

Return to Work Experiences of Employed Women

with Breast Cancer in Trinidad

by

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Abstract

This qualitative study explored the experiences of employed women with breast cancer. The narrative approach using Frank's (1995) illness types and the feminist perspective were applied in looking at the women's diversity of experiences and meanings. Purposive sampling was used to recruit women aged 30-49 (n=8) who continued working during treatment and after treatment ended. Face to face, semi-structured interviews were conducted. The findings discovered that all the women got reasonable accommodations; work environment was supportive; and the majority was successful in returning to work despite treatment challenges. Two separated participants reported being locked into job because of medical insurance and discrimination. Concerns identified were: More support from health care professionals, information, dietary, counselling and the need to be listened to. This study can help social workers and other health care professionals to review their roles in supporting women who return to work and in managing the cancer experience.

Keywords: qualitative, narrative, employed women, breast cancer, feminist, return to work, support.

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Dedication

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Return to Work Experiences of Employed Women with Breast Cancer in Trinidad

Chapter One: Overview of the Study

Work is meaningful for cancer survivors because it helps to normalize their lives while coping with the illness. In working, survivors return to their preferred status and have a sense of control over their own lives (Brown & Tai-Seale, 1992; Edbril & Rieker, 1989; Feldman, 1987; Maunsell, Brisson, Dubois, Lauzier, & Fraser, 1999; Mock, 1998; Peteet, 2000; Stagner, 1987; Staley, Kagle, & Hatfield, 1987). Thus, work can be seen as a coping mechanism for the survivor in managing the psychosocial and economic stress of the disease (Brown & Tai-Seale, 1992; Clark & Landis, 1989; Edbril & Rieker, 1989; Jungman, 1999; Mock, 1998; Staley et al., 1987). The literature emphasizes that there has been little research on the work experiences of cancer survivors (Berry, 1993; Berry & Catanzaro, 1992; Clark & Landis, 1989; Edbril & Rieker, 1989; Maunsell et al., 1999; Staley et al., 1987). It also indicates that more research is needed in this area to keep pace with the technological and medical advancements in cancer detection and treatment.

Purpose

The researcher's interest in cancer and work stems from her professional experience as an oncology social worker in a treatment centre, and as an EAP counsellor in an industrial environment. She has seen many cancer survivors who stopped work because of the illness; while others who continued working during treatment grappled with their fears and concerns. The researcher's experience in these two areas aroused her interest to find out, how successful cancer survivors are in being able to bridge the gap between the diagnosis and 'returning to work.' The literature has shown that while returning to work is a positive experience for many survivors, for others it is fraught with difficulties (Clark &

Landis, 1989; Edbril & Rieker, 1989; Millette & Franco, 1987; Mock, 1998; National Cancer Institute, 1998; Staley et al., 1987). Some of these studies have also found that there are women survivors who may be emotionally affected long after their diagnosis (Davis, 2004).

The incidence and prevalence of breast cancer in Trinidad and Tobago (T&T) highlights this as a crucial area for attention (National Cancer Registry of Trinidad and Tobago [NCRTT], 2003). However, from the researcher's investigations she has not been able to unearth any research done in Trinidad and Tobago on women with breast cancer and their experiences on re-entering the workplace. The lack of research in this area deepened the researcher's resolve to discover how women cope with the diagnosis, the treatment, and returning to work.

Most of the studies on breast cancer in the literature have been mainly on women as they are at greater risk in developing the disease (Ellingson & Buzzanell, 1999). Because breast cancer is predominantly a female disease (Broom, 2001; Ellingson & Buzzanell, 1999) this qualitative research will focus only on women.

This study used a narrative approach to explore the holistic, categorical experiences of women with breast cancer who returned to the workplace during treatment and after treatment has ended. This narrative approach also advanced the feminist perspective that gives women, in sharing stories and restorying, a voice to discuss their diversity of experiences and meanings, which can help to increase understanding and enhance women's lives (Wilkinson, 2000).

The following section will discuss the location of the study with a brief overview of Trinidad and Tobago, and will elaborate on the cancer situation in Trinidad and Tobago.

The Location of the Study

Brief overview of Trinidad and Tobago.

Trinidad and Tobago is a twin island State located at the southern end of the Caribbean chain of islands and is situated approximately seven miles off the eastern coast of Venezuela. It is a democratic republic within the British Commonwealth, and has a multi-ethnic and multi-cultural population (Pan American Health Organization [PAHO], 2001; PAHO, 2005) of approximately 1.3 million (Ministry of Planning and Development [MOPD], 2004). Based on the 2000 census population, the ethnic groups are 40.0% East Indian descent, 37.5% African descent, 20.5% Mixed descent, 0.6% White, and 0.3% Chinese. Trinidad the larger island has a land area of 4,828Km² and Tobago's land area is 300 Km² (MOPD, 2009).

Trinidad's hydrocarbon resources and natural gas reserves have made Trinidad and Tobago the most industrialized country in the English speaking Caribbean (Ministry of Trade and Industry, 2005). The energy sector is the key source of government exports and revenues. This sector is being expanded along with agriculture, manufacturing, tourism, and services to develop growth in the economy (Budget Statement 2012, 2011; Review of the economy, 2011)

The cancer situation in Trinidad and Tobago.

Cancer is the second major cause of death after heart disease in Trinidad and Tobago (McDougall, Roach, Byam, Bodkyn, & Henry, 2002). For a number of years, the Ministry of Health has recognized that the country's oncology resources have been targeted toward late stage treatment of cancer and palliative care of terminal patients. In addition, the facilities for radiation therapy are inadequate to meet treatment demands

(Comprehensive Care International [CCI], 2004). The government of Trinidad and Tobago entered into a contractual arrangement with the Canadian government in 2000 to develop and implement a National Oncology Centre and a National Oncology Programme (CCI, 2004; Doon, 2004).

In order to reduce morbidity and mortality the new Centre will provide a “comprehensive...and equitable system of cancer control” (CCI, 2004, p. 4), that emphasizes prevention, screening, early diagnosis and care, treatment, palliation and support, expansion of services, development of programmes and resources. The new Centre will give strategic direction and co-ordinate services on a national level. The long-term objective of the National Oncology Centre is to reduce the economic and social burden of cancer. Once this goal is achieved Trinidad and Tobago will become a regional leader in oncology with outcomes that meet international benchmarks (CCI, 2004).

The implementation of this plan began in January, 2005 (CCI, 2004) and the construction of the three storey building started in April 2007. However, there were delays “due to the need to engage more effective project management services.” (Ministry of Planning, Housing and the Environment, 2009). S. Smith, Senior Health Systems Advisor reported that the government has given approval for the recommencement of building the Centre which is scheduled for the first quarter of 2012 (personal communication, November 29, 2011).

A private facility called the Brian Lara Cancer Treatment Centre (BLCTC) was opened in April, 2007 and is located in capital, Port of Spain. It is the second Centre in Trinidad and Tobago to offer both radiation and chemotherapy treatment. This researcher had the opportunity to tour the new Centre, which can boast of state of the art technology

in cancer treatment (Osman, 2007). Another private facility, the Southern Medical Oncology Centre (SMOC) was established out of a private hospital in the second major city of San Fernando. According to I. Cielto Oncology Nurse, the SMOC which also provides both radiotherapy and chemotherapy began operations in July 2008 (personal communication August 25, 2008).

This study will contribute to the major changes taking place within the country's oncology system. The researcher's findings may confirm present limitations within the oncology delivery system; identify further gaps, and offer recommendations for developing more efficient and effective client centred services, especially for cancer survivors who re-enter the workplace.

The Prevalence of Breast Cancer

Breast cancer in Trinidad and Tobago.

It is estimated that 1 in 25 women will develop breast cancer in Trinidad and Tobago (NCRTT, 2003). Breast cancer is the leading cancer among women and the main cause of cancer death in women, attributing to over 1 in 5 female cancer deaths [22.2%] (NCRTT, 2003). Most recent figures from the NCRTT (2011) indicated that breast cancer accounted for 15.8% of all new cancers (both male and female) during the period January 2000-December 2007. During this same period, the National Cancer Registry recorded 8,094 new cases of female cancers in the country. Breast cancer represented 31.8% (2575) of this total figure. The number of female cancer deaths reported was 4,690, breast cancer caused 23.7% (1,111) of these deaths. It should be noted that the deceased women may not be the same individuals diagnosed within the time period recorded (NCRTT, 2011).

V. Roach Cancer Registrar, indicated that the figures for breast cancer suggest that although there have been more breast awareness campaigns in Trinidad in recent years there are still certain barriers to accessing screening services (Modeste, Caleb-Drayton, & Montgomery, 1999; personal communication, May 6, 2005). This point was evident in Modeste et al.'s, 1996 survey study of 265 women in Tobago, on the barriers to early detection of breast cancer. Some of the barriers that were discovered: A low level of breast self-examination, no available mammography services in Tobago, cost of screening, fear of cancer, and "a belief that no matter what they did, if they were to get breast cancer, they would get it" (p. 154). Although no comparable study has been done in Trinidad, some of Modeste et al.'s (1999) findings are similar to those found by this researcher in her practice experience in Trinidad and Tobago.

In Trinidad, mammography services have been offered at private institutions for a number of years (NCRTT, 2003). This researcher also discovered such a system in her own efforts to procure these services for clients. The Ministry of Health has now provided mammography machines to all the major hospitals (John, 2005) including Tobago (V. Roach, personal communication, November 9, 2011).

The Trinidad and Tobago Cancer Society conducts mammography tests in house at a cost. In April 2005, the Trinidad and Tobago Cancer Society commissioned a mobile mammography unit (John, 2005). It seems that earlier screening services and education are instrumental in diagnosing breast cancer in women during the early stages of the disease (Carter, 1994; Modeste et al., 1999). This can assist women to make the necessary lifestyle adjustments in both their personal and work lives (Carter, 1994).

V. Roach (personal communication, May 6, 2005; June 20, 2011) stated that the National Cancer Registry which was established in 1994, has no data available for the five year survival rate for any of the cancers. In the United States the five year survival rate for white women in all stages of breast cancer combined is now 90%, and for African-American women 77%. This difference is mainly due to later detection, lack of health insurance, and other risk factors (American Cancer Society [ACS], 2011). Although speculative at this juncture, it appears that socio economic factors and lack of education may affect early detection, treatment and survival among some women in Trinidad and Tobago. This assumption is based on Modeste et al.'s (1999) findings in Tobago, and this researcher's assessment in her intervention over the years with some women.

The rising incidence of breast cancer in both developed and developing countries is a major health concern (Modeste et al., 1999). For example, breast cancer is also the leading cancer among women in North America affecting 1 in 8 females in the United States (ACS, 2011). In Canada 1 in 9 Canadian women is expected to develop breast cancer in her lifetime, and 1 in 29 women will die from this disease (Canadian Cancer Society [CCS], 2011).

Labour force characteristics in Trinidad and Tobago.

This study looked at women who are in the work force. Economic trends have shown that there are more women employed outside the home (International Labour Organization [ILO], 2004; United Nations, 2006). According to Bushunow, Sun, Raubertas, and Rosenthal (1995) many women see employment as an "important aspect of economic, social, and psychological well-being" (p. 76). The increasing number of

women in the labour force signifies that many women will develop cancer at some point in their work lives.

In Trinidad and Tobago, the labour market participation rate for the non-institutional female population 15 years and over in 1994 was 44.3% compared to 74.6% for males that year. During the past 13 years (1994-2006) the participation rate for females has grown steadily with the highest rate being 53.1% in 2006 (MOPD, 2011). This trend indicates that more women are entering the labour force because of increased educational opportunities, a need to contribute to household incomes and other social economic factors (United Nations press release on T&T CEDAW twenty-sixth session meetings, January 21, 2002). Since 2007 there have been some fluctuations and the participation rate dropped to 51.1% in 2009. Between 2007-2009 there were more women employed, but fewer women who did not have jobs were seeking employment (MOPD, 2011). It is uncertain what factors could have contributed to this decline. The participation rate for males in the last sixteen years varied slightly, and was 74.3% in 2009 (MOPD, 2011).

