed (Dean, 1985; Frank-Stromborg, 1984). It is premature to generalize that the current instruments designed for cancer patient populations can adequately capture the unique quality of life experienced by bone marrow transplant survivors. Even the most comprehensive quality of life instruments do not capture processes involved in maintaining life quality.

Quality of Life Studies

There are numerous quality of life studies in the literature both for cancer patients and other patient populations. Studies conducted on other patient populations include organ transplantation (Evans, Manninen, Maier, Garrison, & Hart, 1985; Lough, 1988), chronic illness (Burckhardt, 1985; Laborde & Powers, 1980), and the elderly (Magilvy, 1984; Palmore & Kivett, 1977).

General Patient Populations

Evans, Manninen, Garrison, et al. (1985) conducted a large multicenter quality of life study on four end-stage renal disease patient populations. The sample included 859 patients who were either undergoing home dialysis, inpatient hemodialysis, continuous ambulatory peritoneal dialysis, or post-renal transplantation. The authors found that 79.1% of the transplant patients were able to function at nearly normal levels as compared with 47.5 to 59.1% of the patients treated with dialysis. Nearly 75% of the transplant patients were able to work as compared to 24.7% to 59.3% of dialysis patients. Among dialysis patients the subjective quality of life assessments (perceived quality of life) were favorable even though objectively these patients did not work or function at the same level as people in the general population. This finding suggests that patients with end-stage renal disease are able to adapt to adverse life circumstances and express satisfaction with their lives.

Laborde and Powers (1980) compared hemodialysis patients (n = 20) with osteoarthritis patients (n = 20) who rated their quality of life using Cantril's Self-Anchoring Scale. Each subject was asked to imagine the best possible life as 10 and the worst possible life as 1 and indicate where they would place themselves on the scale. Respondents were asked to rate their life quality five years ago, at present, and five years in the future. Hemodialysis patients reported a higher present life satisfaction, while past life satisfaction was the same for both groups. Dialysis patients viewed present life better than past life, but arthritis patients reported the opposite view.

Quality of life studies have emerged with cardiac patient populations as therapeutic interventions such as cardiac bypass surgery and cardiac transplantation have extended life in these patients. Following bypass surgery, patients reported significantly improved quality of life in regards to level of angina, level of physical activity, family life, social life, and sexual life (Penckofer & Holm, 1984). Future life satisfaction was rated excellent, and past life satisfaction was rated lower than present or future satisfaction. Packa (1989b) evaluated cardiac transplant patients using Cantril's Self Anchoring Scale and found similar results. Life satisfaction prior to transplant was rated poor, and good to excellent at time of interview. Future projection of life satisfaction was rated excellent. Overall, quality of life was rated as excellent by patients following cardiac transplantation.

Lough, Lindsey, Shinn, and Stotts (1987) studied the impact of symptom frequency and symptom distress on quality of life of heart transplant patients. Results showed a negative correlation with both symptom frequency and symptom distress, but found that 89% of the sample (n = 75) reported high satisfaction with quality of life, the factor which had the greatest impact on current quality of life for these patients. The results suggest that while physical symptoms and emotional distress may be experienced by these patients, other life factors have greater impact on perceived quality of life.

Cardiac transplantation dramatically impacts on all areas of life functioning for both patients and their families requiring adjustment and adaptation. Exploration of the process of family adjustment before, during, and after heart transplantation was conducted by Mishel and Murdaugh (1987) using grounded theory methodology. "Redesigning the dream" was the central theme that emerged from the data describing how family members modify their beliefs about organ transplantation and develop attitudes and beliefs to meet the challenge of living with continual unpredictability. The adjustment processes of immersion, passage, and negotiation outlined by Mishel and Murdaugh (1987) mirror the transplantation process of waiting for a donor, hospitalization, and recovery.

Oncology Patient Populations

Oncology nurse researchers have examined the quality of life of patients and families experiencing cancer in relation to symptom distress (McCorkle & Young, 1978), psychological needs (Frank-Stromborg & Wright, 1984), anxiety (Welch-McCaffrey, 1985), family coping (Thorne, 1985), as an outcome variable (Padilla & Grant, 1985), and personal control (Lewis, 1982). Other areas of research in the oncology literature involve quality of life as it relates to adjustment to diagnosis and treatment (Longman & Graham, 1986; Northouse, 1989), cancer recurrence (Chekryn, 1984; Gotay, 1984), and hope (Owen, 1989).

Longman and Graham (1986) did a content analysis of interviews of persons with malignant melanoma, using a semi-structured interview guide called the Life-Change Scale. This tool consisted of areas associated with quality of life including physical appearance and endurance, sense of achievement, job satisfaction and performance, relationships with spouse, family, and friends, religious involvement, and support systems. The sample consisted of 60 patients diagnosed and treated with malignant melanoma who were interviewed. Six categories emerged from the data: (1) living with cancer; (2) thoughts about treatment for melanoma; (3) changes in making life meaningful; (4) alterations in life-style; (5) relationships with others; and (6) social support adaptation. The analysis revealed a wide variety of reactions to the diagnosis and treatment of malignant melanoma. Depression was found to be the most common initial reaction and goal-directed behavior a common response to treatment decisions. The responses of the subjects were limited to the categories of the Life Change Scale and therefore do not represent the total cancer experience.

Personal control and quality of life was studied in late stage cancer patients (Lewis, 1982). It was hypothesized that increased personal control led to an increase in quality of life as measured by self-esteem, anxiety, and purpose in life. Findings indicated that the measure of personal control over life correlated with self-esteem ($r = -.33$; $p = .001$), purpose in life ($r = .45$; $p = .001$), and anxiety scales ($r = -.30$; $p = .001$). Control over health weakly correlated ($r = -0.18$, $p = .05$) with the study variables, and may be relinquished in end stage cancer patients as a means of managing anxiety; therefore, increasing cancer patients personal control over health may only have a limited effect on the quality of life they experience.

Dirksen (1989) also studied control and its relationship to perceived well-being in malignant melanoma survivors. Locus of control, social support, self-esteem, and the effect on perceived well-being provided the framework for the study. The sample of 31 patients completed six scales; three measuring locus of control, and one each measuring social support, self-esteem and well-being. Results of the study indicated that an individual with an internal *locus of control* (degree to which individuals believe they have control over events that happen to them) had a greater sense of well-being. When survivors of malignant melanoma had high self-esteem ($B = .31$; $R2 = 0.11$; $p = 0.05$), they also had an increased perception of well being. Social support contributed to self-esteem, where the greater the perception of support, the higher the level of self-esteem.

Research on quality of life in hospice patient populations identified discrepancies between perceptions of terminally ill cancer patients and their primary caregivers

(Curtis & Fernsler, 1989; Grobe, Ilstrup, & Ahmann, 1981; Jennings & Muhlenkamp, 1981). Grobe, Ilstrup, and Ahmann (1981) found disagreement between patient and family members regarding their perceived needs for symptom management and ambulation. Jennings and Muhlenkamp (1981) concluded that caregivers inaccurately perceive needs of patients and sometimes expect the patient to feel worse than they actually do. Miscommunication between hospice patients and their caregivers could lead to isolation and loss of identity. Curtis and Fernsler (1989) found that hospice patients report significantly less pain than their caregivers report ($p = .027$), and subsequently patients report less fun and sex than their caregivers perceive. These discrepancies between patients and their caregivers impact on the way in which needs of terminally ill cancer patients are met and can therefore impact quality of life for these patients.

BMT Patient Populations

Studies of the quality of life and adaptation of long-term survivors of bone marrow transplantation are beginning to appear in the medical literature, as a result of increasing survival rates from this procedure. Research regarding the quality of life following BMT suggests considerable variability among patients. While some patients experience few post-BMT complications and report an essentially "normal" life, other patients report a variety of residual difficulties. Hengeveld, Houtman, and Zwaan (1988) interviewed 17 patients one to five years following BMT. Reports of daily life being hampered by physical complications, sexual problems, infertility, and/or failure to return to work were obtained from 40% to 50% of patients. Wolcott, Wellisch, Fawzy, and Landsverk (1986a) evaluated 26 patients at least one year post-BMT (mean 42 months) and found that 25% of the sample reported significant emotional distress, chronic physical symptoms, low self-esteem, and less than optimal life satisfaction.

Andrykowski, Henslee, and Farrall (1989) assessed psychosocial functioning in 23 adult patients with a mean of 26 months post-BMT. The subjects reported greater mood disturbance when compared to samples of other cancer patients (McCorkle & Quint-Benoliel, 1983; Rieker, Edbril, & Garnick, 1985), and a sample of healthy bone marrow donors (Wolcott, Wellish, Fawzy, & Landsverk, 1986b). Age at transplant was significantly related to post-BMT outcomes; patients transplanted after age 30 reported lower functional quality of life ($p = 0.013$) and greater mood disturbance ($p = .075$) than patients transplanted before 30 years of age (Andrykowski, Henslee, & Farrall, 1989). Two follow-up assessments identified little or no change in psychosocial functioning, indicating lack of improved quality of life with time (Andrykowski, Henslee & Barrett, 1989). At the time of the third assessment (mean of 52 months post-BMT), 50% of the subjects were unemployed for health-related reasons, while patients who were employed often cited restrictions in work activities or the number of hours worked.

Andrykowski, Altmaier, Barnett, Otis, et al. (1990) evaluated the quality of life of BMT patients with a matched sample of renal transplant patients. The samples were matched by age, sex, and time since transplant. Results indicated no significant difference in quality of life across numerous domains between the groups, but the overall quality of life reported was less than that considered "normal". Among the BMT group, less education, dose of total body irradiation, and older age were associated with poorer status; yet, time since BMT was unrelated to post-BMT quality of life. Patients preconditioned for BMT with total body irradiation have demonstrated cognitive impairment involving slower reaction times, reduced attention and concentration, and difficulties with problem solving and reasoning (Andrykowski, Altmaier, Barnett, Burish, Gingrich, & Henslee-Downey, 1990).

The studies on BMT patient populations are preliminary, and identify only limited domains of quality of life. The small sample sizes used limit the generalizability of the results to the population of bone marrow transplant survivors.

Long-term Survival

Within the past 10 years the number of cancer survivors has grown as treatment modalities have become more complex and effective. Cancer survivors represent a unique group of patients who have overcome cancer, but may be at risk for developing physical and psychological post-treatment sequelae.

Survival after a cancer diagnosis has been determined by a five-year mark after treatment for most malignancies in which the patient remains disease free (Dow, 1990). For survivors of bone marrow transplantation survival is determined in stages and is continually being adjusted. Acute survival is absence of original disease for 100 days, as the immune system takes up to one year to stabilize and return to normal (Corcoran-Buchsel, 1986). For many cancer patients survival begins at diagnosis and represents an ongoing process (Mullan, 1985). Mullan (1985) viewed survival as consisting of seasons which begin at diagnosis and treatment (acute survival), proceed through remission (extended survival), and arrive at cure or the small likelihood of recurrence (permanent survival). Cancer patients experience fear and anxiety, confront their own mortality, and endure the toxic effects of chemotherapy and radiation during acute survival. Extended survival is dominated by fear of recurrence, uncertainty, and the experience of diminished support by the medical staff as the patient requires less regular surveillance. Permanent survival entails returning to life functions previously enjoyed and during this time many survivors experience problems with employment and insurance. Patients may experience long-term consequences of treatment including sterility, second malignancies, lung disease, and cognitive difficulties (Deeg, Sanders et al., 1984; Meadows, et al., 1981; Pratt, Ransom & Evans, 1978.).

Loescher, et al. (1990) evaluated 17 adult cancer survivors using the Cancer Survivor Questionnaire which assessed physiological, psychological, and socioeconomic problems of these patients. The subjects reported physiological problems of infertility, decreased energy, decreased endurance, episodes of tachycardia, hearing loss, increased infections, and constant pain. Psychosocial concerns were numerous with fear of recurrence, concern for general health, and changes in physical appearance reported. Socioeconomic difficulties included changes in relationships with family members, inability to work, and insurance problems.

Late Effects

A whole array of physiological and psychosocial effects can confront the cancer survivor. Physical effects of surgery, chemotherapy, and radiation can affect nearly every organ system and impact on the cancer survivor's life. For example, cardiac and immune system disturbances can result from bone marrow transplantation. Psychosocial late effects can include fear of recurrence, adjustment to physical compromise, alterations in relationships with others, and employment discrimination (Welch-McCaffrey, Hoffman, Leigh, Loescher & Meyskens, 1989).

The immune system is affected in nearly every cancer patient to some degree as a result of aggressive therapy. Some cancer survivors experience long-term immune deficiencies, especially those treated for leukemia, Hodgkin's disease, and breast cancer (Workman, 1989). Impairments of the T-lymphocytes and a decrease in immunoglobulin are seen, leading to frequent infections for these patients. Radiation to the thymus area as a part of cancer treatment is thought to contibute to the late effects on the immune system.

Late effects can occur in other body systems including the lungs (pulmonary fibrosis), gastrointestinal system (chronic enteritis, hepatic fibrosis, cirrhosis), genitourinary system (chronic nephritis, hemorrhagic cystitis), and cardiovascular effects which include cardiomyopathy, and pericardial damage (Loescher, Welch-McCaffrey, Leigh, Hoffman, & Meyskens, 1989; Pratt, Ransom & Evans, 1978; Wickham, 1986). Second malignancies as a result of cancer treatment include acute nonlymphocytic leukemia following treatment with alkylating agents and solid tumors following radiation (Fraser & Tucker, 1989). The risk of second malignancies is small (5% -13.5%) and dose dependent.

Fear of recurrence is a prominent concern for cancer survivors, which can result in some degree of immobilization (Quigley, 1989). Schmale, et al. (1983) compared 104 cancer survivors three years after treatment with a matched sample of healthy controls. The authors found a greater incidence of health worries associated with recurrence and a sense of lowered self control in the survivor sample. Fear of recurrence can lead to physician avoidance or an excessive concern regarding physical symptoms. Northouse (1981) examined fear of recurrence among mastectomy patients and noted that when individuals have insufficient knowledge about when and if symptoms would occur, they experienced less control over their life.

Disabilities related to the cancer or its therapies may remain a source of ongoing psychological distress during survivorship as physical impairment can generate anger and symptoms related to depression. Fobair, Hoppe, Bloom, Cox, Varghese, and Spiegel (1986) studied survivors of Hodgkin's disease and found energy loss to be correlated with both depression and age. Patients under age 34, had a faster return of energy (within 1 year), and older patients required more time. The sample consisted of 403 patients and 37% reported a lack of energy return.

Relationships with others can be altered as part of the cancer experience, and many survivors report being treated differently by others (Loescher, et al., 1990; Welch-McCaffrey, et al., 1989). Schmale, et al. (1983) found that both survivors and family members were more cautious and less active even in the absence of physical limitations. Reiker, Edbril, and Garnick (1985) described changes in relationships among men with cured testicular cancer. Marital relationships were found to be strengthened but non-marital relationships were strained. Isolationism can be a part of altered social relationships for the cancer survivor either by isolation of others or self-isolationism.

Cancer survivors have reported employment difficulties or discrimination following the diagnosis and treatment of their malignancy. Hoffman (1989) states that approximately 25% of the five million cancer survivors in the United States will face employment difficulties. Cancer survivors experience a variety of employment problems including dismissal, failure to hire, demotion, denial of promotion, denial of benefits, and hostility in the workplace (Fobair, et al., 1986; Hoffman, 1989; Loescher, et al., 1990; Schmale, et al., 1983; Welch-McCaffrey, et al., 1989). Employment changes experienced by cancer survivors can cause financial burdens, role changes within families, and can also significantly impact their quality of life.

Summary

Included in this chapter was a review of the literature on the bone marrow transplant process including a discussion of both the physical and psychosocial complications associated with this therapy. Quality of life was addressed in terms of definitions, domains, instruments, and research among oncology, cardiac, renal, and chronic illness patient populations. Long-term cancer survivors are confronted with a wide range of physiologic and psychosocial difficulties including loss of a body part or function, sterility, fear of recurrence, and employment discrimination; which can have a significant impact on their perceived quality of life.