This study focussed on employed women 30-49 years, who are neither too young and inexperienced nor too close to retirement age. In 2009, the labour force participation rate for women in the 30-49 age range was 70%. Within this age span, the 35-39 group had the highest participation rate of 70.9%, and the 30-34 age group followed closely with 70.8% (MPOD, 2011).

V. Roach, (personal communication, May 6, 2005) noted that there is a trend that younger women in Trinidad and Tobago are being diagnosed with breast cancer. From January 2000 - December 2007, 34.3% (882) of women in the 30-49 age range were

diagnosed with breast cancer. During this same period, women with breast cancer in the 35-39 and 30-34 groupings were 5.8% (149) and 3.1% (79) respectively (NCRTT, 2011). The researcher wonders whether there are more women from these two age groups that are unknown to the Cancer Registry. Mrs. Roach reported,

That the data provided is a representative of the cancers recorded in our Registry at this time, because data relevant to any particular year continues to be received for a long time after the end of that year. The database is therefore continually being updated (personal communication, July 12, 2011).

In the five year age group distribution (20-24, 25-29 etc.) of all females with breast cancer in Trinidad and Tobago, the highest percentage was located in the 45-49 age group [14.4% = 371] (NCRTT, 2011). It appears therefore, that the rising number of breast cancer cases in Trinidad and Tobago is found in women during the most productive years of their work lives.

Theoretical Perspective

For many individuals a cancer diagnosis is a life threatening stressful event which can lead to emotional, physical and mental distress. The most frequent emotions experienced by cancer survivors are depression, anxiety and stress, which may be due to the intense feelings about the cancer and its treatment (Katz, 2003; Kayser, Sormanti, & Strainchamps, 1999; Krause, 1993). These emotions can influence the individual's social roles and overall functioning (Forjaz, 2000).

A feminist perspective was used in this research because it has contributed greatly to recent cancer discourse, and has brought to the forefront some important women's issues (A Feminist Voice in Cancer Debates, 1998). According to feminists' thinking, it is

difficult for women to make sense of their experiences because of various conflicting attitudes that are steeped in powerful biomedical discourse and convoluted cultural and historical views. For example, the individual has little power or authority, illness is seen as bad, and illness is a biological experience (Collie & Long, 2005). The feminist and postmodern perspectives believe that knowledge is subjective and they identify and respect women's subjective experience (Marshall & Rossman, 1999).

Coping with breast cancer can be physically and emotionally difficult for women and their families (Choumanova et al., 2006; Nezu, Nezu, Houts, Friedman, & Faddis, 1999). Coping strategies have been linked with adjustment to breast cancer (Henderson, Gore, Davis, & Condon, 2003), and women use various coping strategies that change over time based on the course of the disease and treatment (Dukes Holland & Holahan, 2003). According to Livneh (2000) adaptive coping strategies can lead to less psychological distress and improved well-being (Sorajjakool & Seyle, 2005).

Many breast cancer survivors require support in adjusting to the illness and treatment. According to Manne (2003), there is a body of empirical evidence that social support plays an instrumental role in maintaining health, adjusting to illness, enhancing psychological well-being, and reducing occupational stress for the individual (Chapman, 2000; House, 1981; Schnoll, Knowles, & Harlow, 2002). In fact, social support has been shown as a key factor in helping women to cope with breast cancer (Davis, 2004; Roberts, Cox, Shannon, & Wells, 1994).

Thus, coping and social support are two constructs that were used in this study to determine how employed women experience living with cancer.

Relevance to Social Work and Workplace Policies

This exploratory study will add a new body of knowledge to the field of social work and specifically to social work in Trinidad and Tobago. Understanding the psychosocial effects of cancer on the work lives of breast cancer survivors can aid to improve social work services to this clientele. It will help to reinforce the need for social work intervention soon after the initial diagnosis when some breast cancer survivors are also dealing with concerns such as body image, sexuality, and relationship issues. These concerns can make them apprehensive about having treatment and returning to work.

During the disease course women go through various stages from diagnosis to survivorship (Sadeh-Tassa, Drory, Ginzburg, & Stadler, 1999). According to Sadeh-Tassa et al., each stage uses various coping and adaptive methods. The social worker can help the survivor transverse the various medical systems of hospitalization, surgery, treatment planning, laboratory blood work, required diagnostic tests, and follow up medical appointments. This is especially important during a time when the individual is experiencing anxiety and mental distress. To ascertain the individual's ability to cope in the present and for the future, the social worker assesses the individual's strengths and limitations in order to assist her to manage the new reality of breast cancer (Sadeh-Tassa et al., 1999).

The strategies that women used to cope with life before breast cancer are not as effective with this new reality. Therefore, clinicians need to be aware of where women are in the adjustment process and disseminate information relevant to their present emotional condition (Lethborg, Kissane, Burns, & Snyder, 2000).

Roberts et al. (1994) noted that a clearer insight as to the role of social support in women's lives would be of value to social workers in their management plan. The types of social support may include emotional support which covers counselling and showing empathy, instrumental support such as attending to various needs, informational support as it pertains to managing health related issues, and appraisal support which looks at self evaluation (House, 1981). In addition, social workers can assist women who have cancer to develop a return-to-work schedule which can also help to minimize absences (Berry, 1993).

This study can educate social workers and other health care professionals about the importance of returning to work for cancer survivors. It can identify how certain dominant discourses influence some professional attitudes which can impede the reintegration process. The results can be useful to new social workers and social work students in understanding the various issues that women with breast cancer may encounter in the workplace.

The findings can also assist professionals to develop interventions and programmes aimed at the workplace for survivors, co-workers and employers. The literature outlined a number of approaches for supporting cancer survivors return to the workplace. Various studies recommended and promoted the benefits of a number of workplace programmes to reduce the effects of cancer on the individual and the organization. Some of these studies looked at a comprehensive work re-entry programme which involved counselling; educational sessions in the workplace to address myths about cancer; and cancer survivors' competence in being able to perform their jobs (Brown &

Tai-Seale, 1992; Carter 1994; Clark & Landis, 1989; Crothers, 1987; Feldman, 1976, 1987; McKenna & Togia, 1989; Peteet, 2000; Sanchez, 2001).

For example, Stagner (1987) described Work Site Counselling and Consultation Service sponsored by Cancer Care Inc., in New York which provided: (i) lunch time education and training workshops; (ii) consultation with personnel regarding job performance issues; (iii) help in developing and/or running worksite support groups; and (iv) access to professional social services with an emphasis on total confidentiality (Crothers, 1987). This programme appears to utilize an EAP approach which is similar to EAPs in Trinidad and Tobago. However, there are no specific work site cancer programmes in Trinidad and Tobago for helping survivors reintegrate into their jobs.

The corporate world views the thrust towards health promotion and illness prevention as providing a healthier workforce (McKenna & Togia, 1989). The benefits of instituting many of the organizational health promotion and wellness programmes in the workplace, [which are in existence in Trinidad] outweigh the costs of labour turnover, recruitment and training of new workers. These programmes also send a strong message that employers value employees' quality of life which in turn can boost employee morale and loyalty (McKenna & Toghia, 1989; Stagner, 1987). The experiences of breast cancer survivors can encourage employers in Trinidad and Tobago to review whether their organizational policies support cancer survivors returning to the workplace.

National organizations that may be interested in the findings from this study are the Trinidad and Tobago Cancer Society; the Associates of the Radiotherapy Centre Limited in Trinidad; and the Cancer Support Organization in Trinidad. These organizations can

use the results to influence social policy on issues impacting work ability, and to provide opportunities for the recovered cancer survivor in Trinidad and Tobago.

Summary

This chapter outlined the nature, purpose, and the theoretical perspective of the research. It gave an overview of the location of the study, the cancer situation and the prevalence of breast cancer in Trinidad and Tobago. The relevance of the study to social work and workplace policies were delineated. The next chapter will review the literature on cancer and work, legislation in Trinidad and Tobago and the various strategies women use in managing the breast cancer experience. It will also discuss the feminist perspective and the narrative approach to dealing with breast cancer.

Chapter Two: Literature Review

Studies on Cancer and Work

This thesis will now explore whether and in what ways the incidence and prevalence of cancer impacts on the work lives of affected persons. A review of the literature found only a limited number of studies directly relating to cancer and ‘returning to work,’ and fewer studies on women with breast cancer in recent years (Clark & Landis, 1989; Maunsell et al., 1999; Maunsell et al., 2004). Berry and Catanzaro (1992) reported that, “current knowledge about the return-to-work experience for individuals with cancer is limited and often anecdotal” (p. 44).

Various studies discovered that cancer survivors faced a number of issues when they re-enter the workplace. These interrelated concerns are: i) attitudinal and behavioural changes; ii) physical changes in functional abilities, both short and long term; and iii) financial problems (Brown & Tai-Seale, 1992; Crothers, 1987; Mellette, 1985). An individual’s personal life and work life are closely knit; therefore, reintegration into the workplace is a complex process. For example, the survivor has to manage the psychosocial stress of learning to live with the illness, the effects on her or his well-being, and its impact on the work situation (Jungman 1999).

In their study on cancer survivors’ work related issues, Schultz, Beck, Stava, and Sellin (2002) found that most cancer survivors do not present with employment related concerns. Many are easily integrated back to work and are supported by co-workers and employers (Clark & Landis, 1989). From their study 7.3% (110 out of 1,526 who were working when surveyed) experienced job discrimination. The authors admitted that, “for those who have cancer related issues, little is known about their experiences. Research

data are scant and heterogeneous” (Schultz et al., 2002, p. 226). They also noted that the type of cancer, age (Berry, 1993), gender and ethnic group influenced whether the survivor returned to work (Schultz et al., 2002).

Today, more people with cancer continue to work while undergoing chemotherapy and radiotherapy (Edbril & Rieker, 1989; Messner & Patterson, 2001; Schultz et al., 2002; Spelten, Sprangers, & Verbeek, 2002). In fact, in their review of 14 studies, Spelten et al. (2002) indicated that the mean rate of survivors who returned to work after treatment was 62% (range 30-93%) (Berry, 1993; Bloom et al., 1988; Bushunow et al., 1995; Crothers, 1987; Edbril & Rieker, 1989; Feldman, 1976; Greenwald et al., 1989; Mellette, 1985; Petet, 2000; Razavi et al., 1993; Sanchez, 2001; Staley et al., 1987; Steele, 1993; van der Wouden et al., 1992). These research studies revealed that cancer survivors are just as productive as other employees, and their absenteeism does not exceed those of other workers (Brown & Tai-Seale, 1992; Shultz et al., 2002; Ziegler, 1998). Yet there is still pessimism among the lay public and employers concerning a cancer diagnosis (Berry, 1993; Hoffman, 1989; Shultz et al., 2002; Steele, 1993).

A number of common themes appeared throughout the literature regarding the return to work experiences of cancer survivors and have been highlighted as follows.

Pre- illness histories.

An area that needs to be considered in the cancer equation is, to what extent does cancer alone cause employment problems, and to what extent are non-cancer problems a deciding factor? (Brown & Tai-Seale, 1992; Houts et al., 1989). The illness can be seen as another problem compounding an already untenable situation. In their investigation, Houts et al. (1989) identified that individuals dissatisfied with their jobs before the illness,

were more inclined to have negative feelings and grievances post diagnosis. This occurred mainly in relation to supervisors and fellow workers, and suggested that previous interpersonal problems on the job are a probable cause (Houts et al., 1989).

Cancer myths.