CHAPTER THREE

METHODOLOGY

The methodology and design of the study are described in this chapter. In addition, the sample, the setting, data collection, data analysis, and human subjects considerations are addressed.

Quality of life is an especially important consideration in experimental treatments for cancer, like bone marrow transplantation. Available medical research on BMT patients' quality of life has used objective tools to measure physical functioning and satisfaction with life (Andrykowski, Altmaier, Barnett, Otis, et al., 1990; Hengeveld, Houtman, & Zwaan, 1988). It is premature to generalize that the current instruments designed for general cancer patient populations can adequately identify unique aspects of quality of life experienced by bone marrow transplant survivors. Quality of life of cancer patients is found in the literature however, the quality of life of the BMT survivor has been sparsely investigated. In light of this knowledge, a qualitative approach to investigate the experienced quality of life of BMT survivors is warranted. Grounded theory methodology allows the exploration in detail of the experience of bone marrow transplant surivors to capture quality of life aspects unique to this patient population.

Qualitative methodology was selected to investigate the processes involved in maintaining or enhancing quality of life following bone marrow transplantation. Knafl and Howard (1984) have identified many areas within research where qualitative methods have proven useful. Qualitative data are useful in the development of instruments, the sensitization to a particular population's point of view, to conceptualization and theory building, and to the elaboration of findings in large quantitative research projects. Previously unexplored areas of human behavior can also be addressed with qualitative research methods (Chenitz & Swanson, 1986).

Design

Grounded theory, an inductive qualitative method used to generate theory, was used to identify and describe processes involved in maintaining or enhancing quality of life in adults following BMT (Glaser & Strauss, 1967). The grounded theory method refers to theory generation from data grounded in words, phrases, or sentences (Hutchinson, 1986). The researcher uses two techniques, theoretical sampling and constant comparative analysis, to discover the social processes involved in the phenomena of interest (Glaser & Strauss, 1967). From the data bits gathered, content categories are formed and compared to determine how they relate to one another, and during analysis the categories are merged into concepts (Chenitz & Swanson, 1986).

In grounded theory, the sample is not selected from the population based on certain variables prior to the study. Theoretical sampling is based on the need to collect more data to examine the categories and to assure the representativeness of the categories (Chenitz & Swanson, 1986). Each category needs to be tested against incoming data to determine the full range of the category, this can be accomplished by the use of theoretical sampling. The researcher purposely selects subjects who will substantiate or further explore the emerging concepts in the data (Knafl & Webster, 1988). Categories emerge from comparing the content of the first interview with each subsequent subject interview. This technique, called constant comparative analysis, is combined with theoretical sampling until no new data emerges and the categories are considered saturated (Simms, 1980).

Setting and Sample

The primary setting for the collection of data was the subject's home or an alternative site selected by the subject, in southwestern Arizona. The setting was relatively free of distractions during the interview and was an environment where the subject felt comfortable. The sample included five adults who were more than 87 days and less than three years post-BMT and who were English speaking. Subjects were recruited by the Nurse Coordinator for Bone Marrow Transplantation for the Arizona Cancer Center, and were then contacted by the investigator to arrange for an interview time.

Protection of Human Subjects

This study was reviewed by the Ethical Review Committee of the College of Nursing and was approved as exempt from full University review (Appendix A). Written permission from William Dalton, MD (Physician Director of Bone Marrow Transplant Program for the Arizona Cancer Center) was obtained, and submitted to the Internal Review Board of the Arizona Cancer Center following Human Subjects approval to gain access to the subjects (Appendix B).

A subject disclaimer explaining the purpose and procedure of data collection was given to each subject in conjunction with a verbal explanation by the investigator prior to data collection (Appendix C). Subjects were advised that they could withdraw from the study at any time, and that the study would not threaten them in any way. The subjects were assured that all information would remain confidential.

Data Collection

Data collection began with selection of the first subject who met the inclusion criteria. Data were gathered using tape-recorded interviews.

The interviews were initiated with two grand tour questions: "When you think of quality of life, what is most important to you?"; and "How has your life quality changed since receiving a bone marrow transplant?". The grand tour questions provided a focus for the subject on the primary topic of interest to the researcher (Chenitz & Swanson, 1986). The purpose of these questions was to elicit information regarding each subjects' definition of quality of life and processes involved in maintaining life quality. Follow-up questions served to broaden the scope of inquiry and to obtain data about specific quality of life domains identified by the subject.

Each interview lasted approximately one hour, and verbal permission from the subject was obtained for interviews lasting much longer than one hour. In addition to tape-recording verbal data, the investigator made field notes during the interview concerning the setting and non-verbal behaviors of the subjects.

Demographic information was collected after the interview and included age, date of transplant, type of transplant, time since transplant, primary diagnosis, marital status, and chemotherapy or radiotherapy used as preconditioning for the transplant. The demographic information was written down by the investigator and was not included in the tape-recorded interview (Appendix D).

Data Analysis

Data analysis occurred simultaneously with data collection through theoretical sampling and constant comparative analysis (Chenitz & Swanson, 1986; Simms, 1980). At the completion of each interview, data were transcribed verbatim and entered onto a computer storage disc. Field notes were also transcribed and stored in a similar manner. Data were then coded, or sorted into categories according to similarity of content (Chenitz & Swanson, 1986). Using constant comparative analysis, the content of the first interview was compared with the second interview and coded either by using original content categories from the first interview or by developing new categories (Knafl & Webster, 1988). Theoretical sampling involves decisions by the researcher into purposeful selection of the next subject who might more fully define the emerging concepts (Glaser & Strauss, 1967).

Each interview was compared with previous data collected and placed into categories that were analyzed to identify processes (Chenitz & Swanson, 1986). The researcher's thoughts or impressions regarding the data were recorded as theoretical notes, and were considered in terms of coding and analyzing data. Constant comparative analysis was conducted for each interview to add data to already established categories or to identify new categories until no new data emerged or the categories were saturated (Hutchison, 1986).

Trustworthiness of the Data

Lincoln and Guba (1985) and Guba (1981) identified factors used to assess rigor or trustworthiness of the data. They are credibility, transferability, and confirmability.

With qualitative methods internal validity or credibility is determined by confidence or truth value of the data. According to Murdaugh (1989), truth value refers to the credibility of the research or confidence in the truth of the findings. Techniques used to determine truth value of the findings included discussion of the findings with peers for feedback and agreement enabled the researcher to have confidence in interpretation of the data. Another method used was called triangulation, or having multiple slices of data from a variety of sources and perceptions. "The use of field notes, observations, and documents can be used to capture the subject's true responses" (Murdaugh, 1989, p.57).

External validity was measured by transferability or whether the findings "fit" other contexts outside of the one being studied. Murdaugh (1989) stated that generalizability is increased through use of theoretical sampling because sample selection is governed by insights about what is relevant and important to the subjects. The subjects were not limited to one type of transplant or one specific pre-transplant diagnosis, and these measures increased the range of data obtained.

Confirmability was enhanced in two ways. Peers were asked to read coded data and assign categories to test for congruence or inter-rater reliability. Member checks were also done, to return data to subjects or other BMT survivors for confirmation.

Summary

Grounded theory, an inductive qualitative approach was used to identify and describe the processes involved in developing or maintaining quality of life following bone marrow transplantation. The limited research on quality of life of this specific patient population influenced the decision to use this qualitative method to elicit comprehensive, in-depth data on quality of life from the patient's perspective.

CHAPTER 4

ANALYSIS OF DATA AND PRESENTATION OF FINDINGS

In this chapter the analysis of the data is described. Categories and processes induced from the data and a description of the properties within the categories are presented.

Description of the Sample

The sample consisted of five adult BMT survivors living in Southwestern Arizona. Their ages ranged from 28 to 41; four were female, one was male. Three were married, one was single and one divorced. Time since transplant ranged from 87 to 578 days; the primary diagnosis varied (Table 1). Two individuals received an allogeneic transplant and three received an autologous transplant. All the subjects had received conventional chemotherapy for their disease prior to being considered for transplant. All subjects were

Table 1
Summary of Demographic Data

Subject	Age	Sex	Primary Diagnosis	Type of BMT	Time since BMT (days)
1	30	F	HL*a	Auto*d	114
2	33	F	CML*b	Allo*e	224
3	37	F	NHL*c	Auto	315
4	41	M	NHL	Auto	578
5	28	F	CML	Allo	87

*a Hodgkin's Lymphoma
*b Chronic Myelogenous Leukemia
*c Non-Hodgkin's Lymphoma
*d Autologous BMT
*e Allogeneic BMT

Caucasian and spoke English as their primary language. Pre-transplant conditioning varied among the group and consisted of high dose chemotherapy and/or radiation therapy (Table 2). All subjects were interviewed one time.

Coding, Analysis, and Categorization

Data analysis began with the first interview and continued through the fifth. Analysis included categorization and clustering of data bits and the description of the final process. The first subject was a 30 year-old female who underwent an autologous BMT for

Table 2
<u>Preconditioning Protocols Used Prior To Transplant</u>

Subject	Chemotherapy	Radiation
1	MCVB*a	None
2	Cytoxan	TBI*b
3	MCVB	Cons*c
4	MCVB	None
5	Cytoxan	TBI

*a Mitaxantrone, Cytoxan, VP-16, BCNU
*b Total Body Irradiation
*c Consolidated Radiation given after transplant

Hodgkin's Lymphoma. The area of inquiry as data collection began was to explore the quality of life of adult BMT survivors and describe processes involved in maintaining quality of life. These areas of inquiry were addressed with the grand tour questions. Categories which began to emerge from the data were <u>Lifestyle changes</u>, <u>Relationships with others</u>, <u>Uncertain future</u>, <u>Dependence on others</u>, and <u>Fearing complications</u>. The central process of maintaining quality of life was initially identified as coping. Initial codes from the analysis of the first interview are summarized in Table 3.

Descriptions of the content categories from the first interview included <u>Lifestyle changes</u> which comprised data bits about being out of work during the recovery phase of

Table 3

Initial Categories After Analysis of First Interview

Initial Categories
Coping
Decision to Undergo Transplant
Dependence on Others
Doing Better Than Others
Emotional Response to Treatment
Fatigue and Stamina Changes
Feeling Normal
Infections
Lifestyle Changes
Looking Ahead
Physical Changes
Reactions of Others
Reactions of Self
Relationships with Others
Returning to Work
Uncertain Future

transplant, changes in intimacy during periods of neutropenia, and limits placed on activities of daily living (unable to drive, clean house). Relationships with others included changes in relationships as a result of cancer and the transplant encompassing both strengthened and diminished relationships. Concerns about the future and the possibility of cancer recurrence were grouped as Uncertain future. The category Dependence on others comprised data bits from the hospitalization and discharge phases when physical dependence is required. Physical changes described data about side effects of chemotherapy from going through early menopause to dryness of mucosal tissues. Fatigue was identified as a limiting factor and was grouped with decreased stamina as Fatigue and stamina changes. The category Emotional responses to treatment included data regarding a variety of emotions such as crying, wide mood swings, despair, and elation.

Coping was a general category that included data regarding the subject's individual coping strategy selected. The category included internal strength, positive attitude, a strong will to live, distancing, and keeping busy. Making her decision for transplant as the choice for cure comprised Decision to undergo treatment. In the category Doing better than others, the subject viewed her progress post transplant by comparing herself to others. Infections included data regarding her past experience with infections, frequency of infections, and fears regarding them since her spleen was removed. Both positive and negative responses from friends, neighbors and strangers encompassed Reactions of others, while her own reactions specifically to physical appearance alterations (alopecia) were included in a separate category Reactions of self. Feeling normal described her feelings regarding looking more like herself, and feeling better (less tired). Returning to work were her comments regarding her desire and her ambivalence about resuming work. She equated working with stress and in the past connected very stressful times in her life to the development of cancer recurrence. The final category Looking ahead described her view of the future.

The second subject was a 33 year-old female who underwent an allogenic transplant for Chronic Myelogenous Leukemia (CML), and whose sister was the donor. This subject was selected because her type of transplant differed from the first subject. She was divorced and had two children. The second interview began with the same grand tour questions and major themes identified were financial difficulties and family stress. Data were coded and compared with the results of the first interview. Several of the original codes were reinforced as well as the formation of new content categories. Financial burdens, maintaining two households, waiting for disability to begin, and being unemployed were grouped as Financial changes. Relationships within the family were stressed especially between the subject and her donor. In addition, her children had difficulty adjusting to the transplant, and these data bits comprised the new category of Family stress. Seeking support through her mother, social workers, and a counselor encompassed Support systems. Her comments regarding values, priorities, and outlook following both the cancer experience and BMT were labelled Changes in outlook/priorities. Spirituality described her personal belief system and religious affiliation. The final category, Harder than expected, included her feelings regarding protective isolation, Hickman catheters, and being separated from her family. As with the initial interview, coping strategies emerged from the data as the major processes used to maintain or enhance quality of life.

Selection of the next subject was done by choosing a different primary diagnosis and marital status. The third subject was a 33 year-old female with Non-Hodgkin's Lymphoma who underwent an autologous BMT. She was single, had no children, and was 224 days post transplant at the time of the interview. Central themes from the interview included frustrations with both waiting for the transplant, problems with control, and anger at being readmitted during the recovery phase for an infection.

Analysis of the third interview added several new categories to the data base and when compared with the other interviews resulted in recoding of data. Lifestyle changes was renamed Tolerating lifestyle changes, and included four subcategories Limitations on ADL's, Role changes, Dependence on others, and Financial changes. Fatigue and stamina changes were included under Limitations on ADL's. Relationships with others was separated into Supportive, Stressful, and Diminished relationships and Family stress was included under Stressful relationships. The categories of Uncertain future, fearing complications, and anticipating problems became Living with uncertainty. Physical changes became Physical complications and was placed as a subcategory under Managing setbacks. Emotional response to treatment was renamed Allowing emotional responses. Infections were included in Physical complications while Reactions of self was renamed Physical appearance changes. Feeling more normal was changed to Rediscovering self, and Returning to work became Resuming activities.

Using constant comparative analysis and coding for the third interview several new categories emerged. Managing setbacks encompassed the subject's physical complications with treatment, returning to the hospital to treat complications, and dealing with aspects of the transplant that she found personally difficult. Role changes included sick role, lack of work role, and role reversals secondary to dependence or limitations. Seeking information was formed and included preparation for the transplant, asking questions, and reading printed material. Managing delays referred to frustrations with schedule changes, waiting for a confirming diagnosis prior to transplant, and the general time lapse from diagnosis to transplant being constantly extended. The category Tolerating testing described the subject's feelings on the numerous preparatory tests and when testing didn't go well (failure to get central catheter to work for stem cell collection). Fearing recurrence was identified as a separate category from Living with uncertainty. The subject described her fears of cancer recurrence after treatment with BMT, and concerns over treatment options still available to her, and these concerns were of a greater significance than the everyday uncertainty surrounding the transplant experience.

At this point, coded data sheets from the first three interviews were distributed to raters who were asked to provide categories for the data; a measure of inter-rater reliability. One of the raters was knowledgeable regarding BMT, and the other rater worked outside the area of oncology. The raters experienced difficulty coding for the category of Coping, and thought that it included too many different ways of coping. Coping was delineated into separate categories. These categories were Seeking information, Distancing, Facing reality, Searching for control, Denial, Seeking support, Spirituality, Allowing emotional responses, Setting goals, Maintaining a positive attitude, and Doing better than others.

The category Distancing refers to activities subjects employ to take their mind off the transplant or physically distancing themselves from others as a means of coping. Facing reality occurs after the decision for transplant has been made and is underway with the tremendous realization that death is a possibility. The third subject's feelings of lack of control or efforts made to maintain control comprise *Searching for control*. *Denial* incorporates feeling of not being sick or reluctance to discuss what is happening to them. Short and long term accomplishments used to cope with transplant were coded as *Setting goals*.

The subject for the fourth interview was a 41 year-old male who was nearly two years post autologous transplant for Non-Hodgkin Lymphoma. This subject was selected to explore both the male perspective of transplant and the long-term adjustment following transplant. The theme of the fourth interview was that strong relationships with family and friends, and job security were indicators for good quality of life. Treatment-related late effects identified included hearing loss and decreased lung capacity related to earlier treatment of the lymphoma. Fear of recurrence was another theme that did not dissipate over time since transplant.