Misconceptions about cancer are caused by myths that still flourish in society, and are perpetuated in the workplace through subtle or deliberate discrimination (Burrage, 1999; Messner & Patterson 2001; Ziegler, 1998). These attitudes are steeped in ancient beliefs that people with cancer are unclean and immoral, and should feel guilt and shame about the cancer (Feldman, 1987). Also, in the early 1900s few people survived the disease and hence it was viewed as a death sentence (Feldman, 1987; Ziegler, 1998).

Three of the most prominent beliefs are: 1) Cancer is a death sentence; 2) Cancer is contagious; and 3) Cancer survivors are an unproductive drain on the economy (Brown & Tai-Seale, 1992; Burrage, 1999; Clark & Landis, 1989; Hoffman, 1989, 1991; Schultz et al., 2002). Society's fears about cancer and social labelling of cancer survivors have contributed to some survivors hiding their diagnosis to avoid being stigmatized (Broom, 2001).

People's beliefs about cancer can affect their perceptions and interactions as seen in the following two surveys. For example, a telephone survey (1997), cosponsored by the National Coalition for Cancer Survivorship and Amgen Inc. in the United States, surveyed 662 people without cancer. The findings showed that although 87% acknowledged work contributed to emotional stability among individuals, 42% felt people with cancer "would have special needs and require special arrangements" (National Cancer Institute, 1998, p.

191). Twenty seven (27%) percent believed “they would have to pick up the slack for a co-worker with cancer” (National Cancer Institute, 1998, p. 191).

Another survey (1996) cosponsored by Amgen and Working Woman magazine, contacted 500 employed cancer survivors undergoing treatment, and 100 co-workers and supervisors of cancer survivors. They found that 81% of cancer survivors saw their jobs providing “emotional stability during treatment” (National Cancer Institute, 1998, p. 191). Fourteen percent (14%) had reduced work responsibilities due to the diagnosis. Although, 33% of supervisors believed that the survivor could not manage their job and the disease; only 19% of co-workers felt this way. Thirty one percent (31%) of supervisors maintained that cancer survivors “needed to be replaced” (National Cancer Institute, 1998, p. 191).

Discrimination.

The early studies on cancer and work focussed on discrimination which was based on anecdotal reports from cancer survivors returning to work (Chapman, 2000; Feldman, 1976; Mellette, 1985; Mor, 1987). Some of the major outcomes of job discrimination highlighted in the literature were dismissal, transfers, demotion, refusal to accommodate, reduction in fringe benefits, hostility/acceptance, and denial of new jobs (Feldman, 1976; Hoffman, 1991; Maunsell et al., 1999; Maunsell et al., 2004; McKenna & Togia, 1989; Weis, Koch, Kruck, & Beck, 1994).

The literature presented mixed views about the extent of discrimination in the workplace. Many of the studies focussed specifically on individuals who were employed at the time the study was carried out, which ranged anywhere from 2 years - 5years after diagnosis. This raised the question, what about those individuals who encountered discrimination and left their jobs before the study period. Schultz et al. (2002) referred to

this point in their study when they reflected that, “some of the individuals who may have experienced job discrimination in the past and were no longer working have been eliminated from the analysis” (p. 225).

Maunsell et al. (2004) conducted a retrospective study in Quebec on the work experiences of 646 women with breast cancer three years after diagnosis. A matched control group of 890 employed women without cancer were also interviewed over the telephone. The women were under 60 years when they were treated for breast cancer. In both groups, participants who were no longer employed indicated that they left work voluntarily, and those still employed did not experience any “deterioration in working conditions” (Maunsell et al., 2004, p. 1813). The researchers concluded that women with breast cancer do not experience more discrimination in the workplace than other women. They noted that this finding could be useful for employed women who are anxious about working after breast cancer.

In Spelten et al.'s (2002) examination of 14 studies, discrimination was not a major issue in returning to work. Chapman's (2000) research on employed women with breast cancer had inconclusive findings about discrimination due to the small number (0.8%) who reported being laid off. Sanchez's (2001) research on vocational rehabilitation among colorectal cancer survivors found only a small percentage (2.4% = 4 people) of employment discrimination. She suggested that the American with Disabilities Act was creating a difference. Zieglar (1998) on the other hand, postulated that discrimination continues even with the legal protections in place to manage this issue (Burrage, 1999; Chapman, 2000). Messner & Patterson (2001) also maintained that despite these legal

protections, there are employers, supervisors and co-workers who believe that people with cancer are a liability in the work environment.

Legislation in Trinidad and Tobago

Discrimination is an important issue that should be factored into studies on employment and cancer. However, as in most studies there will be limitations to securing this information because of individual beliefs, the organizational culture of the work setting, social systems, and norms (Chapman, 2000). There is also the reality that discrimination does not always happen overtly (Beck, Reitz, & Weiner, 2002; Sanchez, 2001).

The advent of the 21st century saw issues of equal rights and equality of treatment being embedded in laws of equal opportunity in many countries. However, inequality continues to flourish in the professional and public arena because attitudes, stereotypes, and role images are still heavily governed by patriarchal traditions (Wodak, 2005).

With these caveats in mind, this section will look at the key legislative frameworks in Trinidad and Tobago that address employment equity, women and disabilities. Most of the discussions pertaining to Trinidad and Tobago legislations and women's issues are found in the United Nations (UN) and International Labour Organization (ILO) reports on Trinidad and Tobago. These two organizations have local offices in Trinidad.

The Trinidad and Tobago Committee on the Elimination of Discrimination against Women (CEDAW) delegation reported during the twenty-sixth session to the United Nations in New York, 2002, that there are certain disparities in the law re discrimination and employment of women. For example, it is stated that discrimination by sex is prohibited in the Constitution, but there is no definition of discrimination in the

Constitution of Trinidad and Tobago, or in other legislation (UN press release on T&T CEDAW meetings, 2002).

In reference to the public sector, the Constitution assures, “the right of the individual to equality of treatment from any public authority in the exercise of any function” (The Constitution of the Republic of Trinidad & Tobago Act of 1976, chap.1, sect. 4 d, p. 17). However, since the inception of the Constitution, there have been many claims about the contravention of the right to equality of treatment and the Courts have had to give respite to applicants in many cases (Hosein, 2005).

The Trinidad and Tobago CEDAW delegation noted that the Ombudsman has the authority to investigate complaints from individuals whose constitutional rights have been breached by any government agencies or agent of the State. The delegation further explained that an individual might file a motion with the High Court for reparation (UN press release on T&T CEDAW meetings, 2002). However, judicial review can be a lengthy and costly process, beyond the means of the average complainant (Hosein, 2005). In addition, “the Constitution does not prohibit acts of discrimination by non-State or private bodies, nor is there any legislation dealing with such” (UN press release on T&T CEDAW meetings, 2002, p. 4; Hosein, 2005).

Trinidad and Tobago’s Equal Opportunity legislation of 2000 was enacted to prohibit discrimination made by persons both in the public and private sector on such grounds as sex, race, ethnicity, marital status, religion or disability (The Equal Opportunity Act of 2000). An Equal Opportunity Commission was set up with the power to hear and investigate complaints. An Equal Opportunity Tribunal was also appointed whereby the Commission could refer any unresolved complaints (Hosein, 2005; ILO, 2004; The Equal

Opportunity Act of 2000). Trinidad and Tobago's Equal Opportunity Act of 2000 helps to ensure equality in the private sector. Persons who report discrimination by an employer or another individual in the private sector now have a course of redress.

The Trinidad and Tobago general industrial relations policy is founded on the voluntary collective bargaining between employers and workers, through their various representative bodies [Unions] for terms and conditions of employment. Under the Industrial Relations Act (1972, chap. 88:01 of the laws of Trinidad & Tobago) an employee cannot represent him or herself as an individual to a trade dispute (ILO, 2004). However, because of the increase in non-unionized contract employment, the legislature passed the Retrenchment and Severance Benefits Act of 1985, and the Maternity Protection Act of 1998. Both these Acts allow the non-unionized individual worker to seek redress before the Industrial Court (ILO, 2004).

The Trinidad and Tobago CEDAW delegation stated in their 2002 report to the United Nations that, "special needs and concerns of women are integrated in all employment policies" (UN press release on T&T CEDAW meetings, 2002, p. 6). Some women with breast cancer will have difficulty in performing their jobs because of limited physical functional ability or cognitive functioning. It will be useful to find out whether employment policies in Trinidad provide reasonable accommodations for women returning to work after breast cancer surgery and treatment. Even with the enforcement of Trinidad and Tobago's Equal Opportunity Act of 2000, it will also be important to discover to what extent discrimination occurs among breast cancer survivors who return to the workplace.

The Americans with Disabilities Act (ADA, 1990) includes cancer as a disability. The ADA also mandates that reasonable accommodations be provided for employees with

disabilities in order to improve their work performance (Allen & Carlson, 2003; Burrage, 1999; Hoffman, 1991; Messner & Patterson, 2001). The definition of disability in Canada's Employment Equity Act (1996) allows for liberal interpretations, and can be applied to people who have cancer and other illnesses that affect their functioning. At present Trinidad and Tobago's legislation does not cover illnesses per se.

Physical Changes in Functional Abilities

The various studies on work also accentuated survivors' functional abilities after cancer. In their research on breast cancer, Bushunow et al. (1995) and Satariano and DeLorenze (1996) identified that over 70% of the women returned to work in three months and over 90% returned after six months. Based on these statistics it appears that more women with breast cancer will continue to return to work.

Studies highlighted that women with breast cancer took the most time off work mainly because of surgery. Mellette (1985) cited Feldman's (1978) blue collar study, where 59% of the women with breast cancer were absent for nine weeks and more after surgery. In addition to surgery, many women with breast cancer may also have combination therapy – radiotherapy, chemotherapy, and hormone therapy and will experience different reactions to the treatment regimen (Bushunow et al., 1995; Dukes Holland & Holahan, 2003; Maunsell et al., 1999; Mock, 1998). This is dependent on the stage and type of breast cancer (Bushunow et al., 1995; McKenna & Toghia, 1989).

Women returning to work during and after treatment may have certain fears about the treatment affecting their jobs, and this period can be very stressful for the individual. Some may have few side effects, while others may become so fatigued and debilitated that they may have to stop work (Chapman, 2000; Maunsell et al., 1999). Mock (1998)

reported that fatigue has been correlated with activity level, emotional distress, anxiety, and depression. In addition, women have acknowledged that fatigue contributed to a reduction in work hours, more time off, and being less productive both physically and cognitively (Chapman, 2000; Mock, 1998; Weis et al., 1994).

Findings from Chapman's (2000) research showed that variations in the time women were off their jobs were related to physical limitations following chemotherapy or surgery. Her results are contradictory to Bushunow et al. (1995) who concluded from their research, that chemotherapy did not impede women with early breast cancer from returning to work. This incongruence may be owing to differences in their populations, treatment regimen or other unmeasured factors (Chapman, 2000). In fact, Bushunow et al. (1995) stated that in describing employment-related disability, "the primary endpoint was return to work" (p. 76) which may have produced a different outcome than those found in previous studies. Mellette (1985) also discovered that women on treatment for breast cancer, including some women with advanced disease, continued in their jobs with few absences and minimal work related problems (Berry & Catanzaro, 1992; Mellette, 1985).

Job characteristics.

In their examination of 14 studies, Spelten et al. (2002) deduced that manual labour and physical demands of the job heavily influenced return to work (Sanchez, 2001). Greenwald et al.'s (1989) study showed that individuals whose jobs were physically strenuous appeared to experience some type of work disability. Those who had high time discretion [flexibility in working hours] and skill discretion [pace of work] seemed to stay in their jobs, and functioned at previous levels of energy and skill (Greenwald et al., 1989). However, Chapman's (2000) research found that a flexible work environment was linked

to work interruption. She attributed this result to women who may have been managers working in jobs that were not only quite flexible, but also very demanding (Chapman, 2000).

Satariano and DeLorenze (1996) noted that being on leave three months after breast cancer was associated with limitations in upper body strength, jobs requiring physical exertion, and a need for assistance with transportation. Also women whose jobs entailed more rigorous physical activity were less likely to return to work, than females whose jobs required minimal physical endurance (Chapman, 2000; Greenwald et al., 1989; Satariano & DeLorenze, 1996).

Cancer survivors working in blue collar/low income or seasonal jobs tended to encounter employment problems (Feldman, 1976, 1987; McKenna & Togia, 1989; Mor, 1987; Satariano & De Lorenze, 1996; Weis et al., 1994). Some individuals either changed to less demanding work or gave up their jobs (Weis et al., 1994). Sanchez (2001) discovered that survivors in service occupations [waitresses, salespeople, etc.] were more likely to experience return to work delays, than those in white collar [professional and managerial] occupations. Another interesting perspective raised by Maunsell et al. (1999) is whether the problems women encountered are due to the breast cancer or prolonged absence from work. For example, the treatment regimen may cause some women to be off the job for six months or more (Maunsell et al., 1999).

Financial Problems

Medical benefits.

In most of the studies, health insurance is stated repeatedly as a particular concern for individuals. For example, Van der Wouden et al. (1992) found that 35% of the

respondents attempted to either procure insurance or amend their insurance policy, while those between the ages of 21-45 encountered problems due to the cancer. They were either denied coverage, had to pay higher premiums or undergo medical re-examinations (Mellette & Franco 1987; van de Wouden et al., 1992). Chapman's (2000) research highlighted that all the women who had paid disability benefits, used those benefits which accounted for the most leave days taken. She believed that women, who are physically well and can work, might utilize their disability leave because it is accessible. This can also explain women's delay in returning to work (Chapman, 2000). The implication here is that women may use the opportunity to take the time needed to heal, unlike women who are forced to re-enter the workforce due to lack of funding.

Accessibility of treatment services in Trinidad and Tobago.

In Trinidad and Tobago, treatment for both radiotherapy and chemotherapy at the government run National Radiotherapy Centre is provided free of charge through the Ministry of Health (MOPD, 2004). Dr. W. Dhanessar Oncologist, indicated there are occasions when some chemotherapy drugs are not available and have to be bought by the survivor (W. Dhanessar, personal communication, April 8, 2006). In addition, some required diagnostic tests are not offered at the hospitals, and are expensive privately. For example, bone scans can be obtained only at two private facilities. That situation existed in the past when this researcher was involved in helping to procure diagnostic services for clients. Dr. Dhanessar confirmed that this was still the current situation.

From this researcher's experience, there are survivors who choose to have their surgeries, chemotherapy and diagnostic tests at a private hospital or facility. This is dependent on their ability to pay, medical insurance, and the wait time for certain

procedures. For instance, magnetic resonance imaging (MRI) is done at only one government hospital. The other two Centres that offer this procedure are privately owned (Dr. W. Dhanessar, personal communication, April 8, 2006).

However, in more recent years the Ministry of Health has improved facilities and is now providing a number of free cancer care services throughout the public health sector. The National Radiotherapy Centre which is still the principal referral centre for cancer care uses cobalt machines to treat patients. According to V. Haynes a medical social worker at NRC, in August 2007 a Cabinet appointed committee was set up at the Ministry of Health to establish a clinical assessment committee. Ms. Haynes who sits on this committee, stated that the Ministry of Health has outsourced radiotherapy from both the BLCTC and the SMOC which have linear accelerator radiation machines. Patients with certain types of cancers are referred for treatment. For example, women who attend NRC and have cancer of the left breast [closer to the heart] received radiotherapy at these two private facilities (Personal communication, November 1, 2011).

Another development is that three satellite cancer units now give chemotherapy treatment in three major hospitals, two in Trinidad and one in Tobago (Khan, 2011). Many individuals no longer have to travel from all over Trinidad and Tobago to access chemotherapy free of charge at NRC. In addition, patients who required medical investigations at the beginning, middle and end of treatment are referred to the Medical Social Work department. They are assessed and based on their ability to pay contributed a portion towards the procedure. Some of the tests are bone scans, MRI, CT scans, lymphatic scans and others that the Ministry pays for each patient (V. Haynes, personal communication, November 1, 2011). It would appear that financial assistance in having

diagnostic tests privately would avoid some of the long wait time for individuals in starting treatment.

Reconstructive surgery is an expensive operation privately. However, women with breast cancer can now have breast reconstruction free of charge. A specialized breast cancer clinic has been set up at NRC where tumour removal and reconstructive surgeries are performed (Khan, 2011). Ms. Haynes reported that this service began in October 2010, and to date there has been 137 breast reconstruction surgeries (personal communication, December 8, 2011).

McKenna & Toghia (1989) noted that individuals who are in the lower income bracket and without medical insurance would have difficulty in accessing adequate treatment and care. It would seem that based on improved services many more breast cancer survivors would have entry to quality treatment in a timely manner. However, this researcher believes that it will be important to understand to what extent medical benefits or lack of, is an issue for employed women with breast cancer in Trinidad.

Coping, Social Support and Illness

Both coping and social support will provide a conceptual framework for this thesis on how women with breast cancer adjust to the illness and work. According to Manne (2003), coping and social support are two constructs which: i) describe why certain individuals are more prone to develop illnesses such as cardiovascular diseases and cancer; ii) why some individuals have difficulty in adjusting once they become ill; and iii) more recently, they have been associated with the disease course and survival after diagnosis.

Coping.

Over the past twenty years, coping has been widely studied as it relates to health and illness (Manne, 2003). Henderson et al. (2003) noted that the term ‘coping’ has been used interchangeably with words like adaptation, mastery, resiliency, management, and adjustment. The concept of coping has been closely associated with stress and there are several definitions of coping to be found in the literature (Henderson et al., 2003).

The most popular definition of coping is Lazarus and Folkman’s (1984) transactional stress and coping paradigm (Manne, 2003). Lazarus and Folkman (as cited in Fridfinnsdottir, 1997) defined coping as, “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Fridfinnsdottir, 1997, p.526; Culver, Arena, Antoni, & Carver, 2002; Gall, 2000; Heim, Valach, & Schaffner, 1997; Henderson et al., 2003; Holland & Holahan, 2003; Kayser et al., 1999; Krause, 1993; Livneh, 2000; Manne, 2003; Nezu et al., 1999). Lazarus and Folkman separated coping into two major functions: emotion-focussed coping which controls the emotions that originate out of the distress, and problem-focussed coping which refers to changing the problem causing the distress (Fridfinnsdottir, 1997; Krause, 1993; Manne, 2003; Nezu et al., 1999).

Nezu et al. (1999) stated that Lazarus and Folkman (1984) viewed problem solving as a form of problem-focussed coping, and its effectiveness pertained to problem situations that are evaluated as changeable. However, when a stressful situation is evaluated as unchangeable, the individual’s only recourse is on emotion-focussed coping to effectively deal with the stress (Nezu et al., 1999). Lazarus and Folkman outlined emotion-focussed

coping as avoidance (denial), minimization, distancing, selective attention and wresting positive value from negative events (Fridfinnsdottir, 1997).

Stanton, Danoff-Burg, and Huggins (2002) reported that a diagnosis of breast cancer can contribute to overwhelming personal and interpersonal challenges especially in the first year of the illness (Dukes Holland & Holahan, 2003). During this period, women have to deal with difficult decisions, exhausting treatments, and face fears surrounding their life, well-being, and important relationships (Stanton et al., 2002). Although most women do adjust to the cancer over the long term, there are some women who exhibit acute distress (Dukes Holland & Holahan, 2003; Stanton et al., 2002; Thewes, Butow, Girgis, & Pendelbury, 2004).

The literature has indicated that there are many studies on coping strategies for managing breast cancer (Henderson et al., 2003; Dukes Holland & Holahan, 2003; Manne, 2003; Sadeh-Tassa et al., 1999; Stanton et al., 2002). Over the disease course women used a number of coping strategies to improve their adjustment as they moved through the stages of diagnosis, treatment and recovery (Gall, Miguez de Renart, & Boonstra, 2000; Lethborg et al., 2000; Sadeh-Tassa et al., 1999). Henderson et al. (2003) observed that some of the coping strategies that women used are prayer (Choumanova et al., 2006; Gall, 2000; Gall et al., 2000), social support (Fridfinnsdottir, 1997; Dukes Holland & Holahan, 2003; Lethborg et al., 2000; Manne, 2003), positive reappraisal (Dukes Holland & Holahan, 2003; Manne, 2003) and escape-avoidance (Dukes Holland & Holahan, 2003; Manne, 2003; Reynolds et al., 2000; Stanton et al., 2002).

However, there are instances when the results on coping strategies have been confusing and inconsistent across studies (Dukes Holland & Holahan, 2003; Livneh, 2000;

Reynolds et al., 2000; Stanton et al., 2002). For example, some studies showed positive outcomes in the use of avoidance and or denial as a coping strategy for breast cancer (Heim et al., 1997; Dukes Holland & Holahan, 2003). Other studies have shown that women with breast cancer who used cognitive and behavioural escape-avoidance strategies experienced more distress (Culver, Arena, Wimberly, Antoni, & Carver, 2004; Hack & Degner, 2004; Dukes Holland & Holahan, 2003; Stanton et al., 2002).

For instance, Stanton et al.'s (2002) longitudinal study of 70 women with early stage breast cancer looked at the various coping strategies along with the attribute hope, which women used from the initial diagnosis through to the first year. They found that coping through active acceptance at diagnosis led to more positive adjustment, and that avoidance-oriented coping contributed to further fears and distress (Hack & Degner, 2004; Stanton et al., 2002).

In their study, Hack and Degner (2004) tracked 55 women with early breast cancer, looking at coping responses at the time of treatment, and subsequent adjustment three years later. They found that women who showed depressive symptoms and cognitive avoidance (acceptance/resignation) at the time of treatment had poor psychological adjustment three years later (Gonzalez & Lengacher, 2007; Hack & Degner, 2004). Hack and Degner acknowledged that the significant relationship between acceptance/resignation and poor psychological adjustment contradicted two earlier studies by Carver et al., 1993 and Stanton et al., 2000 which discovered, "that acceptance and active acceptance at diagnosis are significantly related to positive adjustment to cancer" (Hack & Degner, 2004, p. 244).

Hack and Degner (2004) explained that the COPE inventory was used in both the Carver et al., 1993 and Stanton et al., 2000 studies and that their own study used the Coping Responses Inventory (CRI) to measure acceptance. The authors stated that these two inventories which measure acceptance might be looking at two separate concepts that correlate differently to adjustment.

In another study, Dukes Holland and Holahan (2003) examined the relation of the roles of social support and coping to positive adaptation to breast cancer. The participants were 56 women diagnosed with stage I and stage II breast cancer from 1-26 months earlier. The results confirmed that women who had more social support stated that they had better psychological well-being and were engaged in more positive health behaviours. In addition, approach coping strategies such as positive reappraisal, planful problem-solving, confrontive coping, and seeking social support contributed to greater adjustment. As they had predicted there was no relation between total avoidance coping and total psychological wellbeing (Dukes Holland & Holahan, 2003).

Heim et al. (1997) in their 5 year study of 74 women with breast cancer focussed on changes over time and stages in coping and psychosocial adaptation to cancer. They discovered a distinct relationship between coping and psychosocial adaptation in only three distinct stages of the illness - hospitalization, chemotherapy and rehabilitation (Heim et al., 1997; Dukes Holland & Holahan, 2003; Reynolds et al., 2000). Different coping strategies were used depending on the stage of the illness. Heim et al. concluded that variability was more apparent when coping was connected to illness stages and not mainly to time.