New categories emerging from the data included *Better than expected* which described aspects of treatment that were a pleasant surprise. The subject discussed his surprise at the lack of actual physical pain, the use of Hickman catheters for administration of fluids and medications, and the lack of serious illness (colds, flu) since transplant. *Accepting losses* comprised the treatment related late effects discussed in the interview. Overall, the subject reported his quality of life as good, especially in the area of changed outlook and priorities.

The fifth subject was selected by type of transplant, which was allogeneic, whereby her brother donated marrow. She was a 28 year-old female, married with no children, and diagnosed with CML. Only four months elapsed between diagnosis and transplant. The theme of the interview surrounded her disappointment with relationships that were not supportive, especially from family members. She worried more about support for her husband, and also identified financial strains. The fifth interview contributed to the richness of the data categories but offered no new categories after analysis.

The method of analysis from all five interviews produced the following changes. Managing setbacks was established to encompass the subcategories of Physical complications and Returning to the hospital. Physical appearance changes were divided into Personal response and Reaction of others. Concerns about discrimination was separated from Resuming activities and became one category. Defining quality of life emerged as the personal descriptions of the subjects regarding quality of life and important aspects of life quality.

Recoding

As part of the analysis, data were shared with peers and member checks were accomplished to refine the process. Throughout data collection the process of COPING emerged as the means of maintaining or enhancing quality of life following bone marrow transplantation. When coping was proposed to subjects as a process they agreed, but added that different ways of coping were required at different times throughout the process of recovery. Reexamination of the data bits comprising Coping resulted in identification of NAVIGATING SURVIVAL as the process of coping with changes required of BMT survivors as they sail through unchartered waters in their quest for quality of life.

The reorganization of the data identified three stages where quality of life is disrupted in the transplant process and distinct coping tasks are required to maintain or enhance quality of life. The three stages were named Deciding for Life, Waiting for signs of success, and Reconstructing normalcy. The surviving concepts and categories of the process NAVIGATING SURVIVAL are presented in Table 4.

The first stage where quality of life is disrupted is called Deciding for Life, and factors that impact quality of life during this time are Rushing to Treatment, Tolerating

Table 4
Final Categories Resulting From Data Analysis

Quality of Life Alterations	Processes Used to Maintain or Improve Quality of Life
Better Than Expected	Accepting Losses
Concerns About Discrimination	Allowing Emotional Responses
Deciding For Life	Changing Outlook
Fearing Recurrence	Defining Quality of Life
Lifestyle Changes	Denial
Living With Uncertainty	Distancing
Physical Appearance Changes	Doing Better Than Others
Managing Delays	Facing Reality
Rediscovering Self	Keeping Busy
Relationship with Others	Looking Ahead
Resuming Activities	Positive Attitude
Role Change	Searching for Control
Tolerating Treatment	Seeking Information
	Seeking Support
	Setting Goals
	Spirituality

treatments, Managing delays, and Revising Expectations. This period extends from a few days to a few weeks where the subject is dealing with diagnosis, and there is a rush to begin transplant. Coping during this time falls into the concept of Adapting to transplant and subjects use many

Table 5
Concepts and Processes for Stage One of Navigating Survival

CONCEPT	PROCESS
Deciding For Life	Adapting to Transplant
-Rushing to Treatment	-Seeking Information
-Tolerating Treatment	-Distancing
-Managing Delays	-Facing Reality
-Revising Expectations	-Keeping Busy
	-Searching for Control
	-Denial

coping mechanisms including *Seeking information*, *Distancing*, *Facing reality*, *Keeping busy*, *Searching for control*, and *Denial* (Table 5).

The second stage of NAVIGATING SURVIVAL called *Waiting for signs of success*, can hamper quality of life as many limitations are imposed, physical complications must be managed, and uncertainty pervades. *Waiting for signs of success* involves *Tolerating lifestyle changes*, *Managing setbacks*, *Altered relationships with others*, *Physical appearance changes*, and *Living with uncertainty*. Tolerating lifestyle changes includes subcategories of *limitations on ADL's*, *role changes*, *depending on others*, and *financial changes*. The category of *Managing setbacks* includes *physical complications*, and *returning to the hospital* *Altered relationships with others* incorporates *supportive*, *stressful*, and *diminished relationships*. *Physical appearance changes* includes *personal response* and

Table 6
Concepts and Processes for Stage Two of Navigating Survival

CONCEPT	PROCESS
Waiting for Success	*Searching for Meaning*
-Lifestyle Changes	-Seeking Support
Limitations	-Spirituality
Role Changes	-Allowing Emotions
Dependence on Others	-Setting Goals
Financial Changes	-Positive Attitude
-Managing Setbacks	-Doing Better Than Others
Physical Changes	
Returning to Hospital	
-Relationships with Others	
Supportive	
Stressful	
Diminished	
-Physical Appearance Changes	
Personal Response	
Reactions of Others	
-Living with Uncertainty	

reactions of others. During this time the patient has been discharged from the hospital and navigates survival by *Searching for meaning*. This includes the mechanisms of *Seeking support*, *Spirituality*, *Allowing emotional response*, *Setting goals*, *Maintaining a positive attitude*, and *Doing better than others* (Table 6).

The third stage, *Reconstructing normalcy*, impacts quality of life as the individual returns to work or resumes activities of daily living. *Resuming activities*, *Rediscovering self*, *Fearing Recurrence*, and *Concerns about discrimination* are included in this concept. *Discovering a difference* reflects the coping processes used to improve or maintain quality of life. It includes _Changing outlook/priorities_, _Accepting Losses_, _Looking ahead_, and _Defining quality of life_ (Table 7).

Table 7
Concepts and Processes of Stage Three of Navigating Survival

CONCEPT	PROCESS
Reconstructing Normalcy	Discovering a Difference
-Resuming Activities	-Changing Outlook/Priorities
-Rediscovering Self	-Accepting Losses
-Fearing Recurrence	-Looking Ahead
-Concern of Discrimination	-Defining Quality of Life

A final recheck of the original topics identified after the first few interviews showed a great deal of reshuffling of content categories. The data bits from the fourth and fifth interviews contributed to the richness of the selected categories, but added very few new categories. The model showing the relationship of the concepts and categories of the NAVIGATING SURVIVAL process is depicted in Figure 1. Selected examples of categories with specific data bits are listed in Appendix E. The next section further clarifies the content and properties of the process of NAVIGATING SURVIVAL.

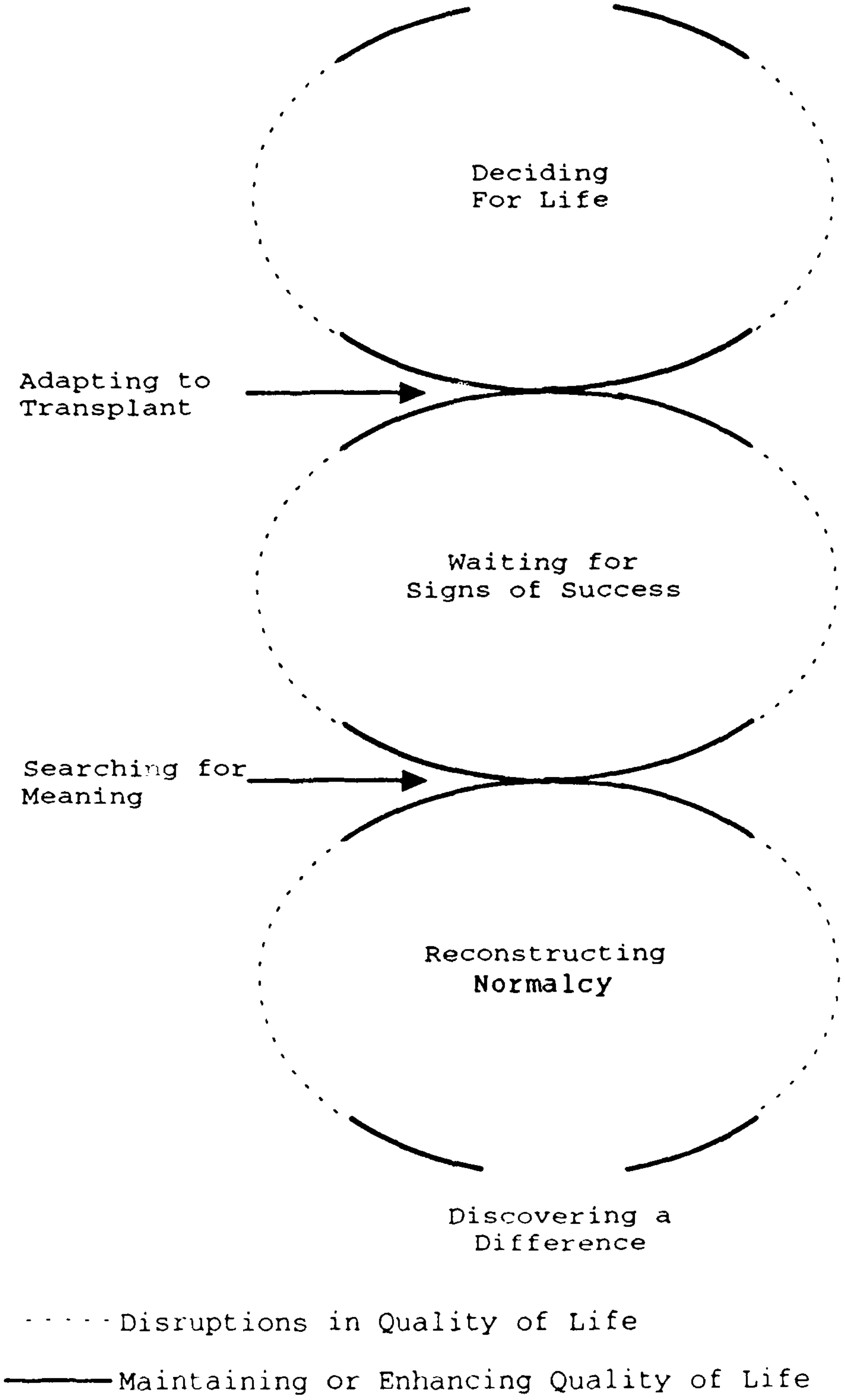

Figure 1: Relationship among the concepts of Navigating Survival ·

Navigating Survival as a Process

The analysis of the data generated the phenomenon of NAVIGATING SURVIVAL. This is a process of describing how adult BMT survivors maintain or enhance quality of life during stages of bone marrow transplantation and subsequent recovery. The process begins at the time of choosing transplant as a treatment option and continues through hospitalization, recovery of the immune system, and resuming activities such as work. Survivors of BMT experience numerous disruptions in quality of life at different stages in the transplant process, and must use individual coping styles to navigate survival and maintain quality of life.

Major Concepts of Navigating Survival

Three major concepts emerged as the stages of NAVIGATING SURVIVAL in addition to coping tasks identified for each stage. The three concepts are Deciding for Life, Waiting for signs of success, and Reconstructing normalcy. Each BMT survivor has to use coping mechanisms in each stage. The coping tasks identified are Adapting to transplant, Searching for meaning, and Discovering a difference.

DECIDING FOR LIFE

This marks initial consideration of BMT as a treatment option, when the patient is confronting numerous tests and overwhelming information on the transplant process in a very short period of time. This concept includes four categories: Rushing to treatment, Tolerating treatments, Managing delays, and Revising expectations.

Rushing to treatment: The individual has to deal with both cancer recurrence and transplant as an option for cure. For most patients there is a feeling of urgency to undergo transplant rapidly, once the decision has been made.

> Before the transplant I went through a lot of vacillating back and forth whether I even was gonna do it. Because I, you know, I did have a choice to not do it. The doctors assured me that I ... what they told me is if I had the transplant I had a 30 percent chance of being cured, but if I didn't have the transplant, there was 100 percent chance that the cancer's gonna come back again. (A:32)

> I didn't really feel like I could say to them, 'no, we're not going to do it this way, we're gonna do it that way.' Because I had been told that we've got this window of opportunity and it's better for you the sooner we get all this stuff done. (C:99)

> and they did all their testing in two days, and then at the end of the two days we had our little conference with the doctors and I was more or less given my options as far as they saw them. (D:30)

Tolerating treatment: The preparation for transplant involves numerous diagnostic and preparatory tests. Insertion of Hickman catheters, and preparatory chemotherapy and radiation therapy can be painful and/or frightening.

> That was something that was kind of a hard thing to go through, too, because they, phoresed me two times, in two weeks, two different weeks. That was something that was pretty discouraging because they had a lot of trouble with the catheters that they put into my shoulder, and they had to remove 'em, and the first time the one got infected, the second time they had trouble putting it in, it only worked the one time, they had to take it out, they had to put it back in again, they had various problems getting it in, and that was...to me, that was probably one of the hardest parts of the whole transplant. (D:28)

> I think as far as treatments and things, the Radiation treatments, those were real scary for me. And having to just lay there, and the last one, I was just, oh, thank goodness, it was just a, a wonderful feeling that this is the last one. 'Cause I, I was really worried about what is this doing to my body, the rest of me, and I know it's killing everything in my body, but, to what extent, I mean, are my brain cells going with this, (E:31)

Managing delays: Once the decision to undergo transplant has been made, delays are met with anger and frustration. Patients worry that a delay might affect the success of the transplant.

> for me what was happening was that the time table kept changing and the equation kept changing, and what they had to do kept changing, and it was really frustrating because it seemed like nobody really knew what was going on and that's why they were changing everything all the

time. And that was frustrating for me. (C:84)

> When they decided that they needed a confirming diagnosis that nobody had mentioned before, I wanted to know why is this needed, you know, why are things changing. (C:97)

Revising expectations: The stresses of the pre-transplant and early hospitalization period can be relieved by having aspects of the procedure go better than anticipated. In contrast, the patient may also experience stress when elements of the transplant are more difficult that expected.

-Better Than Expected:

> the physical part of it was not, except having Hickman's, that was pretty awful. But the physical part of it was, was ok. You know, I mean it wasn't anything unbearable. (B:61)

> I remember thinking at the time after the first one of being terrified of the thought of the radiation treatment, that this wasn't so bad, it wasn't like Chemo. (C:17)

> I was surprised at the lack of actual physical pain. I thought that I would be more uncomfortable from a pain standpoint than I was, even though there's some discomfort, but it's more the way they put it, you feel crummy, rather than feel pain. (D:53)

-Harder Than Expected:

> The hardest part was, I don't know why it was so hard, but just getting through day to day in that room. (B:63)

> You know, family or, or emotional, just dealing with all of it. 'Cause I'm single, I'm divorced, and so, things are left up to me. (B:14)

Adapting to the transplant: The coping process required in the first stage to maintain quality of life is adaptation. This represents the first hurdle in NAVIGATING SURVIVAL. A variety of coping mechanisms are used by BMT survivors to establish balance during this period. Categories identified in this stage are Seeking information, Distancing, Facing reality, Keeping busy, Searching for control, and Denial.

Seeking information: Concrete information on the complex transplant procedure including risks, benefits, and side effects can relieve stress and assist with understanding and comprehension of the treatment.

> Try to get information. And to intellectually find out what's going on, and what they're going to do about it, and what the course should be, and if it works, and stuff like that. Just deal with it very intellectually. (C:52)

> I was amazed that everybody was more than willing to sit down and explain things in as much detail as I needed to know to satisfy me as far as what I had and what treatment I was going to go through and what to expect from those treatments. (D:16)

Distancing: This coping style is used to remove oneself from the transplant situation either physically or mentally until such a time as the individual is ready and prepared to deal with it.

> Sometimes I think that, those kinds of things that my mind does, it helps me. I think if I'd have been thinking about how sick I was and, worrying, stuff like that, I don't think I'd have done as well. (A:42)

> But most of it wasn't to do with Cancer. Most of the reading material I had was, oh, just novels, and biography type things. Stuff that took, that took me totally away from it, so you could be absorbed in the book or magazine or article and just completely forget about it. And to me I found that easier than going and checking out all the books on cancer and everything to try to find out what I wanted to know. (D:13)

> When I was in the hospital I would have a hard time telling my wife how I felt. And talking about me and my predicament. I mean, I would rather, when she called I would much rather talk to her about how she was doing, how, we have a granddaughter, I mean I would focus on other things rather than focus on me and how I felt that day, (D:18)

> So...just have to deal with right now, being by myself, or trying not to think about me. (E:06)

Facing reality: BMT is a life threatening treatment modality, and often after the transplant is underway patients reflect on how close to death they were and what might have happened.

> But, when they say cancer in the past, and this time my, my brain sort of shuts down as far as realizing how sick I am and just concentrating on getting well. And it's sort of, just after a time that those kind of thoughts come back, and you think about, oh, wow, you know, I almost died, and it's really scary. (A:43)

> So I wasn't really too hot on going down there because there's...you don't want to face the reality, I didn't want to face the reality that it was, it had already come back twice, there was a real good chance I was gonna have it again. My doctor told me that. And I was kind of down on going down there. (D:08)

Keeping busy: Activity assists in coping with the long periods of isolation and during the recovery phase. Often patients have diminished endurance and shortened attention span which makes activities difficult.

> I've been having friends come to me, 'cause I don't feel comfortable going out. So maybe once a week or so, like tonight I'm having two girlfriends come over for dinner. I talk on the phone a lot. (A:54)

> I had taken down some sewing projects, and some reading, and some tapes, and all that kind of stuff. (B:65)

> I never would have said I watch soaps before this, but, with plenty of time on my hands, it fills the void. And, then I might take a nap, or write letters, or do some reading, 'cause I really enjoy reading, and maybe take a walk, which is very rare, lately anyway, and also the stairmaster, I do hop on that once in a while, (E:82)

Searching for control: Control is often relinquished by the BMT patient as initial treatment phases are very structured, and independence is severely curtailed. Individuals can gain control in some areas to assist with coping.

> I was gonna shave my head the second time rather than watching my hair fall out. Which the doctor didn't understand, and I said, 'I won't watch it come out again.' That, that hurt too much, I will not watch it (C:71)

> I had taken charge and said, 'no, I'm gonna have some control over what happens. I may not be able to control when it happens, but...' (C:76)

> the control really, I don't think I had any control. I really didn't feel that I had any control. But I wanted to understand what was happening. And why

things were changing. (C:98)

Denial: Some patients experience denial during the decision making process or during aspects of the treatment that they find especially frightening.

> while at the same time telling myself that they don't seem to be overly worried about it, so you know, hopefully it'll be a brief time like I'm being told. (C:53)

> But after the second one they told me that they had me in remission again and that they wanted me to talk to the people here. At that time I thought it was kind of silly to do because here I'd just been told that I was clear again. (D:06)

WAITING FOR SIGNS OF SUCCESS

The second stage of NAVIGATING SURVIVAL occurs after the transplant as the patient waits for the immune system to respond to the treatment. This continues after discharge, and this period is punctuated by many actual and potential complications, and limitations are imposed on activities and relationships. The major concepts of this stage include Tolerating lifestyle changes, Managing setbacks, Altered relationships with others, Physical appearance changes, and Living with uncertainty.

Tolerating lifestyle changes: The early phase of BMT recovery involves many alterations in lifestyle including limitations on activities of daily living secondary to fatigue or neutropenia imposed limits; role changes as work role is relinquished; dependence on others for everyday tasks like driving or housecleaning; and financial changes as work ceases and in many cases a temporary household must be established near the treatment site for several months. Data bits reflective of the lifestyle changes experienced by BMT survivors which impact quality of life include:

-Limitations in activities of daily living:

> well this is going to sound silly, but I can't clean up my house. It really bugs me. 'Cause, that was one of the things in the discharge book it just said not to do...not that my house was always clean before I got sick, but I could do it when I felt like it. (A:84)

> And physically I'm just, I'm not able to do like I used to do. I used to be an old work horse. And it's just, I can't do like I used to. (B:28)

> The early part when I was still restricted to not being around very many people there was not a lot of incentive to be out of the house (C:24)

> When I first came home from the transplant, I was pretty weak, I wasn't really doing a whole lot of anything. Just lounging around here, doing what I felt like doing, and take care of whatever I felt like taking care of. (D:44)

-Role changes

> And like in my family unit as well, it was like I've always been the nucleus, the strong person, and, so it's been real hard on everybody around me, too, because, you know, I've been weakened. (B:15)

> my husband is legally blind. And it was very difficult for me to get sick, because I've, I mean not

that I feel like I'm taking care of him, but certainly we share each other's, um, whenever there's a problem we help each other out. (E:10)

-Depending on others

> But I really needed her, and she was there. So I guess the different part about it would be the physical dependence. I really physically depended on her in the hospital. She helped me shower, she, helped me to go to the bathroom, she helped me clean up, anything you can think of that physically you do, she was there to help me with it. So that was, that was the big change. (A:12)

> I do appreciate when people are concerned, they want to care for me. But I'm a real independent person. And, this, this being cooped up and having someone wait on me just really bothers me. (E:91)

-Financial changes

> finances are, it's, the word is devastating. (B:05)

> Like when we lived down here, I had to pay to live down here, plus I had to keep my other residence going, and I wasn't working. (B:07)

> I felt pinched, but I was receiving a disability income from the office, which was not as much as my paycheck, but it was enough to pay my expenses. So, the summer before I had a big problem, but this year, I mean, this last year wasn't that bad. (C:117)

> It was tough for us, but it's a little bit easier to face when you know you're not going to be missing your paycheck and, even though you're running up these outrageous doctor bills and hospital bills, that you do still have something coming in, plus your medical plan and hospitalization plan that will help you pay for them. So, you know, that, that made me feel a lot better about it. (D:50)

Managing setbacks: Numerous physical complications can confront the BMT survivor during this phase of waiting, and sometimes a second hospital stay is needed. Setbacks are closely followed by both anger and fear, and some survivors have difficulty managing certain aspects of the transplant. Areas comprising Managing setbacks include Physical complications and Returning to the hospital.

-Physical complications:

> Since I've been out of the hospital, the worst thing that I can think of is I'm going through menopause, the doctor thinks I'm going through menopause. I've been having the hot flashes, those are real uncomfortable, very very uncomfortable. (A:16)

> I had the host versus graft, and it's just real stinky to get through it. (B:53)

> I still had shaking spasms, which I had had in the hospital, and they tell me that's when the drugs were hitting me. It was upsetting to me, because I thought I'm not on those drugs anymore, why am I still shaking like this periodically. (C:13)

> I mean it probably sounds like a small thing to a lot of people, but, when you've had all this done for you and everything, and you haven't had to worry necessarily about eating, now all of a sudden you know you've got to eat because you need the nourishment, and you're, it's like your body's turning on you, so to speak. (D:23)

-Returning to hospital:

> I was really upset. 'Cause I had told them on the phone the night before that I don't want to be back in the hospital, I'm not interested in being back in the hospital. (C:45)

> Fear. And anger, frustration. Um, which is a form of anger. I think it was just, that I was so tired of being in that one room. And so looking forward to never having to be in the hospital again (C:48)

> I knew that, from the discharge book that I'd been given, that the possibility was maybe not excellent but at least good that I'd spend some more time in a hospital during the first year. I didn't really think it was going to be that fast, and I didn't really think it was gonna be me, anyway. Because I had been doing so well. (C:54)

Altered relationships with others: The cancer experience and undergoing BMT alters relationships. Some grow stronger through mutual support, others are stressed by the crisis, and some diminish due to absences at work or fears regarding cancer. Data bits for this category fell into three areas:

-Supportive:

> The relationship with my family has changed. I think I actually am relating better with my husband. We were newlyweds to begin with, so this sort of punched us right into crisis, so that I think that we communicate better. (A:05)

> We have a pretty good rapport about the whole thing, we've talked about about it a lot, we discussed everything, obviously, that went on and was going to go on. She will remind me a lot of times of different things that I had or problems that I had, or, or anything like this. (D:24)

> There's certain people that I feel I've grown maybe a little closer to that I considered friends before, but I feel better about their friendship now because maybe they came down to see me, or, they stayed in contact with me (D:31)

> I think especially after this, my brother (donor) and I are really...seem to be closer. And, I mean it, he really sacrificed. He gave up beer for a whole month, he lost a lot of weight, and then he also had to take finals the week after he donated. He really had to sacrifice, and to go through something like that and then have to take finals, I just, I really thanked him for, and I continue to thank him. (E:107)

-Stressful:

> It was real hard on my kids. Their school grades went way down and their behavior changed. Even though, you know, we talked it over with them and stuff, it's still scary to kids. (B:25)

> I focus a lot on anger at my husband's brother right now. I mean, not directly, I've talked with his wife. I let her know that this is not right, that he has not really contacted my husband. It's strange, because I don't care if he would contact me or not, it's his brother that needs him. (E:14)

-Diminished:

> Other people who were friends, like just at work, those have obviously drifted a little bit. I wouldn't say the friendships are gone, it's just that they're work friendships, and I'm not at work. I'm not there to nurture them or anything. (A:57)

> there are others who still try to maintain a friendship, but it's real difficult, and they don't understand. So it's like, the relationships with my friends have changed. (B:80)

> And, see, that's the problem with some of these people that I thought would come through. And they haven't. I mean, in the beginning, 'oh, no problem, any time you need a ride. We're gonna come down and visit all the time,' you know, no problem. You know, there's something that's just not happening. And I've decided that's just the way people are, sometimes they can't just, they can't cope with this. (E:109)

Physical appearance changes: Altered appearance directly affects self image and is very distressing to the BMT survivor. Alopecia, weight gain, and facial hair growth on women are among the changes these patients experience. The physical appearance alterations affect the way in which these patients relate to others and can provoke reactions from others. Personal response and Reactions of others encompass this category.

-Personal response:

> this is the first time I lost my hair. And it was very, very very very upsetting. (A:69)

> 'Cause I, I saw somebody in the mirror who wasn't me. (A:73)

> It looked strange, and it didn't look, and still when I look in the mirror, I don't even see who I'm looking at, it's such a shock. When I look in the mirror, just 'cause of how my face looks now just everything is physically different. (B:109)

> My physical appearance changed radically with my first course of Chemo, because I was taking Prednisone, and because my hair fell out. And the combination to me was devastating. (C:60)

> One thing that really bothered me is that I gained a lot of weight. I gained around 50 pounds. Which, to me, bothered me a lot then, and still bothers me, but I haven't really been able to take it off, (D:26)

> when I go past a mirror at this point and I don't have anything on I look at myself and I think, oh gosh, this is awful...I don't feel sexy, that's one thing I don't feel. (E:64)

-Reactions of others:

> little kids look at me, they're real curious. But I'll usually talk to them, I usually say 'do you want to ask me why I have this thing on my head?' And they'll say 'yeah,' you know, 'cause they're curious. (A:67)

> It upset my daughter. Even though I'd told her that I wouldn't have any hair, still when you see somebody like that, I mean, I looked like Mr. Clean, all I needed was a little gold earring. It upset my son, but he holds all that in. (B:108)

Living with uncertainty: The transplantation process is filled with uncertainty as patients wait for recovery of the immune system. Problems are both feared and anticipated, as well as personal doubt about the success of the transplant.

> And that's something else that's changed, is it puts little fear in you, what can happen. What can go wrong next. It almost makes me, I don't know about other people, but you have a little fatalism in your, your outlook. Is that the right word, fatalism? You know, you're not so, not quite so optimistic and worry about things that can go wrong. (B:10)

> And I'm still really freaked out scared to like go into crowds, and stuff like that, I'm like absolutely sure I'm gonna die. 'Cause somebody's gonna cough on me or sneeze on me and I'm gonna get the flu and have to go back to the hospital. So, those are things that are really different since I've been sick. (A:08)

> She was probably scared, and I was just annoyed. but I was scared, too, because I didn't know whether this was going to go into something else, and staph infection, for somebody who doesn't know much about medicine, it sounds pretty scary. So, it was, it was both scary and annoying. (C:51)

> and you know it gets to kind of be a drag just telling everybody that, 'oh, I feel fine, I'm doing ok.' You know, 'everything's going ok.' When in reality you don't know whether it is or not. They tell you it is, and there's no tendency to lie to you in those circumstances, which I appreciated. (D:19)

Searching for meaning: The second coping task in NAVIGATING SURVIVAL involves the personal meaning of the cancer experience and includes activities to bring meaning into everyday life. Searching for meaning includes the categories of Seeking support, Spirituality, Allowing emotional responses, Setting goals, Maintaining a positive attitude, and Doing better than others.

Seeking support: Support systems are used in many ways by BMT survivors. Talking with family members, relying on social workers, seeing an individual counselor or attending support groups have been reported as beneficial by BMT survivors.

> the social worker at the U of A, she was a real big help in a lot of things. (B:23)

> I thought I'd see a counselor, I started to see a counselor, it's a lady I used to see before. I prefer that to group stuff, because it's hard for me to be in a group setting counseling. (B:82)

> I think in retrospect that would have been more helpful if somebody had said there are people you can talk to who've gone through this, if you'd like to know that, but maybe I didn't give them a chance to. So it's hard to say whether that would have happened if I hadn't said anything. (C:95)

> We have an outpatient group that we meet with every Thursday, and there's about six, and of course, ever growing because more people are being discharged, and that is a very, very, good thing for me to attend, and to hear what other people are going through and similar experiences, and actually talking to people who can really understand, and have been there, and maybe they've got different perspectives on what they've gone through, but at least there's a strand of similarity between us in some ways. And that's really been very helpful for me, (E:77)

Spirituality: A personal belief system or religious affiliation has been cited by survivors as helpful in the management of uncertainty.

> when I was in the hospital, what got me through

day by day, 'cause that was so horrible, was a lot of prayer. (B:49)

> prayer has really helped me, too. And I feel like there, there are challenges that are being, not maybe thrown at me, but, or I'm being faced with challenges that, that are to strengthen me in some way. And are given to me for a certain reason because I can, I can handle these challenges. (E:74)

Allowing emotional responses: Often patients feel they have no control over the emotional response to treatment which can vary greatly. By giving themselves permission to experience emotional responses as a normal part of the recovery phase can contribute to their recovery.

> but the other thing is that there doesn't seem to be any in-between. It's like I'm either way up here or I'm despairing. So, that's really hard. (A:28)

> I just, I cry a lot. Not so much, but it's easy to cry, you know. (B:29)

> sometimes I get depressed. 'Cause I think about myself too much, you know. So I get depressed and I think, well, I don't know why I'm alive. You know, this is crazy, I'm thinking about myself, maybe I should go in the bathtub and cut my wrists and I wouldn't get everything messy, but then I go, well, that's crazy because here I've been given a second chance, and that would be a waste. (E:05)

> although I'm physically ok, emotionally I've been struck heavily. I've really never felt this emotional about anything like this before. I mean, I really get upset over certain things that I probably would have just said, oh, well...but things really bother me now. (E:79)

Setting goals: Small goals which can be set and then met can increase self-esteem and help to measure progress. While in the hospital goals are often set such as when discharge will take place, or after discharged when the patient will return to work.

> so it wasn't as horrible as I thought it was going to be, but then on the other hand it was worse. Because I'm a very impatient person, ... my sole goal, I was, it was like blinders, the only thing I wanted to do was get out of there. (A:41)

> In the hospital, I'd think I'll be out of here by Christmas, I'd say to myself, by Christmas I'll be home, and everything will be more normal. (B:92)

> Now I look at things in terms of working towards getting better to go back to work. I really miss working. And so, that's kind of like how I'm measuring things now. (B:93)

Maintaining a positive attitude: Mental preparation for the transplant begins at decision but frequent setbacks and physical limitations make this difficult to sustain during the recovery phase. Being optimistic, having a strong will to live, and demonstrating internal strength contribute to maintaining a positive attitude during this time.