Research has shown that religion and spirituality have helped people cope with life threatening illnesses such as cancer (Choumanova et al., 2006; Gall, 2000; Gall et al., 2000; Krause, 1993). According to Gall (2000) the empirical value of religion and spirituality as a resource for adjusting to cancer has been given passing attention in the literature. For instance, when these themes are incorporated in adjustment studies they are either labelled in a simple way or are listed under general headings of resources such as avoidance coping behaviour (Gall, 2000). This point was evident when Krause (1993) cited 23 methods of coping from the literature as being essential to managing cancer. Krause found that only one method considered the spiritual domain of hope and none of the other methods covered religious aspects. It was only when Krause asked her participants directly how they coped with their illness and resultant emotions that their religious behaviours and beliefs became known (Gall, 2000; Krause, 1993).

Some studies have demonstrated that religious coping is more evident in later stages of the disease course. The reason for this is that survivors have passed through the acute phase of the diagnosis and treatment. They are now coming to terms with the fact that cancer is a chronic illness which they will need to start assimilating into the very fabric of their lives (Gall 2000; Gall et al., 2000). Gall (2000) examined the role of religious resources in long term adjustment to breast cancer with 52 female survivors. Most women stated, “that religion (66.6%) and spirituality (84.6%) were important or very important in their lives” (Gall, 2000, p. 171).

In a similar study, Gall et al., (2000) looked at religious resources in long-term adjustment to breast cancer with 32 survivors. The factors the researchers considered were relationship with God or god image, nonreligious resources (e.g., optimism), and

emotional and spiritual well-being. Their findings revealed that relationship with God and religious coping behaviours were linked to the survivors' well-being. For example, women who felt God's presence in their lives said that their view of life was more optimistic which in turn improved their emotional well-being (Gall, 2000; Gall et al., 2000).

In their research, Culver et al. (2004) examined the similarities and differences in coping with early stage breast cancer by 236 African-American, Hispanic, and non-Hispanic White women. They confirmed that religious coping such as finding religious or spiritual comfort as well as prayer or meditation is more prominent among African Americans and Hispanics than among non-Hispanic whites. This finding was similar to an earlier study by Culver et al. (2002) with a different group of 131 African-American, Hispanic, and non-Hispanic White women.

As previously shown, most individuals use a number of coping strategies which changed over the disease course (Heim et al., 1997; Dukes Holland & Holahan, 2003). Suls and Fletcher (as cited in Dukes Holland & Holahan, 2003) did a meta-analysis of 43 studies of coping with cancer. They concluded, "that avoidance strategies were effective when outcome measures were immediate, while attention strategies were more effective when outcome measures were long term" (Dukes Holland & Holahan, 2003, p.18).

Stanton et al. (2002) noted that some studies suggested that avoidance could be adaptive in the short term, but maladaptive in long term adjustment. This point is also borne out by Gall et al. (2000) who indicated that some women used avoidance and diversion during the diagnosis stage. Hagopian (as cited in Lethborg et al., 2000) explained that different levels of avoidance, acts as a shield to gave individuals a respite

before coming to terms with the new reality. Lethborg et al. (2000) reported that although the end of treatment is a significant milestone, there is still a measure of uncertainty and fear of the future. It is during this time that women begin to process what they have experienced and integrate it into their present lives.

The recent cancer literature has been empirically addressing the role of emotional expressivity in the successful adjustment to cancer. Evidence indicates that emotional expression is significantly connected to poor adjustment, and that negative expression specifically leads to cancer advancement (Hack & Degner, 2004). However, other research outcomes have revealed the opposite with regard to adjustment. For example, a fighting spirit is seen as positive while repressing emotions impeded the adjustment process. Stanton et al. 2000 (as cited in Hack & Degner, 2004) study results showed that emotional expression is positively linked to adjustment. Reynolds et al.'s (2000) research also discovered that emotional expression was related to better survival in women with invasive breast cancer.

Hack and Degner (2004) concluded that the wording and methods used to conceptualize and measure emotional expressivity may contribute to some of the inconsistent results. They suggested that one way to address the disparity would be to list the items in scales and questionnaires that are not well known in published reports. In this way the reader would be better informed when interpreting the results.

Early studies of coping with cancer that used Lazarus and Folkman's stress and coping paradigm were cross sectional and depended on retrospective information from scales such as the Ways of Coping Checklist. Later research studies have looked at specific types of coping (Manne, 2003). However, there have been only a few longitudinal

studies on coping and adjustment to cancer (Heim et al., 1997; Livneh, 2000; Manne, 2003; Stanton et al., 2002). Livneh (2000) in his purview of studies in the literature found that the scores on coping with cancer scales showed variation over time. He recommended that longitudinal studies would give a more accurate assessment of the coping strategies used in adjusting to cancer.

Also, there needs to be more clarity and agreement between investigators when defining coping for research (Manne, 2003). For instance, as shown by the various studies cited, the descriptions assigned to scales may be interpreted differently among investigators (Moorey, Frampton, & Greer, 2003). Hence, coping is seen as, “a deceptively simple concept which is in fact highly complex” (Moorey et al., 2003, p.238). In the researcher’s exploratory study, coping will be defined as the strategies that employed women use in facing the challenges of breast cancer in Trinidad.

Social support.

Social support has been identified as an essential coping resource (Fridfinnsdottir, 1997) in managing health-related issues (Dukes Holland & Holahan, 2003). House (1981) defined social support as, “the flow of emotional concern, instrumental aid, information, and/or appraisal (information relevant to self evaluation) between people” (p. 26). House further expanded on these four types of support: i) emotional support includes trust, caring, love (Fridfinnsdottir, 1997), counselling, and showing empathy; ii) instrumental support involves helping others do tasks, attending to their needs, and giving financial aid (Fridfinnsdottir, 1997); iii) informational support pertains to giving information, advice, and suggestions in order to cope with both personal and environmental issues (Fridfinnsdottir, 1997); and iv) appraisal support deals with self evaluation and

affirmations based on feedback from others. The type of social support that is given will influence how an individual mitigates stress and adjusts to illness (Clark, 2001; House, 1981). Davis (2004) identified four main sources of likely support as family, friends, health care professionals, or support groups.

Although social support has been linked to a variety of health outcomes this is dependent on the type of health problem being investigated. Several studies indicated that the majority of research on social support is based on the psychological outcomes of individuals facing illness. These studies showed that social support influenced recovery from cardiac disease, low blood pressure, birth outcomes, arthritis and breast cancer (Manne, 2003; Roberts et al., 1994).

Numerous studies have been conducted on social support and its effects on cancer survivors as they coped with the diagnosis, treatment and long term survival (Roberts et al., 1994). The literature also abounds with research on the psychosocial effects of breast cancer and the importance of supportive interventions (Chapman, 2000; Fridfinnsdottir, 1997; Gonzalez & Lengacher, 2007; Hirschman, & Bourjolly, 2005; Dukes Holland & Holahan, 2003). However, few studies have looked at the importance of social support in the workplace for cancer survivors (Chapman, 2000).

Support and disclosure at work.

In Staley et al.'s study (1987) about 48% of their participants expressed that if they were beginning a new job they would disclose their cancer diagnosis to new co-workers; while the other half said they would refrain from doing so. This decision was based on survivors' perceptions about co-workers attitudes and survivors' feelings about themselves (Staley et al., 1987). Therefore, it is important to recognize that survivors' reactions to the

cancer can affect others' behaviour. For instance, Feldman (1976) found that individuals who had their own negative feelings about the disease, anticipated and at times experienced antagonism from supervisors and co-workers [self-fulfilling prophecy] (Staley et al., 1987).

The theme of mobilizing social support as presented in the following three studies examined how interpersonal relationships affected the survivor's adjustment to cancer and work. Chapman (2000) noted that only a small number of studies have considered the significance of social support at work for women with breast cancer. In exploring this variable for her doctoral research on 364 women with breast cancer, Chapman discovered certain limitations in her study. She summarized the causes from her perusal of the literature:

These studies point to a number of difficulties in measuring social support at work. The impact of social support from co-workers and supervisors can be expected to vary widely depending on the type of organization, the model of management, the type of relationship, and frequency of contact between workers and supervisors and workers and co-workers (p. 25).

House (1981) postulated that one method for addressing these issues would be to train supervisors and other employees on how to give and receive social support.

Berry (1993) carried out a longitudinal, qualitative study on the return to work experience of 19 survivors with genitourinary cancer. The process of mobilizing social support was the major theme, whereby the social network of the workplace offered an avenue for various levels of support. Her findings suggested that social support at work contributed to psychological well-being and returning to work (Berry 1993).

Sanchez (2001) adapted Berry's (1993) expanded mobilizing social support to investigate the association between social support in the workplace, and disclosure in colorectal cancer survivors. She learnt that employed survivors had greater difficulties adjusting when co-workers were less supportive. Individuals with social support had a more positive outlook, were readily integrated and encountered fewer problems at work (Sanchez, 2001; Spelten et al., 2002).

Sanchez's (2001) findings showed that 79% of the survivors acknowledged having cancer to employers, and 84% admitted the illness to co-workers. Tebbi, Bromberg, and Piedmonte (1989) conducted a telephone study on the vocational adjustment of 40 cancer survivors diagnosed during adolescence. Their results were different to Sanchez's. They found that 85% of the survivors disclosed their cancer to employers and 67% shared it with their co-workers. Tebbi et al.'s research did not identify why more employers were told than co-workers. They noted however, that the majority of problems which survivors stated they experienced were because employers knew of the cancer (Tebbi et al., 1989).

Survivors who feel obligated to inform their employers may do so because they need time off during the treatment regimen (Sanchez, 2001). Sanchez also discovered that survivors who did not divulge the diagnosis took longer to return to work. However, there were some individuals who discussed the illness with peers during the diagnosis period. This is a crucial time for survivors who may be experiencing high anxiety and require social support to help them through the recovery period. This information is useful to health care professionals in assisting survivors to deal with the sensitive issue of when and whether to disclose the cancer on returning to work (Berry, 1993; Mock, 1998; Sanchez, 2001; Staley et al., 1987). As cancer survivors work through their decision about

disclosure, they are also starting the journey of assimilating the diagnosis and its meaning into their lives (Staley et al., 1987).

Support from family and friends.

Studies on women diagnosed with breast cancer raised a number of core issues: (a) Fear of death and grief over multiple losses; (b) Anxiety over bodily disfigurement; (c) Worry about alienation from both family and significant others (Dibbell-Hope, 2000; Rendle, 1997; Thorton, 2002); and (d) Fear of recurrence (Rendle, 1997; Thorton, 2002).

Individuals with breast cancer who received emotional support from their partners were less anxious and coped better than individuals who did not (Sormanti & Kayser, 2000). It seems that emotional support is the most important type of support and has a positive effect on women's psychological well-being (House, 1981; Siegal, 1990; Sormanti & Kayser, 2000). Although Ell (as cited in Roberts et al., 1994) believed that social support is a key factor in coping with breast cancer, she warned that relationships might also contribute to negative actions and behaviours.

For example, a partner who has not come to terms with the illness based on his fears about death and dying, or negative remarks from others, may show avoidance behaviours towards the breast cancer survivor. This may be interpreted by the survivor as a lack of emotional support (Roberts et al., 1994). Therefore, how well the survivor adjusts to the cancer is dependent on the quality of support from her partner (Kayser et al., 1999; Weihs, Enright, Howe, & Simmens, 1999). Other studies have shown that how well the partner adjusts to the cancer is dependent to a great extent on how well the survivor has adjusted (Gonzalez & Lengacher, 2007).

In their study, Roberts et al. (1994) sent questionnaires to 135 newly diagnosed breast cancer survivors during the months following treatment. They wanted to ascertain what effects emotional support from family, friends and spouses had on survivors' psychological adjustment. The researchers indicated that their findings confirmed those of other authors that, "the characteristics of the person, rather than the situation, underlie the apparent relationship between social support and adjustment to illness" (p. 162). They stated that social workers in their psychosocial assessment should place more emphasis on the individual's past psychological adjustment and stressful life events, rather than on social support (Roberts et al., 1994).