> I do have a very strong will to live. I mean, I've made it this far, and I, I do want to live. Very much. And I have, you know, more extra reason because of my husband now, I really, I want to grow old with him. (A:35)

> I had to live, because I have children, and I have responsibilities, you know, I mean, you can, things become so much clearer. (B:36)

> I think to start with, I'm a strong person physically and I think emotionally, too, and I think that has been a big factor in carrying me through it. (B:59)

> it doesn't upset me, I mean it does, it upsets me when certain things don't go the way they are supposed to. But, I gotta think about it awhile, and I say, well, there's a reason why this is happening. And we'll get through it. It's not the end of the world, type thing, you know. (E:75)

Doing better than others: BMT survivors monitor their progress by comparison with others, especially those with the same primary diagnosis. Comparisons are made regarding side effects experienced, rate of hair regrowth, and time spent in the hospital.

> Oh, yeah, from what I understand, I'm really fortunate, I mean that my transplant has gone so well in that, you know, with the autologous you shouldn't have to worry about graft versus host disease, or any of that. (A:37)

> The other patients that I did get to meet in the hospital, they had leukemia, but they had the other kind. What's the other, not autologous, but... Allogeneic. They had allogeneic. And they were having problems. They had to take other medicines and everything, which I was really glad I didn't have to go through that. (A:38)

> you know the commercial with, the McDonalds kids, the, I guess his name is Mike Stool. He's got Down's Syndrome, and he works at McDonalds' McJob program. And...I cry every time I see that commercial, 'cause I think, they're people struggling more than I am, and I shouldn't be thinking about myself as much as I do. (E:76)

RECONSTRUCTING NORMALCY

This is the third phase in NAVIGATING SURVIVAL and occurs after 100 days when the acute complications are no longer a threat, patients are feeling better, and side effects of treatment (alopecia) are resolving. Increased independence is obtained and patients face the task of going back to work. Areas where quality of life is affected include Resuming activities, Rediscovering self, Fearing recurrence, and Concerns about discrimination.

Resuming activities: Work is resumed during this time and tasks previously limited can begin. Patients are no longer neutropenic and therefore not required to wear a mask. There is some ambivalence expressed about returning to work if their job was viewed as stressful.

> Yeah, well, I real ambivalent about that too. I work in television, and it's a very high stress job, one that, it's, it's prestigious, but it's stressful. I was having a hard time with it before I got sick, and now, like I can take my time, I don't have to go back. (A:86)

> I know that there's really no proven link between stress and cancer, but it seems like whenever I've had a major stressful time in my work, closely following that I've had my recurrence with cancer. (A:88)

> In fact, I was supposed to go back to work full time on September first, originally, I mean, that's, that sort of what we had planned all along, and I decided I wanted to go on some kind of a vacation before I did that. (C:28)

> It was pretty trying to get back in to a regimented lifestyle where you have to get up at a certain time, where when I stayed home, I would get up when I felt like getting up, around 8:30 in the morning. But to know you were going to get up early and then go to work and then be there all day and then come home, when I'd get home the first few months that I went back to work, I would just come home and go right to sleep, I mean, I'd sleep a couple of hours and eat dinner and watch TV for a little while, then go to bed. It was pretty rough. (D:48)

> So, I'm really happy I've got a job waiting for me, whether I'm mentally ready for it or not, that's another question. (E:105)

Rediscovering self: This is an especially uplifting time for the transplant survivor as their physical appearance begins to return to normal. Hair growth, weight loss, and swelling resolve. Applying makeup was cited as an activity that made patients feel healthy again.

> I put some makeup on the other day and it looked more like me. I could see me in my face more. (A:81)

> My hair started growing back, that was a big thing...to not be bald. (B:104)

> The most obvious change for me is that I feel well now, for the first time since before I was originally diagnosed. That didn't happen immediately after the transplant, it took a while. (C:01)

> looking at myself in the mirror as my hair started to grow out, feeling more like me and less like somebody I never recognized. (C:101)

Fearing recurrence: Fears about recurrence are especially prevalent during this time as things seem to be improving. One common fear stems from the realization that BMT is an aggressive option and if the cancer should recur, options for treatment may be limited or non-existent.

> I'm afraid of...I try not to be. But every once in a while, you know how, sometimes your defenses are down. Sometimes I am actually afraid that I won't be able to get a good job, and I don't want to get bone cancer again. It's not like I go around worrying, you know, what disease am I gonna get...but like I say, every once in a while you have weak moments, and that

> does make me angry to think that you do everything you can, and then if you come down with it again...that's rotten. A raw deal. (B:96)

> So, it's real scary because I can expect it again and I don't know if they can pull me through it again, if I can pull me through again. (A:30)

> My original plan when I got out of the hospital last year was that I was going to leave this spring, after it had been a year. Before it got hot. But somebody else that they had introduced me to, who had Non-Hodgkins lymphoma had gone through transplant the previous July recurred last August. And that frightened me a lot. (C:103)

> And at first I was a little worried because of the type of transplant they did on me. I wasn't real sure that, I mean, if you stop and try to reason it out yourself, I'm no medical person, but to me, taking your stem cells out of your body and then giving them back to you doesn't seem like there's a real good chance that you're going to be here way down the road. I mean, in my way of looking at it, that's pretty shaky thing. It's not as sure as taking a healthy person's bone marrow and giving it to you. You're taking a real small thing there, and even though you're taking a lot of them, you're trying to build somebody completely back up from that. And, at times I'm really amazed. (D:62)

<u>Concerns about discrimination</u>: As transplant patients return to work or seek employment, discrimination is a tremendous fear. In addition, problems obtaining insurance coverage are a reality following transplant.

> I worry that because I've had cancer, employers will, you know, back off from that person, and they do that, even though they say they can't, 'cause it's discrimination. You can always find a reason if you don't want to hire somebody. (B:115)

> I'm staying at the job that I've got now, and I'm, as long as they'll keep me, and concerned about my insurance benefits, which is part of the reason for staying there. (C:105)

> Because I it's very difficult to get insurance now. I've talked to these other gals, and, and no one wants to insure you, if you've had any kind of cancer. I've heard about the problems with job hunting. Jobs...if they've got any kind of idea that you had cancer of any kind, they think this person get sick a lot, or, this person, you know, is gonna die on me, or who knows what they think... (E:104)

Discovering a difference: The transplant process changes the survivor both physically and mentally, and these changes must be incorporated into their new lives. Tasks required of BMT survivors include Changing outlook/priorities, Accepting losses, Looking ahead, and Defining quality of life.

Changing outlook/priorities: Dealing with a life threatening illness provokes changes in the way individuals see themselves and re-prioritization often takes place. Many view successful transplant as a second chance at life, and establish an agenda for accomplishing things which have renewed importance.

> and like with my kids...how have I changed... I know things are different. Things have changed. I think I'm more, I'm more intent on developing an even better relationship with my children. To let them know that I love them. And not take them so much for granted. (B:44)

> Nothing is black and white anymore, because, overnight things change. You just hope that it will be, nothing too bad, and something that you can handle. You can handle anything you have to, what else you gonna do? But it'd be nice if it wasn't a bad thing. (B:95)

> Another way, and it's really difficult for me to know if it's the transplant or just the whole thing of

the last couple of years, has been my outlook -- it's just gotten a lot more positive than it was. (C:05)

I'm not a real materialistic person to a great extent, at least I don't think of myself as one, but, since then, since I was diagnosed, I concentrate more on what we can do together, or what we can maybe do for each other or for, you know, one of our children or our granddaughter, or something along that line. (D:34)

we've done a lot more things that we wanted to do. Hey, I would really like to do this, I mean, you know, it's something that you really want to do rather than, well, let's go buy a new car and let's go buy this, or I really would like that just because I want it, you know. (D:37)

I'm more aware of myself now after this experience. And...I feel, I do feel stronger in one sense, and, and I'm more aware of everything around me, definitely. (E:01)

<u>Accepting losses</u>: Cancer treatments can produce a certain amount of morbidity, and long term or permanent late effects must be managed by cancer survivors. Early menopause, loss of hearing, and decreased lung capacity are among the problems faced by these survivors.

I'm still trying to come to grips with the fact that I won't be able to have a baby. And I wanted to have a baby. My husband has two children from a previous marriage, but I wanted us to have a baby. So, that's the future part that bothers me, (A:91)

One of the real discomforts from this whole thing, actually I guess the problem started when they were giving me my Chemotherapy here before I was going to go down and be phoresed, but I developed a problem with my hearing. I have constant ringing in my ears, I mean it's like somebody just set a fire cracker off next to me, and my ear's ringing. They do that constantly. Evidently, they either gave me too much, or I hit my tolerance, but, this happened whenever I was in the hospital here, and it's been going continually since

> then, I mean, it's stayed with me all during the transplant and, you know, my doctor here in town told me that it would probably never go away. (D:55)

> what I really notice is, it seems to me like an enormous loss of lung capacity. Now I don't know if part of it might be due to the treatments or the Chemotherapy, or the transplant, or whether it's due to physically not being in as good a condition or good a shape as I was, I would like to be or I used to be, I'm not real sure, but I can tell I've lost a lot of lung capacity. (D:56)

Looking ahead: The ability to view the future and make plans in the future is an important task at this phase. Looking ahead results in looking forward to working, accepting routine medical exams, and long range plans.

> But, as far as I see, I mean, I just see myself getting healthier and healthier, and going back to work in a few months, and just trying to pick up where I left off, and just start having our life again. (A:92)

> I know you have to go back once a year, I don't know for how long, to get those bone marrow aspirations. And those are very unpleasant. (B:112)

> long range, I plan to go back to the bay area in California. Which has been what I've been intending to do since right around the time I got sick. So it's been, that's been the next year goals for about two years now. (C:106)

> As far as what I look to for the future, I plan on being around a long time. I feel real good about the transplant, (D:59)

Defining quality of life: Quality of life changes over time with BMT and at this stage a re-definition of life quality is often expressed by survivors. This allows them to work to maintain or improve life quality.

> Well, that just means to me how your life, how you live your life, your, your, everything, your emotional

> stability, your physical well being, it's just, that to me is all that combined. (B:01)
>
> That's hard to answer. I mean, like on a scale of one to a hundred, I would say quality, I think I'm going at about 60 percent right now. I expect to get back to 100 percent. You know, so the quality of life right now is diminished. (A:93)
>
> how happy you are, doing what you're doing, how satisfied you are with the way you're living your life, and that takes in a lot of things. (C:56)
>
> As far as my quality of life now, I feel it's good. I, the only thing, if I could change anything as of right now, I would say I wish I was in a little bit better physical shape as far as durability and able to do things, but I really hope that sooner or later that will come around some. (D:58)

Summary

The purpose of the study was identification of processes used to maintain or improve quality of life. The exploratory research, using grounded theory methodology, found the process of **NAVIGATING SURVIVAL**, the continuous coping with quality of life disruptions throughout the BMT experience.

CHAPTER FIVE

CONCLUSIONS

A discussion of the findings and a comparison of the findings to other literature sources are presented in this chapter. Limitations of the study, recommendations for further research, and implications for nursing practice are also addressed.

Discussion of the Findings

In searching to describe the quality of life of adult BMT survivors and to identify processes used to maintain or enhance quality of life following transplant, the data from the study described a series of coping processes called Navigating Survival. The transplant produces many disruptions in quality of life beginning with the decision to undergo transplant as a treatment option, through months of waiting for recovery of the immune system, and well past the 100 day mark as work and activities resume. Methods of coping with these changes varied among survivors, but coping consisted of adapting to transplant, searching for meaning, and discovering a difference.

Adapting to transplant began with the decision to undergo transplant and continued through hospitalization. The patient was confronted with many things during this time: dealing with cancer recurrence, a sense of urgency to decide quickly, an overwhelming amount of information detailing risks, benefits, and side effects regarding transplant including death, and preparing themselves to say goodbye to loved ones. Pre-transplant conditioning (consisting of high dose chemotherapy and/or radiotherapy), was frightening and produced multiple toxicities that the patients experienced in the early transplant period.

At discharge, the patients faced an extended period of waiting to see if the transplant continued to be successful. This time was punctuated by actual and potential problems, and survivors reported an overwhelming feeling of uncertainty. Fatigue played a role in life quality during this time. Numerous restrictions imposed on the patient included: wearing a mask, avoiding crowds, no driving or heavy housework, and abstaining from sexual contact during periods of neutropenia. The coping task required was searching for meaning, or finding ways to incorporate meaning into everyday life to improve quality of life. Setbacks, physical appearance changes, and relationships with others were especially distressing to the BMT survivor during this time.

When medical limitations were lifted and the transplant showed signs of increasing success most patients were given the green light to return to work or resume normal activities. Physical appearance and energy levels were more "normal", but a great deal of emotional trepidation confronted patients during this time. Work was viewed by some as stressful and some patients doubted their ability to handle their jobs. Those who were unemployed worried about discrimination, and insurance worries were common to all. The coping task was for patients to understand that they were not the same persons as before the transplant, not only were they altered medically but their values, outlook, and priorities had also changed. This was viewed as a positive quality of life experience. Long-term late effects were also managed during this time. Fear of recurrence was a concern throughout the transplant process but survivors indicated it grew stronger during this time as they were feeling better. They expressed concern that should their original disease return, what treatment options would be available to them once the transplant had failed. Another worry was the potential carcinogenic effects of the high dose radiation and chemotherapy received prior to transplant.

Comparison of Findings with Other Literature Sources

The three stages of quality of life disruption identified in the study are described in the literature (Brown & Kelly, 1976; Haberman, 1988). Haberman (1988) reviewed psychosocial aspects of BMT and found six different stages that patients proceed through from decision to discharge. Although many more stages are represented here, Haberman identified psychosocial alterations at each stage. Stages 1 to 4 (making the decision, pre-admission, the conditioning regimen, and immunosuppression) encompassed the quality of life disruptions described in Deciding for Life. Stages 5 and 6 (waiting for engraftment, and discharge) followed closely the second area of disruption Waiting for Signs of Success. Brown and Kelly (1976) identified eight stages that BMT patients face from decision to adaptation out of the hospital, with adaptation being identified as a means of lessening the psychological burdens on the patient.

Mishel and Murdaugh (1987) conducted a study on family adjustment following cardiac transplantation using grounded theory. The process identified was Redesigning the Dream and represented how family members gradually modified their beliefs about organ transplantation and developed attitudes and beliefs to meet the challenge of living with continual unpredictability. They identified three concepts called immersion, passage, and negotiation which paralleled the stages of cardiac transplantation of waiting for a donor, hospitalization, and recovery. Although the sample consisted of families and not individuals, the adjustment following cardiac transplantation shares many commonalities with the reported experience of BMT survivors.

Content analysis of the quality of life of malignant melanoma survivors revealed similar concepts to those discovered with BMT survivors (Longman & Graham, 1986). Living with Cancer, one of six categories that emerged from the data, consisted of both cognitive and emotional adaptation. The other categories were Thoughts about Treatment for Melanoma, Changes in Making Life Meaningful, Alterations in Life-Style, Relationships with Others, and Social Support Adaptation. Preliminary model work with malignant melanoma survivors by Graham and Longman (1987) supported the idea that adaptation and realigning of values occurred when individuals are faced with a life-threatening illness.

The BMT survivor faces numerous physical challenges which are managed medically, while less attention is given to emotional disturbances which can linger long after the transplant. Hengeveld, Houtman, and Zwaan (1988) studied 17 patients from 1 to 5 years post BMT regarding emotional adjustment. The subjects reported that although considerable support was given to them during the transplant process, they felt inadequately prepared for the emotional and sexual problems they had to face in the first period after discharge. Another study exploring quality of life of BMT survivors discovered that time post BMT was unrelated to quality of life following transplant, and post BMT affective status was more difficult to predict than post BMT health or functional status (Andrykowski, Altmaier, Barnett, Otis, et al., 1990). Longitudinal assessment of BMT survivors indicated that many experience some long-term difficulties in physical, occupational, emotional, and cognitive functioning (Andrykowski, Henslee, & Barnett, 1989).

Fear of discrimination reported by BMT survivors has begun to appear in the literature as well as other concerns of long-term cancer survivors (Hoffman, 1989; Loescher, et al., 1990). Hoffman (1989) discussed job problems and illegal discrimination, and reported that approximately 25% of the five million individuals with a cancer history experience some form of employment discrimination solely because of their medical histories. Loescher et al. (1990) surveyed long-term cancer survivors (more than two years post cancer therapy), and found that the cancer experience permanently changes life patterns. Content analysis revealed that problems or concerns of cancer survivors fell into three areas: physiological, psychosocial, and socioeconomic. Psychosocial concerns included fear of recurrence, potential long-term side effects of therapy, concerns over body image, changes in physical appearance, and anxiety over new symptoms. Employment and insurance difficulties, and changes in relationships with others encompassed socioeconomic problems. The findings of this study on long-term cancer survivors identified many disruptions in quality of life reported by BMT survivors.

Limitations of the Study

There are several limitations to this study. In selecting the sample, the researcher approached the BMT Nurse Coordinator to obtain names of willing participants. Some subject bias may have been introduced here as the nurse may have identified patients as those "talkative" or "willing to talk". The investigator used a relatively small sample interviewed on only one occasion. Due to the nature of grounded theory methodology, the findings of this study are not generalizable beyond the context of the subjects of this study.

Recommendations for Further Research

This grounded theory study only suggests the process of

Navigating Survival to enhance or maintain quality of life following BMT. Additional exploratory studies are needed to confirm the existence of this phenomenon. Larger sample sizes, more males, and a separation of groups into like diagnosis and type of transplant should be included in future studies to explore the presence of Navigating Survival in other populations.

Quality of life changes over time in all people, and longitudinal studies from diagnosis through resuming activities should be conducted to determine in what ways quality of life changes over time. Within BMT patient populations, quality of life of those patients who experience recurrence following transplant, and family quality of life should be explored to add to the emerging literature on life quality in BMT survivors.

Quality of life among pediatric BMT survivors will add dimension to the data collected in this study. Another area of furthur research would be to explore quality of life of persons who choose not to undergo transplant as a treatment option.

Implications for Nursing Practice

Quality of life in cancer patient populations has been an increasing nursing interest, allowing nurses to intervene to improve quality of life for their patients. Identification and exploration of quality of life issues affecting BMT survivors can provide nurses with valuable information that can be translated into successful nursing interventions.

The vast array of psychosocial sequelae associated with both the diagnosis of cancer and the BMT experience have a profound effect on these survivors. Nurses are present throughout the transplant process from pre-admission throughout hospitalization and outpatient follow-up. In the initial stage of transplant patients feel overwhelmed by information and fearful of pre-transplant conditioning. Nurses can recognize this anxiety, and implement interventions to reduce it. Information can be given in both a written and verbal form, and when possible, patient teaching can be accomplished in stages to allow patients time for understanding.

At discharge the patient leaves a structured environment and may experience separation anxiety and uncertainty about the future. Outpatient support groups or individual counseling can help establish ties to the medical community and to other BMT survivors.

The challenge for nurses caring for BMT survivors is in recognition of their uniqueness and their individual manner in coping with the transplant. As the patient feels better and is beginning to resume activities, emotional problems may still be present. Uncertainty, fear of recurrence, and concerns about employment discrimination may gain importance as physical problems subside. Returning to work may be regarded with ambivalence based on past history with work experience. Lingering feelings of anger or frustration at losses experienced from the transplant may be unresolved. Nursing assessment during this time must go beyond functional status and include psychosocial elements and coping mechanisms to tap quality of life concerns for these patients.

Summary

The processes involved in maintaining or enhancing quality of life were the concerns of this study. A theory of Navigating Survival emerged from the data. Quality of life is altered during the BMT process especially during the decision to undergo transplant, the waiting period following discharge from the hospital, and when returning to normalcy as activities are resumed. The individual finds ways of coping with the changes in the form of adjusting to transplant, searching for meaning, and discovering a difference.

In this chapter, a summary of the process of Navigating

Survival was presented along with literature supporting its concepts. Limitations of the study, recommendations for further research, and implications for nursing practice were also addressed.

APPENDIX A

HUMAN SUBJECTS APPROVAL

THE UNIVERSITY OF
ARIZONA
HEALTH SCIENCES CENTER

College of Nursing

Tucson Arizona 85721
(602) 626 6154

MEMORANDUM

TO: Paula A. Peters
6655 N. Canyon Crest Drive #13273
Tucson, Arizona 85715

FROM: Carolyn Murdaugh, Ph.D., R.N., F.A.A.N.
Director of Clinical Research

DATE: December 14, 1990

SUBJECT: Human Subjects Review: "The Quality of Life of Adult Bone Marrow Transplantation Survivors"

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Subcommittee and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research if you need access to it.

We wish you a valuable and stimulating experience with your research.

CM:dbr

APPENDIX B

ACCESS TO SUBJECTS LETTER

Bone Marrow Transplant Program
602 626 4196

ARIZONA
CANCER CENTER

College of Medicine
The University of Arizona
Tucson, Arizona 85724
Fax 602 626 2284

November 8, 1990

To Whom It May Concern:

The research proposed by Paula Peters, RN, regarding "Quality of Life of Bone Marrow Transplant Patients" has been discussed with me. There are no objections, and I have agreed to act as consultant physician.

Sincerely,

Wm S Dalton

William S. Dalton, M.D., Ph.D.
Associate Professor of Medicine
& Pharmacology/Toxicology
Medical Director, Bone Marrow Transplant Program

WSD/ecs

Arizona Cancer Center
a National Cancer Institute designated cancer research center

APPENDIX C

SUBJECT DISCLAIMER

SUBJECT DISCLAIMER FORM

TITLE: QUALITY OF LIFE OF ADULT BONE MARROW TRANSPLANTATION SURVIVORS

"YOU ARE BEING ASKED TO GIVE YOUR OPINION REGARDING YOUR BONE MARROW TRANSPLANTATION EXPERIENCE AND YOUR QUALITY OF LIFE FOLLOWING BONE MARROW TRANSPLANTATION. BY RESPONDING TO THE INTERVIEW QUESTIONS, YOU WILL BE GIVING YOUR CONSENT TO PARTICIPATE IN THE STUDY. YOUR NAME WILL NOT BE USED, AND YOU MAY CHOOSE NOT TO ANSWER SOME OR ALL OF THE QUESTIONS, IF YOU SO DESIRE. YOU ARE FREE TO WITHDRAW FROM THIS STUDY AT ANY TIME. THERE ARE NO KNOWN RISKS TO YOU."

Paula A. Peters, RN
Investigator

APPENDIX D

DEMOGRAPHIC DATA FORM

DEMOGRAPHIC DATA FORM

TITLE: QUALITY OF LIFE OF ADULT BONE MARROW TRANSPLANTATION SURVIVORS

AGE ______________ DATE OF TRANSPLANT ________________

DAYS SINCE TRANSPLANT __________

TYPE OF TRANSPLANT _____________ MARITAL STATUS ________

PRIMARY DIAGNOSIS _________________________________

PRETRANSPLANT CONDITIONING TREATMENT:

CHEMOTHERAPY ______________________________

____

RADIATION ______________________________

APPENDIX E

SELECTED CATEGORIES AND DATA BITS

DECIDING FOR LIFE

RUSHING TO TREATMENT

Before the transplant I went through a lot of vacillating back and forth whether I even was gonna do it. Because I, you know, I did have a choice to not do it. The doctors assured me that I ... what they told me is if I had the transplant I had a 30 percent chance of being cured, but if I didn't have the transplant, there was 100 percent chance that the cancer's gonna come back again. (A:32)

It came from within me, I decided tnat I wanted to live, and that this was like my very best chance at it. So that's why I decided to do it. (A:36)

the whole thing sounded to me like something out of a science fiction story. (C:93)

I didn't really feel like I could say to them, 'no, we're not going to do it this way, we're gonna do it that way.' Because I had been told that we've got this window of opportunity and it's better for you the sooner we get all this stuff done. (C:99)

and they did all their testing in two days, and then at the end of the two days we had our little conference with the doctors and I was more or less given my options as far as they saw them. (D:30)

TOLERATING TESTING

I mean, the transplant they just hook a bag up. And you're hooked to those I-meds, you know, that's a drag, so big deal, that's just something you get through. (B:62)

That was something that was kind of a hard thing to go through, too, because they, phoresed me two times, in two weeks, two different weeks. That was something that was pretty discouraging because they had a lot of trouble with the catheters that they put into my shoulder, and they had to remove 'em, and the first time the one got infected, the second time they had trouble putting it in, it only worked the one time, they had to take it out, they had to put it back in again, they had various problems getting it in, and that was...to me, that was probably one of the hardest parts of the whole transplant. (D:28)

I started, in January, whenever I first went down, January or February, I believe, when I first went down for the tests, and they did two days of tests and in those two days they did more testing than I thought it was possible to do on someone. I told them that I would really like to have everything, if I could, have it set up to have it done in two days. And I was very fortunate in that whoever set them up set them up very well. It was in one and out, and in another one and out, and in another one, (D:29)

I think as far as treatments and things, the Radiation treatments, those were real scary for me. And having to just lay there, and the last one, I was just, oh, thank goodness, it was just a, a wonderful feeling that this is the last one. 'Cause I, I was really worried about what is this doing to my body, the rest of me, and I know it's killing everything in my body, but, to what extent, I mean, are my brain cells going with this, (E:31)

MANAGING DELAYS

at which point I was told well, we need to have a confirming diagnosis. And what we want to do is have you go back to TMC to have the same procedure done that was done last year and, um, and, um, you can guess that I was not happy about that, because that meant two anesthesias in a week, and I just, I didn't like that idea. (C:78)

Because instead of then coming back for the high-dose Chemo and transplant the following week, I was sitting at TMC being infused for a week and had to wait three weeks for a CAT scan. (C:80)

Um, so at that point there was this little breather. I had been whomped with this time table and then told we have this window of opportunity here but we really have to get going because you have an aggressive disease and if it grows much bigger then the results are not going to be as good, and we really have to get going here, the decision is yours but we really have to get going here, and then to be told, well, you know, we can, we can wait for a month. And I didn't understand that, (C:81)

for me what was happening was that the time table kept changing and the equation kept changing, and what they had to do kept changing, and it was really frustrating because it seemed like nobody really knew what was going on and that's why they were changing everything all the time. And that was frustrating for me. (C:84)

So, from being rushed into this, and then having it telescope and having lots of things change, when I finally got there it seemed to flow. (C:92)

When they decided that they needed a confirming diagnosis that nobody had mentioned before, I wanted to know why is this needed, you know, why are things changing. (C:97)

BETTER THAN EXPECTED

the physical part of it was not, except having Hickman's, that was pretty awful. But the physical part of it was, was ok. You know, I mean it wasn't anything unbearable. (B:61)

I remember thinking at the time after the first one of being terrified of the thought of the radiation treatment, that this wasn't so bad, it wasn't like Chemo. (C:17)

I didn't have any trouble eating. I mean, that's almost unfortunate, but throughout the course of my entire treatment, all the doctors had been telling me, 'you'll have problems with eating,' but that wasn't true, I've never had any problems with eating, never. (C:20)

I was surprised at the lack of actual physical pain. I thought that I would be more uncomfortable from a pain standpoint than I was, even though there's some discomfort, but it's more the way they put it, you feel crummy, rather than feel pain. (D:53)

that was the amazing thing is I didn't get a fever at all. They were all looking at my temperature, they said, 'I don't believe this,' I mean, I kept, you'll see that it was just really boring. And it was funny, 'cause they would say, 'well, you haven't had a fever yet?' And pretty soon I would start to say, 'well, am I normal, or what's the deal? I have no fever, what's the matter?' (E:36)

I really was expecting more to happen, because I, like the mouth sores, they told, they, horror stories about those. I didn't get mouth sores and I didn't get infections, I didn't have any kind of yeast infection, (E:37)

ADAPTING TO TRANSPLANT

SEEKING INFORMATION

Try to get information. And to intellectually find out what's going on, and what they're going to do about it, and what the course should be, and if it works, and stuff like that. Just deal with it very intellectually. (C:52)

I asked for names of people that I could talk to. They weren't, nobody suggested that maybe I might want to talk to somebody. I asked them for their names. (C:94)

I asked for information about the efficacy of the procedure, and was given an article that scared the hell out of me. At which point I decided that maybe I didn't need to know as much as I was asking, that maybe I had to just kind of go on faith with some of this. (C:96)

I was amazed that everybody was more than willing to sit down and explain things in as much detail as I needed to know to satisfy me as far as what I had and what treatment I was going to go through and what to expect from those treatments. (D:16)

the part that really jumps out when you read, I mean there's a lot to absorb when you read that consent form, but the part about aging was just, this thing that says aging, and you know, what does that mean? Am I gonna wrinkle up and get old fast, or what? That part bothered me, that aging part. (E:55)

DISTANCING

Sometimes I think that, those kinds of things that my mind does, it helps me. I think if I'd have been thinking about how sick I was and, worrying, stuff like that, I don't think I'd have done as well. (A:42)

But most of it wasn't to do with Cancer. Most of the reading material I had was, oh, just novels, and biography type things. Stuff that took, that took me totally away from it, so you could be absorbed in the book or magazine or article and just completely forget about it. And to me I found that easier than going and checking out all the books on cancer and everything to try to find out what I wanted to know. (D:13)

I had a hard time talking to others, immediate family in particular, about me being there and how I was doing on any particular day. (D:20)

So...just have to deal with right now, being by myself, or trying not to think about me. (E:06)

FACING REALITY

But, when they say cancer in the past, and this time my, my brain sort of shuts down as far as realizing how sick I am and just concentrating on getting well. And it's sort of, just after a time that those kind of thoughts come back, and you think about, oh, wow, you know, I almost died, and it's really scary. (A:43)

Knowing that I was going to be facing losing my hair, taking all the medications, and just basically everything that it involves. Feeling lousy a lot, only being able to do things that you were able to do or wanted to do for, maybe a couple of days a week, being pretty much restricted around the house, who you could see, who you couldn't see, every thing in general, I was kind of down about it. (D:05)

So I wasn't really too hot on going down there because there's...you don't want to face the reality, I didn't want to face the reality that it was, it had already come back twice, there was a real good chance I was gonna have it again. My doctor told me that. And I was kind of down on going down there. (D:08)

The hardest part, I would say was, I guess actually accepting it. (D:17)

KEEPING BUSY

the cross stitching has been a great help. I've taken back up an old hobby, I hadn't cross stitched in a long time, but now I'm going at it great guns, and I'm actually gonna finish a project. That's helped cause that takes a lot of attention. (A:53)

I've been having friends come to me, 'cause I don't feel comfortable going out. So maybe once a week or so, like tonight I'm having two girlfriends come over for dinner. I talk on the phone a lot. (A:54)

I had taken down some sewing projects, and some reading, and some tapes, and all that kind of stuff. (B:65)

And this really, I found in my case the whole way through is trying to be optimistic, which I'm sure everybody is, but at the same time I would like put it out of my mind and try to concentrate, fully concentrate on something else to, I don't know, maybe it helped me, whenever I had to go down every week and take my Chemotherapy and...(D:11)

I never would have said I watch soaps before this, but, with plenty of time on my hands, it fills the void. And, then I might take a nap, or write letters, or do some reading, 'cause I really enjoy reading, and maybe take a walk, which is very rare, lately anyway, and also the stairmaster, I do hop on that once in a while, (E:82)

SEARCHING FOR CONTROL

I was gonna shave my head the second time rather than watching my hair fall out. Which the doctor didn't understand, and I said, 'I won't watch it come out again.' That, that hurt too much, I will not watch it (C:71)

I had taken charge and said, 'no, I'm gonna have some control over what happens. I may not be able to control when it happens, but...' (C:76)

I didn't feel that I had any control over it. I was terrified. I was convinced that no matter what anybody told me, something horrendous was gonna happen and I was not going to live through the high-dose Chemo, and the first weeks after that. (C:93)

the control really, I don't think I had any control. I really didn't feel that I had any control. But I wanted to understand what was happening. And why things were changing. (C:98)

DENIAL

while at the same time telling myself that they don't seem to be overly worried about it, so you know, hopefully it'll be a brief time like I'm being told. (C:53)