Sanchez (2001) noted that there is scant data relating to the effect of support from significant others on work re-entry and adjustment among cancer survivors. In her research, "family support was associated with physical and mental health well-being" (p. 115). The cancer survivor may feel insecure about her or his ability to be productive; support from family and friends can boost the individual's confidence in returning to gainful employment. Also familial conflicts or absence of social support can have a negative impact on the individual's care. Therefore, involvement of family and friends is key to a successful rehabilitation programme because they can help the survivor to manage the various changes in her or his life (Brown & Tai-Seale, 1992).

In 1987, Feldman conducted 58 telephone interviews with employed female caregivers of cancer survivors. She found that the caregivers had to deal with repeated anxieties over the disease; fear of the anticipated suffering and painful death linked to cancer; and in cases where the survivor was a child, how much she was to be blamed for her child's cancer. Many of the caregivers remarked that fellow workers and employers

were amenable, and assisted in relieving their workload until care giving demands reduced (Feldman, 1987).

Feldman (1987) noted that just as many caregivers commented that co-workers avoided them even those they considered friends. Some were dismissed because of absenteeism, low productivity, and loss wages for hours not worked. The findings revealed that this particular group of women is vulnerable in the workplace, and within themselves (Feldman, 1987). The increased stress that some women experienced while providing social support can also negatively affect the survivor who may be struggling with certain fears and anxieties. The caregiver and the survivor may withdraw either emotionally or physically at a time when they both need each other for support.

Support from health care professionals.

There is little data on the extent to which physicians, social workers, nurses and others concerned with patient care influenced survivors return to work (Mellette & Franco, 1987; Sanchez, 2001). According to feminist thinking, surgeons were seen as having full control in the physician-patient relationship, and women with breast cancer were placed in a passive role (A Feminist Voice in Cancer Debates, 1998; Charles, Redko, Whelan, Gafni, & Reyno, 1998; Collie & Long, 2005; Ellingson & Buzzanell, 1999; Klawiter, 2004).

For example, a breast cancer survivor whose emotional anxiety extends beyond what is deemed normal, and does not comply with medical advice about her treatment regimen; her behaviour may be seen as pathological (Collie & Long, 2005). This label promotes the oppression of women who have no say in the matter (Nichols & Schwartz, 2001). Hence, the power and gender inequalities are intensified between male surgeons

and female patients. Patients have been granted more rights concerning their medical information and their involvement in medical decision-making (Arora, 2003; Charles et al., 1998; Klawiter, 2004). Broom (2001) emphasized that it is vital that women seek information which will help them to have control over their health care choices (Broom, 2001; Charles et al., 1998).

In their qualitative study of 13 breast cancer survivors, Maunsell et al. (1999) discovered that women were anxious about returning to work and performing their jobs. The women stated that no dialogue occurred with physicians about the illness effects on work functioning. The only work related concern that some physicians discussed was the period of sick leave required (Maunsell et al., 1999). Maunsell et al. suggested that physicians' behaviour might have influenced how the women felt about returning to work (Crothers, 1987).

In her research, Sanchez (2001) found that survivors who discussed going back to work with their physicians were more likely to return earlier, and remain in their jobs. She saw her finding as highlighting the valuable role that a health care provider can perform in helping a survivor to return to work.

Feminism and Breast Cancer

The feminist perspective will be used in this study because breast cancer is considered a female disease which may be one of the reasons that women face the benign neglect from employers as well as some medical and social work professionals. Feminist advocacy of breast cancer has emphasized that this disease is a major health concern in respect to both research and prevention programmes (A Feminist Voice in Cancer Debates, 1998).

The type of feminism that is most applicable to this research is postpositivism/critical theory whose main premise is feminist standpoint theory (Campbell & Wasco, 2000). The feminist perspective will emphasize experiential approaches which allow women to express themselves and derive their own meanings from their experiences (Wilkinson, 2000). Feminist experiential approaches have developed from ‘standpoint theory’ which maintains, “that women see the world from a particular perspective, or standpoint, because of the specific experience of being a woman in a patriarchal world” (Wilkinson, 2000, p. 363). This study will highlight the standpoint of women with breast cancer in the workplace.

Over the last three decades, social movements have contributed to the changes that have taken place in breast cancer awareness and management (Klawiter, 2004; Wilkinson, 2001; Yadlon, 1997). During the 1970s and 1980s, disputes about informed consent, radical mastectomy, mammogram screening (Klawiter, 2004; Wilkinson, 2001), the safety of tamoxifen trials, and silicone implants (Wilkinson, 2001); led to adjustments in medical practice methods (Klawiter, 2004). The 1990s saw a rapid increase of the breast cancer movement with a proliferation of breast cancer organizations, the cultivation of new discourses, public events (Klawiter, 2004; 1999), better health care facilities, creation of community-based resource centres, and support services (Wilkinson, 2001). All these changes were fuelled by breast cancer activists and cancer survivors (Klawiter, 1999).

The last decade has also seen an increasing amount of information on breast cancer in the popular media. A deciding factor in this growth is the rising number of women being diagnosed with the disease (A Feminist Voice in Cancer debates, 1998; Yadlon, 1997). Coalition groups were formed to lobby for more research funding and a shift in

research focus to include factors such as environmental causes (A Feminist Voice in Cancer debates, 1998; Brown, Zavestoski, McCormick, Mandelbaum, & Luebke, 2001; Donchin, 2004; Klawiter, 1999; 2004; Wilkinson, 2001; Yadlon, 1997).

According to Broom (2001), the literature utilizes a number of metaphors which describe breast cancer as a battle, invasion, and a defence. For example, a national approach to this disease is often referred to as a war on cancer. Certain cancers are labelled invasive and survivors are encouraged to fight the disease and not give up. The treatment regimen is aggressive and uses the deadly force of slash [surgery], burn [radiotherapy] and poison [chemotherapy] to kill cancer cells. Therefore, the language that is used to denote and interpret the disease and its treatment only reinforces the fears that surround the illness (Broom, 2001).

A woman's breast is seen as part of her femininity and sexuality (Choumanova et al., 2006). Thousands of women who have breast cancer surgery are a hidden population, and this is propagated by the medical and fashion industry (Broom 2001). For instance, there is the belief that after surgery, a woman will either get a breast prosthesis or have breast reconstruction. Hence, no one will suspect that she has had breast cancer and the discourse of concealment is perpetuated (Broom, 2001; Thomas-MacLean, 2005; Wilkinson, 2001).

The politicized feminist position advocates that women should break the silence about their individual experience of cancer (A Feminist Voice in Cancer debates, 1998). Feminist experiential writings have illustrated and confronted the dominant discourses and practices of concealment that affect women (Wilkinson, 2001). Feminists' ongoing contention has been that 'silence and invisibility' contribute to powerlessness (Im, 2000;

Wilkinson, 2001). It is only when women with breast cancer can openly show and recount their experiences that the concerns surrounding breast cancer can be dealt with at a national level (Wilkinson, 2001). This point is brought out in Klawiter's (1999) study on breast cancer activism which looked at three different social movement events within the San Francisco Bay Area. In one of the events, 'Race for the Cure' the message the women publicly conveyed was their refusal to accept the, "cultural code of silence and invisibility, that breast cancer is not shameful, that it is survivable, and that it is neither disfiguring nor defeminizing" (Klawiter, 1999, p. 111).

The discourses that hold people culpable for getting cancer focus on who you are, what you do, and how you think (Wilkinson, 2001). Both the medical and popular literature indicates that women's personal lifestyle choices are responsible for causing their cancer (Brown et al., 2001; Wilkinson, 2001). For example, choices such as oral contraception, choosing not to have children, having too few or delayed childbearing (Broom, 2001; Wilkinson, 2001; Yadlon, 1997); alcohol abuse (Wilkinson, 2001); and obesity (Thomas-MacLean, 2005; Wilkinson, 2001; Yadlon, 1997). The media also depicts women who do not adopt the female norms of obedience and 'domesticity' as being particularly blameworthy (Broom, 2001; Wilkinson, 2001). Hence, the media as a social force has also played a part in framing women's experiences with breast cancer (Brown et al., 2001; Thomas-MacLean, 2005).

Over the years, the psycho-oncology literature has been affirming that cancer morbidity and mortality are linked to one's mental state. The insidious message is that individuals who get breast and other cancers maintain maladaptive coping styles. The popular cultural belief is that in order to recover, individuals need to develop a more

adaptive way of coping which emphasizes positive thoughts and feelings (Charles et al., 1998; Wilkinson, 2001). Thus, people are socialized into accepting this cultural norm (Charles et al., 1998). In fact, there are some women who believe the cancer will recur because they are not being positive enough. Feminists seek to condemn these edicts of blaming the victim in breast cancer. They see women occasionally being, “victims of a patriarchal world order and an inadequate health care system, rather than of our own bodies and minds” (Wilkinson, 2001, p. 275).

The Narrative Approach to Breast Cancer

Although there have been a large number of studies on breast cancer, there are limited investigations on women’s experiences using feminist approaches (Im, 2000; Thomas-MacLean, 2005). This research will use a narrative approach that is grounded in a feminist perspective in looking at the return to work experiences of women with breast cancer.

According to Cheung (1998), “narrative is an ancient concept with a recent popularity” (p. 5). The narrative approach can now be found in nearly every discipline and profession such as history, anthropology and folklore, psychology, sociolinguistics, sociology, law, medicine, nursing, occupational therapy, and social work (Carson & Fairbairn, 2002; Ollerenshaw & Creswell, 2002; Riessman, 2000; Riessman & Quinney, 2005). The literature indicates that narrative inquiry contains realist, postmodern, constructionist (Riessman & Quinney, 2005), feminism, and critical theory (Fraser, 2004) elements. This has caused a debate among scholars as to its origins and specific definitions (Ollerenshaw & Creswell, 2002; Riessman & Quinney, 2005). Hence, there are

several definitions of 'narrative' used by various disciplines and applied in a number of ways (Ollerenshaw & Creswell, 2002; Overcash, 2004a; Riessman & Quinney, 2005).

The term narrative is often used synonymously with the word 'story' (Cheung, 1998; Rapmund & Moore, 2002; Riessman, 2000; Riessman & Quinney, 2005).

Rappaport (as cited in Docherty & McColl, 2003) stated that:

The narrative approach means understanding life to be experienced as a constructed story. The stories that people tell and are told are powerful forms of communication to both others and one's self. Stories order experience, give coherence and meaning to events and provide a sense of history and of the future (Docherty & McColl, 2003, p. 20).

People from every culture use stories to give meaning to their experiences, and make sense of their lives and others (Cheung, 1998; Docherty & McColl, 2003; Ellingson & Buzzanell, 1999; Holland & Kilpatrick, 1993; Ollerenshaw & Creswell, 2002). The literature has shown that women who tell their stories of breast cancer also shared how the experience has brought about identity change and development (Rapmund & Moore, 2002; Wilkinson, 2000). Through stories, women can discuss how breast cancer and its treatments have affected their relationships and identities (Ellingson & Buzzanell, 1999; Mathieson & Stam, 1995).

Frank, in his book the 'Wounded Storyteller' (1995), discussed three types of illness narratives that individuals used in telling their stories. He asserted that:

Each narrative reflects strong cultural and personal preferences. The strength of these preferences presents a further barrier to listening to the ill: both institutions and

individual listeners steer ill people toward certain narratives, and other narratives are simply not heard (Frank, 1995, p.77).

Frank's (1995) three illness types are: 1) Restitution whose focus is to get well and become healthy once more. It shows illness as being "transitory" (Frank, 1995, p. 115; Thomas-MacLean, 2004). Frank observed that the restitution narrative governs most stories and is useful because, "images of health can model behaviour that many people can adopt and adapt" (p. 94). However, he cautioned that the restitution narrative can create problems when the individual is unable to achieve restitution, or when someone who has found restitution meets another person who is terminal (Frank, 1995). Also restitution narrative may be viewed "as a form of social control" (Thomas-MacLean, 2004, p. 1648) whereby the person is expected to return to health. This denies the individual the opportunity to express certain illness experiences (Thomas-MacLean, 2004).