I'm not old enough to have physical problems is the way I looked at it. Illness is something that people get when they're old and they didn't take care of themselves as they got old, it's not something that young people have, certainly not with any forewarning. (C:58)

But after the second one they told me that they had me in remission again and that they wanted me to talk to the people here. At that time I thought it was kind of silly to do because here I'd just been told that I was clear again. (D:06)

WAITING FOR SIGNS OF SUCCESS

TOLERATING LIFESTYLE CHANGES

Limitations in ADL's

well this is going to sound silly, but I can't clean up my house. It really bugs me. 'Cause, that was one of the things in the discharge book it just said not to do...not that my house was always clean before I got sick, but I could do it when I felt like it. (A:84)

losing my stamina, I really don't have much get up and go. (A:19)

And physically I'm just, I'm not able to do like I used to do. I used to be an old work horse. And it's just, I can't do like I used to. (B:28)

I want to clean my house, I can't clean my house. I want to go back to work, can't do that either. I want to go out and go grocery shopping, you know, technically some of those things I guess I can do, but they're asking me to be careful, and it's hard for me to be careful. (A:22)

it's like running out of gas. I do too much, and go, go, go, and all of a sudden it just switches off. I mean I can barely stand up. I have to go and lie down, or else I'm going to fall down. (A:26)

but by the end of the second or the third week I was beginning to notice that I was being pooped a lot of the time, the early, earlier part of the week would be better, and then I'd slide. And by the weekend I just couldn't, couldn't hack it, and then start over again on Monday. (C:18)

The early part when I was still restricted to not being around very many people there was not a lot of incentive to be out of the house (C:24)

When I first came home from the transplant, I was pretty weak, I wasn't really doing a whole lot of anything. Just lounging around here, doing what I felt like doing, and take care of whatever I felt like taking care of. (D:44)

When I got out, I thought that I should have come around a lot quicker as far as regaining my strength from the transplant than I did, and I'd kind of realized that I, that, I don't know, maybe I never will get all my strength back before then, before I was sick. (D:54)

they don't want me to go still into crowds. They still don't want me to do that, but, like last Thursday night, we had planned to go out for dinner because that's our anniversary as well as Valentines, and, it turned out that she, the doctor said, well, that's not a good idea. So, that was kind of a bummer. (E:50)

once in a while I do get tired and I have to take a nap. But I listen to my body, and go ahead and sleep. I have nothing else to do. (E:52)

Role Changes

Well, the biggest change, obviously, is I haven't been at work. I'll have been out, not working, not out of work, but just not working, because my job is being held for me. But April 19th will be a whole year. I can't believe that a whole year has gone by already. (A:04)

The most distressing is not being able to have normal relations with my husband. Being newlyweds and everything, we're just starting our life together, and it just sort of put an abrupt halt to... You know, growing, but especially sexually, it was difficult. I've felt that very keenly, not, not so much as, desire on my part because I was sick. But being real aware of his needs. That was the hardest part. (A:15)

I like interaction at work, you know, that's my social life and my job. So I miss that a lot. (B:101)

And like in my family unit as well, it was like I've always been the nucleus, the strong person, and, so it's been real hard on everybody around me, too, because, you know, I've been weakened. (B:15)

Also having your younger sister telling you what to do is really different. (C:41)

my husband is legally blind. And it was very difficult for me to get sick, because I've, I mean not that I feel like I'm taking care of him, but certainly we share each other's, um, whenever there's a problem we help each other out. (E:10)

There's so many things that I had done, I would go grocery shopping, I would do the bills, I would read to him I wish there was someone that would just say, 'Well, let me do that for you.' 'Cause we're really, he's proud, and he, he's independent in a way, he doesn't want to have to call his mom and dad to come over, who live 15 minutes away, to take him shopping or something like that. (E:23)

Depending on Others

some of that was bad and some of that was good. Sometimes I wanted her to just go away. And we'd talked about that, too, you know, we'd, my mom and I are real good friends, and we know that to keep our relationship friendly we also have to keep our distance sometimes. We, we're real honest about that. (A:11)

But I really needed her, and she was there. So I guess the different part about it would be the physical dependence. I really physically depended on her in the hospital. She helped me shower, she, helped me to go to the bathroom, she helped me clean up, anything you can think of that physically you do, she was there to help me with it. So that was, that was the big change. (A:12)

And my brother, he recently came to live here from California, in December, so, he actually has been a big help. He's helped with my mom, see, and she's had a stroke and she's been ill. So that, that really has helped a lot. (B:17)

it was very helpful to have people here, but at the same time, it almost felt like, like being an infant, you know, where you were testing, you know, not only yourself, but what other people were going to let you do. (C:35)

I do appreciate when people are concerned, they want to care for me. But I'm a real independent person. And, this, this being cooped up and having someone wait on me just really bothers me. (E:91)

Financial Changes

I'd like to be able to overcome it financially, and get back on my feet. I don't have to be a rich person, just to live a nice American life. (B:117)

finances are, it's, the word is devastating. (B:05)

Like when we lived down here, I had to pay to live down here, plus I had to keep my other residence going, and I wasn't working. (B:07)

I almost lost my house, it was in the process of being foreclosed, and finally, my disability started, and I was, I'm still one month behind, but at least it's, you know, it's out of that, that phase. (B:26)

I felt pinched, but I was receiving a disability income from the office, which was not as much as my paycheck, but it was enough to pay my expenses. So, the summer before I had a big problem, but this year, I mean, this last year wasn't that bad. (C:117)

It was tough for us, but it's a little bit easier to face when you know you're not going to be missing your paycheck and, even though you're running up these outrageous doctor bills and hospital bills, that you do still have something coming in, plus your medical plan and hospitalization plan that will help you pay for them. So, you know, that, that made me feel a lot better about it. (D:50)

we're only on one salary, and I did apply for social security disability. And they're gonna start sending that in March, which will help greatly, because when, when my husband signed his contract, he signed it for a nine month period, which means he gets his checks condensed, and rather than over the full year. So that means we'll have no income in, in the summer months. And it's gonna be a little tight then, but since I'll be getting the social security income, that'll sort of offset, I mean it's certainly isn't as much as he's been bringing home, but, it'll help a little. (E:95)

MANAGING SETBACKS

Physical complications

Since I've been out of the hospital, the worst thing that I can think of is I'm going through menopause, the doctor thinks I'm going through menopause. I've been having the hot flashes, those are real uncomfortable, very very uncomfortable. (A:16)

I knew, they had explained to me that I would have problems swallowing, and I did have a little bit of that, but, I guess all the chemicals and the menopause, you know, it caused a lot of vaginal dryness, and that caused problems sexually... that's, I didn't expect any of that. (A:96)

And I'm, I just saw my surgeon on Monday, and he again reinforced how important it is for me, especially since I don't have my spleen, to get any infection under control as fast as I can. (A:48)

I had the host versus graft, and it's just real stinky to get through it. (B:53)

I still had shaking spasms, which I had had in the hospital, and they tell me that's when the drugs were hitting me. It was upsetting to me, because I thought I'm not on those drugs anymore, why am I still shaking like this periodically. (C:13)

But the things that I remember was that I was eating by the time I was discharged, but I was still having nausea bouts. And I don't think I was really vomiting all that much any more, but I was still taking Reglan and Ativan. The instructions were to try to wean myself off that because I was taking them four times a day and, and within not too long period a of time I was weaned. (C:42)

I mean it probably sounds like a small thing to a lot of people, but, when you've had all this done for you and everything, and you haven't had to worry necessarily about eating, now all of a sudden you know you've got to eat because you need the nourishment, and you're, it's like your body's turning on you, so to speak. (D:23)

I did develop a dot on my hand, and they were red, and, um, but the doctor wasn't quite sure if I was getting graft versus host disease or not. And they didn't want to do a biopsy on my hand because they, well, I think they decided we're going to go ahead and say that it was. It was a real mild case. (E:33)

they think I have something, because my bilirubin count, and BUN count is doubled from what it was. And they're not sure if, it's like a mystery because it could be from the Provera could be from cyclosporin, they're trying to pinpoint it, though. The next week hopefully we'll know, (E:47)

Returning to the Hospital

I had to be readmitted for acute kidney failure, but so far as complications ... (B:52)

Um, five days after I was discharged I started running a fever that was high enough to call a doctor, and he had me come into the ER room on Sunday morning. They drew some blood and took a zillion X-rays, and then decided that they were going to admit me, based on, I think it was my temperature, 'cause they hadn't really determined anything. (C:43)

I was really upset. 'Cause I had told them on the phone the night before that I don't want to be back in the hospital, I'm not interested in being back in the hospital. (C:45)

Fear. And anger. frustration. Um, which is a form of anger. I think it was just, that I was so tired of being in that one room. And so looking forward to never having to be in the hospital again (C:48)

I knew that, from the discharge book that I'd been given, that the possibility was maybe not excellent but at least good that I'd spend some more time in a hospital during the first year. I didn't really think it was going to be that fast, and I didn't really think it was gonna be me, anyway. Because I had been doing so well. (C:54)

Harder than expected

The hardest part was, I don't know why it was so hard, but just getting through day to day in that room. (B:63)

Your attention span is so short, and nothing really interests you, and if you could get out you'd probably feel just as bad... But that was so, that was worse than I ever imagined it would be. (B:66)

And of course that all affects me, you know. And having the transplant, I guess 'cause of what your body goes through or something, it's just real difficult to deal with ordinary, everyday problems, let alone bigger problems. (B:13)

You know, family or, or emotional, just dealing with all of it. 'Cause I'm single, I'm divorced, and so, things are left up to me. (B:14)

I think the other experience that I didn't enjoy was getting a catheter, the foley catheter put in. That was a real shock. I think that, 'I do not like this,' (E:32)

ALTERED RELATIONSHIPS WITH OTHERS

Supportive

The relationship with my family has changed. I think I actually am relating better with my husband. We were newlyweds to begin with, so this sort of punched us right into crisis so that I think that we communicate better. (A:05)

People at work, have been terrific. They even took up a collection to help us with our medical costs, and like I said, a friend coordinated the platelet drive, and I felt a lot of support. (A:59)

We have a pretty good rapport about the whole thing, we've talked about about it a lot, we discussed everything, obviously, that went on and was going to go on. She will remind me a lot of times of different things that I had or problems that I had, or, or anything like this. (D:24)

There's certain people that I feel I've grown maybe a little closer to that I considered friends before, but I feel better about their friendship now because maybe they came down to see me, or, they stayed in contact with me (D:31)

we have a very open relationship, if anything since I very first was diagnosed we have gotten closer (D:32)

it's really nice to know there are people that really care. Because if there weren't those people, then I'd really be upset because there's nobody that cares about my husband, and that's not right. (E:22)

I think especially after this, my brother (donor) and I are really...seem to be closer. And, I mean it, he really sacrificed. He gave up beer for a whole month, he lost a lot of weight, and then he also had to take finals the week after he donated. He really had to sacrifice, and to go through something like that and then have to take finals, I just, I really thanked him for, and I continue to thank him. (E:107)

Stressful

It was real hard on my kids. Their school grades went way down and their behavior changed. Even though, you know, we talked it over with them and stuff, it's still scary to kids. (B:25)

So far, you know, I got leukemia, and just things in my family have been really, really stressful. And it's been real stressful on my family. (B:12)

I focus a lot on anger at my husband's brother right now. I mean, not directly, I've talked with his wife. I let her know that this is not right, that he has not really contacted my husband. It's strange, because I don't care if he would contact me or not, it's his brother that needs him. (E:14)

I worried about the people, I worried about him more than about myself, that he would contact me. (E:24)

Diminished

Other people who were friends, like just at work, those have obviously drifted a little bit. I wouldn't say the friendships are gone, it's just that they're work friendships, and I'm not at work. I'm not there to nurture them or anything. (A:57)

there are others who still try to maintain a friendship, but it's real difficult, and they don't understand. So it's like, the relationships with my friends have changed. (B:80)

My other friends...it's hard for some people to know how to behave or react, so they just, they back away from me completely 'cause it scares them. (B:78)

I do think that people don't tell me a lot of things because they think that I can't handle it, that I've got enough to think about. But actually, I would like to think about something else, (E:08)

And, see, that's the problem with some of these people that I thought would come through. And they haven't. I mean, in the beginning, 'oh, no problem, any time you need a ride. We're gonna come down and visit all the time,' you know, no problem. You know, there's something that's just not happening. And I've decided that's just the way people are, sometimes they can't just, they can't cope with this. (E:109)

PHYSICAL APPEARANCE CHANGES

Personal Response

I gained a lot of weight. I gained 50 pounds, and I feel like I'm carrying another person around. (B:03)

Because I look different, you know, I wear the turban because my hair is coming back and everything. (A:66)

this is the first time I lost my hair. And it was very, very very very upsetting. (A:69)

'Cause I, I saw somebody in the mirror who wasn't me. (A:73)

it just doesn't look, to me, it just doesn't look like, like me. Like the me that I see in my head when I close my eyes. It's weird. It's really weird. That's why I don't look in the mirror very often. (A:83)

It looked strange, and it didn't look, and still when I look in the mirror, I don't even see who I'm looking at, it's such a shock. When I look in the mirror, just 'cause of how my face looks now just everything is physically different. (B:109)

My physical appearance changed radically with my first course of Chemo, because I was taking Prednisone, and because my hair fell out. And the combination to me was devastating. (C:60)

And I was really upset, because I looked in the mirror and saw my grandmother. (C:62)

I don't recognize this thing that I'm looking at in the mirror, and I quit looking at myself in the mirror because it was too upsetting. (C:65)

One thing that really bothered me is that I gained a lot of weight. I gained around 50 pounds. Which, to me, bothered me a lot then, and still bothers me, but I haven't really been able to take it off, (D:26)

the catheters that they had for the transplant, they had them in my chest, and that was kind of annoying, especially after I came home and they still had one in there, and that annoyed me more than anything else, because I just wanted to get rid of it, to be rid of the whole transplant thing. (D:43)

And...just going anywhere with a mask, I felt, well, I still feel this way, but, I've gotten used to it now, that I have to put this thing on. And people really don't really notice you. (E:43)

it's coming back in now, and I'm glad. I thought it would come in blond perhaps, but it seems to be coming in darker. And if it comes in dark, that's ok, as long as it comes in, that's what I'm concerned about. (E:62)

when I go past a mirror at this point and I don't have anything on I look at myself and I think, oh gosh, this is awful...I don't feel sexy, that's one thing I don't feel. (E:64)

the thing that bothers me about hair, is that I've got it on my face. And it's the cycloosporin I've been told, that's why. Fortunately I'm not like some of the other gals, they had dark hair that's coming in on their face. And so it, they, I mean, you can really see the hair. (E:67)

Reaction of Others

The only time I've encountered people looking away from me are people that I don't know. (A:65)

little kids look at me, they're real curious. But I'll usually talk to them, I usually say 'do you want to ask me why I have this think on my head?' And they'll say 'yeah,' you know, 'cause they're curious. (A:67)

It upset my daughter. Even though I'd told her that I wouldn't have any hair, still when you see somebody like that, I mean, I looked like Mr. Clean, all I needed was a little gold earring. It upset my son, but he holds all that in. (B:108)

I thought at first, everyone's gonna look at me...the kids do, but they're just curious, you know. They usually say, what's, what are you wearing...and I say I have to watch out for germs. (E:44)

LIVING WITH UNCERTAINTY

We talk about things, and we talk more about future plans, far range future, things like dying, taking care of things in old age. (A:06)

And that's something else that's changed, is it puts little fear in you, what can happen. What can go wrong next. It almost makes me, I don't know about other people, but you have a little fatalism in your, your outlook. Is that the right word, fatalism? You know, you're not so, not quite so optimistic and worry about things that can go wrong. (B:10)

And I'm still really freaked out scared to like go into crowds, and stuff like that, I'm like absolutely sure I'm gonna die. 'Cause somebody's gonna cough on me or sneeze on me and I'm gonna get the flu and have to go back to the hospital. So, those are things that are really different since I've been sick. (A:08)

I'm just afraid... I read my discharge book, they give you a discharge book, and it says that, you know, not to be surprised that in the first year you'll probably have to go back into the hospital for IV antibiotics because of some infection that you'll get. (A:45)

Well, 1990, I call it the black hole. Because it seemed like, it's like a missed year in my life, because everything totally changed, and everything familiar to me changed, my job, and my family, and being in the hospital that long, and living down here. It feels like, it feels like a hole, a hole in my life. (B:90)

And you know it gets to kind of be a drag just telling everybody that, 'oh, I feel fine, I'm doing ok.' You know, 'everything's going ok.' When in reality you don't know whether it is or not. They tell you it is, and there's no tendency to lie to you in those circumstances, which I appreciated. (D:19)

I'm analyzing things a lot more, and just really reaching into the unknown, you know, what if this, or what if that, or...just trying to think about different things like, um, how long am I really gonna live now, you know, is this gonna affect my life span? And, just crazy things that I shouldn't even think about, 'cause you don't need to think about them. There, there aren't any answers. (E:80)

SEARCHING FOR MEANING

SEEKING SUPPORT

Well, my mom, when I was in the hospital, came down here. And if she hadn't been here to, just to call every day, or to visit every day, just for a little bit, 'cause some days I didn't feel like anybody really staying very long. (B:19)

My ex-husband has been real good for the most part. I mean, he's done things to try and help. (B:22)

the social worker at the U of A, she was a real big help in a lot of things. (B:23)

I thought I'd see a counselor, I started to see a counselor, it's a lady I used to see before. I prefer that to group stuff, because it's hard for me to be in a group setting counseling. (B:82)

When they told me that it would be best if I had someone with me during my intensive Chemotherapy, and even during the stay here at the hospital, and of course the apartment here, she didn't hesitate, she said, 'I can do it. I will do it.' And I didn't even, I don't even think I asked her, she just said she was gonna do it. And, that was a big, big relief. And, and it really, really worked out. (E:27)

We have an outpatient group that we meet with every Thursday, and there's about six, and of course, ever growing because more people are being discharged, and that is a very, very, good thing for me to attend, and to hear what other people are going through and similar experiences, and actually talking to people who can really understand, and have been there, and maybe they've got different perspectives on what they've gone through, but at least there's a strand of similarity between us in some ways. And that's really been very helpful for me, (E:77)

SPIRITUALITY

when I was in the hospital, what got me through day by day, 'cause that was so horrible, was a lot of prayer. (B:49)

I think things, I think, I've had a lot of blessings, because of, like to be able to get enough money to keep from losing my house, and, things have worked out. (B:50)

prayer has really helped me, too. And I feel like there, there are challenges that are being, not maybe thrown at me, but, or I'm being faced with challenges that, that are to strengthen me in some way. And are given to me for a certain reason because I can, I can handle these challenges. (E:74)

ALLOWING EMOTIONAL RESPONSES

these real wide mood swings could be attributed to the imbalance of hormones, so he put me on hormones. That's been the worst side effect so far. (A:17)

but the other thing is that there doesn't seem to be any in-between. It's like I'm either way up here or I'm despairing. So, that's really hard. (A:28)

sometimes I get depressed. 'Cause I think about myself too much, you know. So I get depressed and I think, well, I don't know why I'm alive. You know, this is crazy, I'm thinking about myself, maybe I should go in the bathtub and cut my wrists and I wouldn't get everything messy, but then I go, well, that's crazy because here I've been given a second chance, and that would be a waste. (E:05)

although I'm physically ok, emotionally I've been struck heavily. I've really never felt this emotional about anything like this before. I mean, I really get upset over certain things that I probably would have just said, oh, well...but things really bother me now. (E:79)

SETTING GOALS

so it wasn't as horrible as I thought it was going to be, but then on the other hand it was worse. Because I'm a very impatient person, ... my sole goal, I was, it was like blinders, the only thing I wanted to do was get out of there. (A:41)

In the hospital, I'd think I'll be out of here by Christmas, I'd say to myself, by Christmas I'll be home, and everything will be more normal. (B:92)

Now I look at things in terms of working towards getting better to go back to work. I really miss working. And so, that's kind of like how I'm measuring things now. (B:93)

MAINTAINING A POSTIVE ATTITUDE

I do have a very strong will to live. I mean, I've made it this far, and I, I do want to live. Very much. And I have, you know, more extra reason because of my husband now, I really, I want to grow old with him. (A:35)

I had to live, because I have children, and I have responsibilities, you know, I mean, you can, things become so much clearer. (B:36)

I think to start with, I'm a strong person physically and I think emotionally, too, and I think that has been a big factor in carrying me through it. (B:59)

you know, you learn something from everything. There's reasons for things that are happening (E:72)

it doesn't upset me, I mean it does, it upsets me when certain things don't go the way they are supposed to. But, I gotta think about it awhile, and I say, well, there's a reason why this is happening. And we'll get through it. It's not the end of the world, type thing, you know. (E:75)

DOING BETTER THAN OTHERS

Oh, yeah, from what I understand, I'm really fortunate, I mean that my transplant has gone so well in that, you know, with the autologous you shouldn't have to worry about graft versus host disease, or any of that. (A:37)

The other patients that I did get to meet in the hospital, they had leukemia, but they had the other kind. What's the other, not autologous, but... Allogeneic. They had allogeneic. And they were having problems. They had to take other medicines and everything, which I was really glad

I didn't have to go through that. (A:38)

it's coming back. You can see my hair, it's coming back. It's actually going great guns compared to other people. My hair grows pretty fast. (A:71)

I went and had my dental thing last week, and it felt great to have my teeth cleaned...I did have nine cavities, but they were like surface cavities, and the dentist, he has treated other oncology patients, he said my teeth were in real good condition, you know, compared to how some people's were. (B:58)

you know the commercial with, the McDonalds kids, the, I guess his name is Mike Stool. He's got Down's Syndrome, and he works at McDonalds' McJob program. And...I cry every time I see that commercial, 'cause I think, they're people struggling more than I am, and I shouldn't be thinking about myself as much as I do. (E:76)

RECONSTRUCTING NORMALCY

RESUMING ACTIVITIES

Yeah, well, I real ambivalent about that too. I work in television, and it's a very high stress job, one that, it's, it's prestigious, but it's stressful. I was having a hard time with it before I got sick, and now, like I can take my time, I don't have to go back. (A:86)

I know that there's really no proven link between stress and cancer, but it seems like whenever I've had a major stressful time in my work, closely following that I've had my recurrence with cancer. (A:88)

In fact, I was supposed to go back to work full time on September first, originally, I mean, that's, that sort of what we had planned all along, and I decided I wanted to go on some kind of a vacation before I did that. (C:28)

It was pretty trying to get back in to a regimented lifestyle where you have to get up at a certain time, where when I stayed home, I would get up when I felt like getting up, around 8:30 in the morning. But to know you were going to get up early and then go to work and then be there all day and then come home, when I'd get home the first few months that I went back to work, I would just come home and go right to sleep, I mean, I'd sleep a couple of hours and eat dinner and watch TV for a little while, then go to bed. It was pretty rough. (D:48)

they're holding that job for me, believe it or not. It's really great. they put me on medical leave. I didn't work a day for them, although I did order a lot of supplies for the classroom, they got a substitute teacher in for the full year, and I have a job for me waiting in the fall. Now whether or not the doctor will release me to do that, I don't know. (E:88)

So, I'm really happy I've got a job waiting for me, whether I'm mentally ready for it or not, that's another question. (E:105)

REDISCOVERING SELF

I put some makeup on the other day and it looked more like me. I could see me in my face more. (A:81)

They're starting to cut down my medicine, my steroids. And that helps. It gives you an enormous appetite, so I'm starting to have a more normal appetite. (B:97)

My hair started growing back, that was a big thing...to not be bald. (B:104)

But it's real nice to see hair growing in. Although I do have Elvis sideburns from the cyclosporine. And a mustache. (B:110)

The most obvious change for me is that I feel well now, for the first time since before I was originally diagnosed. That didn't happen immediately after the transplant, it took a while. (C:01)

I was beginning to feel better, but not totally better. My face was sort of beginning to get back into its normal contour. I still weighed probably six or seven pounds more than I do now, and was uncomfortable in my clothes. (C:69)

looking at myself in the mirror as my hair started to grow out, feeling more like me and less like somebody I never recognized. (C:101)

FEARING RECURRENCE

I'm afraid of...I try not to be. But every once in a while, you know how, sometimes your defenses are down. Sometimes I am actually afraid that I won't be able to get a good job, and I don't want to get bone cancer again. It's not like I go around worrying, you know, what disease am I gonna get...but like I say, every once in a while you have weak moments, and that does make me angry to think that you do everything you can, and then if you come down with it again...that's rotten. A raw deal. (B:96)

but the fear. The fear is always there. As I've had cancer again and again, it seems the chances get less and less that I'm gonna get better. (A:29)

So, it's real scary because I can expect it again and I don't know if they can pull me through it again, if I can pull me through again. (A:30)

even last time I had cancer, you know, I said, that was the second time, and I said if I ever have this again I'm just gonna die because I can't go through this again. But I did, and... it's, it's that there's a certain amount of fear and it's always there. (A:31)

My original plan when I got out of the hospital last year was that I was going to leave this spring, after it had been a year. Before it got hot. But somebody else that they had introduced me to, who had Non-Hodgkins lymphoma had gone through transplant the previous July recurred last August. And that frightened me a lot. (C:103)

And at first I was a little worried because of the type of transplant they did on me. I wasn't real sure that, I mean, if you stop and try to reason it out yourself, I'm no medical person, but to me, taking your stem cells out of your body and then giving them back to you doesn't seem like there's a real good chance that you're going to be here way down the road. I mean, in my way of looking at it, that's pretty shaky thing. It's not as sure as taking a healthy person's bone marrow and giving it to you. You're taking a real small thing there, and even though you're taking a lot of them, you're trying to build somebody completely back up from that. And, at times I'm really amazed. (D:62)

Both times it came back before, it was less than a year. I mean, I guess the longer you go, the more, I don't know, I guess the more sure you get about it, the less apprehensive...(D:75)

CONCERNS ABOUT DISCRIMINATION

I worry that because I've had cancer, employers will, you know, back off from that person, and they do that, even though they say they can't, 'cause it's discrimination. You can always find a reason if you don't want to hire somebody. (B:115)

The only time ever, in my whole life that I've encountered anyone with a prejudice was a woman, we were looking at an apartment, and the office manager wasn't pleasant to my mother and I, and I think it was because I was sick. She was just unreasonable. To this day that baffles me. (A:63)

I'm staying at the job that I've got now, and I'm, as long as they'll keep me, and concerned about my insurance benefits, which is part of the reason for staying there. (C:105)

Because I it's very difficult to get insurance now. I've talked to these other gals, and, and no one wants to insure you, if you've had any kind of cancer. I've heard about the problems with job hunting. Jobs...if they've got any kind of idea that you had cancer of any kind, they think this person get sick a lot, or, this person, you know, is gonna die on me, or who knows what they think... (E:104)

DISCOVERING A DIFFERENCE

ALTERED OUTLOOK/PRIORITIES

and like with my kids...how have I changed... I know things are different. Things have changed. I think I'm more, I'm more intent on developing an even better relationship with my children. To let them know that I love them. And not take them so much for granted. (B:44)

If a person does look at themself, they can see they need to make changes and what they need to do. But I think I've had shock therapy. So I could see real quick what was important and what wasn't. It certainly puts everything in order. (B:89)

Matter of fact, I feel like I've changed, too, I feel like, I don't even feel like the same person that I was before was real. I feel like a different person. (B:81)

Things aren't so important any more, like to have a nice car, you know, just things like that. (B:37)

If you've got your health you can, you can do almost anything. If you want to go to school, then you do it. And if you want to improve your life, then do it. And don't whine about it. (B:42)

Nothing is black and white anymore, because, overnight things change. You just hope that it will be, nothing too bad, and something that you can handle. You can handle anything you have to, what else you gonna do? But it'd be nice if it wasn't a bad thing. (B:95)

Another way, and it's really difficult for me to know if it's the transplant or just the whole thing of the last couple of years, has been my outlook -- it's just gotten a lot more positive than it was. (C:05)

I realize that I used to take my health for granted, I just assumed that I lived a healthy life, so I'd be healthy. (C:06)

That's changed. Now work is something to go to and do your best at and earn a salary from, but it's not my life. There are other things that are important in my life. (C:107)

What else is important to me is helping other people, not that everybody is as scared as I was, but probably everybody is somewhat scared. So helping other people get through it. (C:116)

I'm not a real materialistic person to a great extent, at least I don't think of myself as one, but, since then, since I was diagnosed, I concentrate more on what we can do together, or what we can maybe do for each other or for, you know, one of our children or our granddaughter, or something along that line. (D:34)

I'm more aware of myself now after this experience. And...I feel, I do feel stronger in one sense, and, and I'm more aware of everything around me, definitely. (E:01)

ACCEPTING LOSSES

I'm still trying to come to grips with the fact that I won't be able to have a baby. And I wanted to have a baby. My husband has two children from a previous marriage, but I wanted us to have a baby. So, that's the future part that bothers me, (A:91)

One of the real discomforts from this whole thing, actually I guess the problem started when they were giving me my Chemotherapy here before I was going to go down and be phoresed, but I developed a problem with my hearing. I have constant ringing in my ears, I mean it's like somebody just set a fire cracker off next to me, and my ear's ringing. They do that constantly. Evidently, they either gave me too much, or I hit my tolerance, but, this happened whenever I was in the hospital here, and it's been going continually since then, I mean, it's stayed with me all during the transplant and, you know, my doctor here in town told me that it would probably never go away. (D:55)

they tell me that I've lost some, but what I really notice is, it seems to me like an enormous loss of lung capacity. Now I don't know if part of it might be due to the treatments or the Chemotherapy, or the transplant, or whether it's due to physically not being in as good a condition or good a shape as I was, I would like to be or I used to be, I'm not real sure, but I can tell I've lost a lot of lung capacity. (D:56)

Well, see, now that did bother me. I thought, oh, I knew I would be affected in some way because my ovaries were gonna be destroyed. Or at least not functioning. There would be a change, and I remember reading in the consent, and I know I talked to a number of other BMT outpatients, (E:54)

But I think in my mind I was attributing, well, this is pre-menopause. Naturally that's part of aging, but I don't think I was really told specifically that I would go through pre-menopause. At any particular point. But I accepted it, I mean, what am I gonna do, I can't change anything. And the hot flashes didn't last that long. I mean, once in a while I still get sweaty or something, but that's not that bad. (E:56)

LOOKING AHEAD

But, as far as I see, I mean, I just see myself getting healthier and healthier, and going back to work in a few months, and just trying to pick up where I left off, and just start having our life again. (A:92)

I just want to try to spend even better quality time with my kids. I think that's important. (B:48)

Trying to look into the future, of when I do go back to work. And, you know, when things will be normal again. 'Cause I don't like being home all day. (B:100)

To lose weight, 'cause I've outgrown all my clothes...I just really look forward to that. (B:103)

What I hope my future will be is to get a good job, I'd like to go back to where I was working, that'd be great. (B:114)

I look forward to being able to take some pride in how I look, you know, looking attractive. (B:116)

As far as what I look to for the future, I plan on being around a long time. I feel real good about the transplant, (D:59)

I do see myself getting on with my life, and I don't see myself hanging around all the time and being pampered, because I certainly am not one to...(E:90)

DEFINING QUALITY OF LIFE

I guess I'd define it as, how fully I'm able to participate in life, and how happy I am with the way that they're going. (A:01)

That's hard to answer. I mean, like on a scale of one to a hundred, I would say quality, I think I'm going at about 60 percent right now. I expect to get back to 100 percent. You know, so the quality of life right now is diminished. (A:93)

How satisfied with where you are physically and where you are, your job, your friends, your health, which again, your, health was not something that I ever really thought about. (C:57)

As far as my quality of life now, I feel it's good. I, the only thing, if I could change anything as of right now, I would say I wish I was in a little bit better physical shape as far as durability and able to do things, but I really hope that sooner or later that will come around some. (D:58)

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