2) Chaos looks at the feelings of helplessness, hopelessness and anxieties that ill persons experienced. In chaos narratives the stories are not ordered, people relate events in a manner that lacks sequence. "The lack of any coherent sequence is an initial reason why chaos stories are hard to hear; the teller is not understood as telling a "proper" story" (Frank, 1995, p. 97). Frank noted that chaos stories can only be told reflectively from a distance. He emphasized that it is important for listeners to hear these stories of "wreckage" (p. 110) because, "people who are being denied cannot be cared for" (p. 109). Thus, hearing and accepting chaos stories can help people to move forward and rebuild their lives (Frank, 1995).

3) Quest is when the individual realizes that there is a sense of purpose to the illness and the resultant change that takes place (Frank, 1995). Quest narratives give the

individual a voice to tell her own story and are found in most of the published literature. Frank identified three quest narratives sub-types: (i) memoir where changes take place based on lifestyle, attitudes or lessons learnt; (ii) manifesto in which there is a need for social change; and (iii) automythology which sees illness as the result of fate or destiny (Frank, 1995; Thomas-MacLean, 2004).

Frank (1995) reported that chaos narratives could be found within restitution and quest narratives. In her research of women with breast cancer, Thomas-MacLean (2004) found that chaos narratives were more frequent around, “bodily difficulties and the involvement of other people in their lives” (p. 1652). She further discovered that even after an interval of time and reflection, there were some stories that are not ordered, especially when people discussed the traumatic periods in their lives. Thomas-MacLean believed that Frank’s three narrative types can help researchers to examine the connections, “between culture, individuals and their experiences of illnesses, such as breast cancer” (p. 1649).

Riessman and Quinney (2005) conducted a literature review to investigate the significance of narrative methods in social work research. Social work is founded on talk and interaction with clients. A key “area of narrative study is human interaction in relationships – the daily stuff of social work” (Riessman & Quinney, 2005, p. 392). Therefore, narrative approaches seemed the most likely avenue for social work researchers to study interactions with clients and in discussions of clients with other professionals. They discovered only a small body of systemic research in this area in comparison to education, nursing and other professions. Riessman & Quinney (2005) deduced from their review that narrative concepts are used for reflective practice and teaching in social work

(Holland & Kilpatrick, 1993), “but only to a very limited degree in research” (Riessman & Quinney, 2005, p. 405).

Fraser (2004) also saw a slow acceptance of the ‘narrative moment’ in what she termed Anglo-American social work. One possible reason for this may be some social workers’ unwillingness to accept “methods of knowledge production” (Fraser, 2004, p. 181) that are not anchored in science (Fraser, 2004; Riessman & Quinney, 2005), “the experimental model, and evidence-based outcome studies?” (Riessman & Quinney, 2005, p. 405). However, Fraser also noted that more social workers are employing various narrative methods in their social work practice.

Narratives are gaining a prominent role in health care’s quest to be more humane and holistic and are now evident in health care practice and qualitative research (Carlick & Bailey, 2004). For individuals diagnosed with breast cancer, narrative research gives a better insight into how the illness affects both the survivor and significant others (Overcash, 2004). For instance, a narrative interview can help the survivor tell her story in a way that can be understood by herself and the listener. This point is reinforced by Frank (1995) who observed that, “telling stories of illness is the attempt, instigated by the body’s disease, to give voice to an experience that medicine cannot describe” (Frank, 1995, p.18).

In addition, Frank (as cited in Carlick & Bailey, 2004) sees stories as providing new meaning(s) and healing the hurt caused by illness (Carlick & Bailey, 2004). This also allows the “why” questions to be brought to the forefront (Hyden as cited in Carlick & Bailey, 2004). Researchers and clinicians’ growing interest on the meanings individuals assign to breast cancer has elicited new insight into the breast cancer experience. It has also clarified the psychosocial needs of breast cancer survivors (Collie & Long, 2005).

Riessman (2000) indicated that narrative is a relational and collaborative practice that has an empathetic component (Marshall & Rossman, 1999; Stiles, 2003). Narrative research relies on some of the same methods used in social work - interviewing, communicating and listening as clients unfold their stories on the effects of the illness in their lives (Overcash, 2004). Narrative research therefore, can provide a deeper understanding about women's decisions, behaviours, and coping skills.

The interview is a central avenue for acquiring narrative data. The type of interview and the type of responses that participants give will provide the researcher with a better understanding of the data. For example, narrative data are often elicited by asking open-ended questions which are part of both structured or semi structured interviews (Overcash, 2004). Tutty et al. (1996) attested that semi structured interviews are suitable for comparing "information between and among people" (p. 56), while the researcher simultaneously tries to fully comprehend everyone's experience (Tutty et al., 1996). Interviews therefore, help to discover, "people's views of reality and allows the researcher to generate theory" (Reinharz, 1992, p. 18).

Narrative data can also help in understanding language, such as its nuances and sub texts (Fraser, 2004). Piaget (as cited in Devault, 1990) pays attention to both the content and construction of speech. Expressions such as emphasis and pauses hint at emotions and meaning which she presents for the readers so that the true meanings of the exchanges are captured (Devault, 1990; Fraser, 2004; Marshall & Rossman, 1999; Padgett, 1998; Riessman, 2000; Tutty, et al., 1996).

Riessman (2000) contended that her approach to narrative analysis does not stress "objectivity," but emphasized "positionality and subjectivity" (p. 19). In this way the

perspectives of both the narrator and analyst are documented. In fact, narrative's ability to offer and present "a plurality of truths" (Fraser, 2004, p. 181; Riessman, 2000) gives a deeper insight into how individuals, groups and societies interact (Fraser, 2004).

Summary

This chapter identified characteristics in the literature on cancer and work. It highlighted the various pieces of legislation in Trinidad and Tobago that deal with employment equity, disability issues as well as accessibility of treatment services in the country. It described the relevant studies on the work experiences of women with breast cancer; reviewed the role of coping and social support; the types of coping strategies used; and various support systems. The feminist perspective and the narrative approach to breast cancer were discussed. The following chapter will explain the methodology utilized to conduct this study.

Chapter Three: Methodology

Research Design

a) Exploratory study.

The literature review highlighted some of the return to work experiences of breast cancer survivors in the United States, Canada and other European countries. To date, no studies have been found that are specific to Trinidad and Tobago on the return to work experiences of breast cancer survivors.

b) Narrative study.

This research used a narrative approach embedded in a feminist perspective in looking at the return to work experiences of women with breast cancer. Narrative analysis offers a methodical study of individuals' personal experiences (Ollerenshaw & Creswell, 2002; Riessman, 2000), and social experiences [interactions with others] (Ollerenshaw & Creswell, 2002). It is used by feminist researchers who are interested in the shifting meaning in women's circumstances (Riessman, 2000). The narrative approach is suitable to this study of qualitative analysis because it deals with a small number of participants.

Riessman (2000) observed that the many different ways that narrative is defined in social research has led to numerous methodological differences in its applications. This research used a narrative tradition that is more limiting in that the relevant stories are short and topically specific. The stories are told based on a series of questions (Riessman, 2000), and are structured around characters, plots (Carlick & Bailey, 2004; Riessman, 2000), and setting (Ollerenshaw & Creswell, 2002; Riessman, 2000) which the narrator saw or experienced.

Although there are differences in the narrative approach, many investigators agree that narration has certain distinct features such as ordering, sequence (Ollerenshaw & Creswell 2002; Riessman, 2000; Riessman & Quinney, 2005), and consequence (Riessman & Quinney, 2005). Cortazzi (as cited in Ollerenshaw & Creswell 2002) stated that narrative emphasis on sequence and chronology distinguishes it from other types of research. Also narrators organized their stories temporally and spatially (Riessman, 2000; Riessman & Quinney, 2005). The temporal ordering of past, present and future allows for an interpretation of different meanings (Carlick & Bailey, 2004; Cheung, 1998; Ollerenshaw & Creswell 2002). Narratives are also structured thematically and episodically (Riessman, 2000; Riessman & Quinney, 2005). As Cheung (1998) summarized, a narrative has, “a chronological sequence, a consequential sequence and a thematic sequence” (p. 5; Holland & Kilpatrick, 1993).

Culture determines human behaviour and relationships (Cheung, 1998) whether it is in the community, workplace or the home (Fraser, 2004). For many decades, feminists have emphasized the importance of linking ‘the personal with the political’ (Devault, 1990; Fraser, 2004; McCarthy & Weber, 2005; Rapmund & Moore, 2002). The plots and themes found in narratives can either reaffirm cultural values (Cheung, 1998; Fraser, 2004) or challenge dominant social customs (Fraser, 2004). The researcher therefore, considers how dominant discourses along with social conventions become part of the interpretative framework that shape participants’ stories (Fraser, 2004; McCarthy & Weber, 2005; Rapmund & Moore, 2002; Riessman & Quinney, 2005).

The research design used in this study was a cross-sectional narrative, as this was most suited to the knowledge sought. The researcher looked at a particular group of

women within a specific time period. This approach allowed women to story and re-storied their experiences with breast cancer and returning to work. It also helped the researcher to identify themes, patterns, and make linkages (Patton, 1990).

The four central questions that guided this inquiry were:

- i) What stories do women recount in coping with their diagnosis?
- ii) What stories do women relate to prepare themselves to return to work?
- iii) What stories do women tell to describe their return to work experiences while on treatment or having completed treatment?
- iv) What stories do women share about the impact of being a cancer survivor and its effects on the various aspects of their lives and their social supports?

c) Definition of term.

In previewing the literature, there appears to be no agreement as to when an individual with cancer becomes a survivor (Rendle, 1997). Carter (1994) defined a survivor as an individual living 5 years and beyond after the diagnosis without recurrence. Meyer's definition (as cited in Rendle, 1997) of a cancer survivor is "anyone who has lived with, through or beyond cancer" (p. 404). In 1995, The National Coalition for Cancer Survivorship (NCCS) formally defined a survivor, "from the time of diagnosis and for the balance of life" (Kaiser, 2008, p. 80). For the purpose of this study both Meyer and the NCCS definition was used.

Setting

The population was drawn from the National Radiotherapy Centre [NRC] which was until April 2007 the only treatment centre in the country for radiation therapy. Chemotherapy and other combination modalities are also offered at the Centre. The

Centre has been in existence since 1974 and survivors are treated through referrals only. Over the last few years, there have been renovations to the physical infrastructure of the Centre to facilitate the increase in patient referrals. In 2006, a chemotherapy suite which can hold twenty eight people was opened for survivors receiving one day intravenous chemo infusion. J. De Souza Head Nurse, indicated that previously there was a 20 bed ward which has now increased to a 40 bed ward where individuals who are too ill or those who live in rural areas can stay during the week. It also accommodates persons who need blood transfusions and other maintenance therapy (personal communication, October 9, 2011). The Centre is closed on weekends. According to V. Haynes, there is a memorandum of understanding between Trinidad and Tobago's Ministry of Health and The Ministry of Health from two other islands St. Vincent and Grenada for their citizens to be treated at the National Radiotherapy Centre (personal communication, October 9, 2011).

For the period 2007-2010, there were a total of 5,127 new malignant cases seen at NRC (Rampaul, 2011). Survivors who have completed treatment [both radiation and/or chemotherapy] are given follow up appointments for the duration of their lives based on the type of cancer and number of years in remission. Between 2007-2010, there were 1,142 new cases of breast cancer seen at NRC (Rampaul, 2011). Thus, the Centre was a rich resource to access breast cancer survivors from the general population who attended NRC for treatment and follow up.

The National Radiotherapy Centre is also a familiar environment for the researcher who has worked there in the past, and continues to maintain an affiliation with the Centre in a voluntary capacity. These factors provided direct accessibility and freedom to meet

and interact with potential participants. The researcher met with the Director of NRC regarding the nature of the study. A formal letter seeking permission to conduct the research was written (Appendix F) and approval was granted (Appendix G).

Recruiting Participants

In this qualitative study, purposive sampling was used to recruit participants through the medical records supervisor at NRC, and by the researcher. The researcher met with the Medical Records Supervisor and briefed her about the study. A script was also given for her to use when contacting potential participants (See Appendix C). The Medical Records Supervisor obtained permission from four (4) potential participants who met the study's criteria. The researcher phoned the four women who were quite willing to be a part of the study. There is a breast clinic held every Thursday at NRC for women who are currently on treatment and for the ones who come for follow up visits. On four consecutive Thursdays, the researcher went to NRC where she mingled in the clinic and the treatment areas to identify potential participants. Four women were eventually selected. Two were found in the clinic having gone for follow up and the other two were located on the chemo ward while receiving treatment.

Sample Selection

Characteristics of participants.

This was a homogeneous group of eight women with breast cancer who were working at the time of the diagnosis and are still employed. Based on the literature, the number of participants chosen for the individual interviews was reasonable as it allowed the researcher an opportunity to explore the topic area fully. Saturation of narrative data

was achieved by the sixth interview. However, the researcher who is a novice at qualitative methods completed all eight interviews to ensure that saturation was attained.

The researcher used purposive sampling to select women based on the following criteria: participants between the ages of 30-49 years who are in the workforce and have been employed full time in their jobs for 5 years or more. During this time women would have established collegial relationships or built friendships and adjusted to working conditions. The researcher was interested in participants at two different time periods in the cancer experience, and equally divided the eight women into two categories. One category consisted of participants who had recently been diagnosed, on treatment and currently working. The other category had participants who were still employed 3 - 4 years post diagnosis, no longer on radiation or chemotherapy and symptom free or in remission [no sign of recurrence]. This time factor is used because it is above the mid way mark for the five year survival rate for breast cancer. The experiences of the women were compared to discover adjustment issues and whether there were commonalities of experiences at different time periods.

Data Collection

Data collection began as soon as approval was granted by the Psychology/Sociology Research Ethics Board (PSREB) of the University of Manitoba.

Informational interviews.

Once potential participants were identified, an informational interview was conducted either face to face or on the telephone. The purpose of the informational interview was to assess whether the women who had indicated interest understood what the interview and study entailed. It would also help them to decide whether they really

wanted to be a participant. Managing all this information up front would allow more time to focus on the actual interview. The researcher did two face to face informational interviews which lasted about 15 minutes with the two women who were on the chemo ward. The informed consent was explained and the participants were given a printed copy with their written consent (Appendix A). Dates and times were discussed for the actual interviews.

The other two women the researcher met in the clinic were interested in the study and gave their phone numbers for the researcher to call them. Informational interviews outlining the nature of the study and confidentiality of shared information were conducted with six participants on the telephone which took about 15 minutes each. Any questions the women had about the study were also answered at this time. All the participants were informed that participation in the study would not affect their continuing health care at NRC. Arrangements were then made for a convenient date and time for the actual interviews.

Scheduling Data Collection

The process of selecting the participants and conducting all the interviews took approximately 6 weeks. Data was collected during May – June, 2011. Respondent burden is a methodological concern for cancer survivors on active treatment as they may experience chronic fatigue which can affect the quality of the data obtained (Siegal, 1990). To address this, the interview schedule was kept at a reasonable length so that the individual did not become fatigued during the interview (Appendix B). There was one interview which took about 45 minutes. All the other interviews were over an hour with

the longest one being 1 hour and 39 minutes. The interviews resulted in detailed thick and rich transcripts.

One interview was conducted in a private area away from NRC, but on the compound. Another interview was done at the researcher's work office. Two interviews were set up at participants' office locations, and four interviews were carried out in the women's homes. During the interview process there was a possibility that some participants in re-living their experiences might become distressed due to unresolved emotional feelings about the cancer. The researcher informed all the women that if they needed further support in this area, there were two medical social workers that were available for them to contact. On the day of the actual interview the researcher gave six participants the consent form to read and signed off. A copy was left with them for their records.

Data Collection Strategies

The researcher kept a log book which was another data source for providing a detailed account of all the steps taken in gathering the data. She recorded details of her observations, participants' verbal and non verbal communication, impressions, feelings, and experiences during this period which can inform the process of recognizing themes within the data (Creswell, 2003). It also allowed the researcher to be more reflective in looking at the data. For instance, field notes were also made during the debriefings with the participants. Here certain issues raised in the interview were discussed and clarified. Some women were given guidance on resources available to them.

The participants consented for the researcher to contact them during the following weeks if she needed clarification on any information. Notes were also made on these

follow up telephone contacts, and through verification of findings. The researcher had indicated to the women that she would be sending them a copy of the transcripts for them to review. All the transcripts were sent to the participants and they corrected any missing words or phrases. The women gave feedback that the data was accurate. This study main avenue of data collection was semi-structured interviews using an interview schedule.

Semi-structured interviews.

Face to face, semi-structured, informal interviews were conducted. The researcher believed that the semi-structured in person interviews was more suitable for this study even though it was more time consuming. The semi-structured interview has a certain level of flexibility (Allen & Carlson, 2003; Docherty & McColl, 2003). Participants can narrate their illness stories and its meaning (Docherty & McColl, 2003) as well as introduce topics or issues not initially identified (Allen & Carlson, 2003). Semi structured interviews utilized interview guides that outlined the topics and issues sought in the interview. The interviewer however, maintains a flexible interview style (Rubin & Babbie, 2001; Tutty, Rothery, & Grinnell, 1996).

The researcher developed an interview schedule in conjunction with her committee members. The questions and probes came from the literature and in discussions with thesis committee members these questions were further refined. The interview schedule is to provide structure and consistency in obtaining information as well as enable the researcher to make comparisons in the data (Padulla & Miller, 1999). The use of open ended questions is good for exploratory research as participants can give opinions and reactions, or explain more about specific situations.

One pre test interview was done on the study procedures in order to explore and reflect on the efficacy of the interview guide. The pre test interview also allowed the researcher to look at her own interviewer skills during the narrative process. In addition, it gave the researcher an opportunity to identify any implementation problems prior to the formal study. The pre test interview script was sent to the researcher's advisor for review. Based on the pre test interview no revisions were needed in the interview schedule. The researcher was able to proceed with the actual interviews.

Audiotaping provides a more accurate account of what was said during the interview. It also allows the interviewer to follow participants' stories closely (Fraser, 2004; Padgett, 1998; Rubin & Babbie, 2001). The researcher utilized two tape recorders during all the interviews. The purpose of having more than one tape recorder was in the event that one of the recorders might fail or not clearly record. No recorders malfunctioned, but there were occasions when the women dropped their voices. Fortunately, the small external mike they wore was able to pick up their words more plainly. When words were not clearly audible the researcher was able to listen to the second tape to decipher incoherencies. The researcher realized that the recorders are highly sensitive to sounds. In a room chosen for the interview at the research site the air conditioning unit hum was quite distinct. This background noise caused the researcher to spend a lengthier time transcribing that particular interview. She decided to look for alternative locations off site based on this experience.

The researcher expected participants to be uncomfortable with the taping, but this was not the case. The recorders were placed on a table next to us and although they knew it was there, it did not restrict the women in their responses. One recorder was a digital

and the other one was a micro cassette. Even when the researcher changed the tape it did not alter the flow of conversation because there was a smooth transition. Maybe if the recorder was held out for the participants to speak into, it would have been more noticeable. This was one of the reasons why the researcher used two recorders so that it would not be a distraction.

Patton (2002) recommended that interviewers should take brief notes of major points and observations during the interview as these notes will be useful when analyzing the tapes (Rubin & Babbie, 2001). The researcher had informed all the women that she would be taking some minimal notes and had her note pad with her. However, no notes were made during the interviews. Although this is recommended, the researcher became completely involved with the participants stories and was able to focus and follow them closely. She also felt more confident because she had two recorders with her. However, a few notes were made during the debriefed regarding some demographic data. After the women left, the researcher recorded her observations and impressions of the interviews. In instances where the researcher went out to the participants' location she would write up her reflections in her car away from their location.

According to Fraser (2004), in narrative research the interview style is conversational, and although researchers may use a topic-based interview schedule, they do not have to adhere to it (Fraser, 2004). The interview schedule had a number of questions that covered a range of topics. The researcher used a conversational style which gave her flexibility to explore for more details as the stories unfolded. On the day of the interview, the researcher engaged the participants before the actual interview. At the beginning of the interview there was a brief introduction of the thesis topic; that

participation was voluntary; their right to withdraw from the study without it affecting their continuing health care; the use of the recorders; length of interview and possible note taking. The interview began by asking each participant to tell about a significant episode, memory or experience that they remember when they first found out about breast cancer. This question caused a few women to hesitate and seek clarification. All the participants started telling their story of how they discovered the lump and their emotional reactions.

Leading from this first question other questions followed in a logical sequence. The areas covered were: what type of person they were during this stage; the significant people in their life; confronting a change in their body; challenges in returning to work; attitude towards work; relationship with others; what important things they have learnt about themselves with breast cancer; the differences in their life now; any other needs not discussed in the interview, and whether they had questions. The final two questions allowed the women to further explore their experiences and this produced rich data. Where the participant was unsure how to answer the initial question, a probe was used to clarify and elicit further information on the topic being discussed.

There were occasions when the women raised some of the other topics in their storying. This is to be expected and in such instances the researcher allowed them to continue. Later on the researcher would summarize what they stated earlier on and moved on to other topics. In other interviews, the researcher realized that although the participants had discussed the topic earlier, by still asking the question later on it elicited more focussed information. All the questions were asked in sequence and all the topics were addressed in the interview guide.

Four interviews were in the women's homes and this contributed to a relaxed atmosphere. In three of these interviews the researcher was introduced to family members. Although the other four interviews were in a more formal setting this did not detract from the participants comfort level. The researcher gave the women control of the interview to tell their stories, but at the same time was able to focus them on the topic areas. In this way the participants felt empowered to share their narratives of the various issues they experienced in their journey. Most of the women gave examples of other people's stories. It was through other people's narratives that they were also telling their own stories and its impact on their lives.

Data Preparation

Data analysis started concurrently with the interviews. Each participant was given a number to maintain confidentiality of the data. The researcher used the numerical starting from 1 to 8 with a pseudonym letter attached to each interview number. This was done to protect confidentiality and anonymity. The researcher transcribed all the audiotapes verbatim into a type written format. Some of the hand written notes taken at the end of the interviews was also typed. The type written transcriptions and digital recordings were stored in a McAfee vault which was password protected on the researcher's computer. A back up of all the data was copied onto a flash drive. All micro cassette tapes, the flash drive, hard copies of transcripts, and research log were locked away in a desk in the researcher's home.

The researcher listened to the tapes after each interview to get an overall feel of the interview. Transcription took place in some instances soon after and on other occasions several days after the initial interview. The researcher's field notes were regularly

reviewed, reflection and general thoughts about the data were noted. For example, emotions expressed during the interview and observed body language helped to gauge participants' feelings and the attendant meanings they ascribed to their situation. The researcher was also cognizant of her own feelings during the interview. The meaning of human experience involves reflection (Carlick & Bailey, 2004). The use of a journal or log helps the researcher to describe the time, place, the various emotions that surface, and the overall feelings of the interviews. These reflections can have a significant impact when making later interpretations of the data (Fraser, 2004; Miles & Huberman, 1984; Tutty et al., 1996).

After each transcription the researcher listened to the tape again and checked it against the transcription for accuracy. This also allowed the researcher to become immersed in the data. Narrative analysis is an arduous task where the researcher has to spend long hours in deciphering paralinguistic aspects of conversation, interactions between researcher and participant, as well as social and historical contexts (Fraser, 2004; Marshall & Rossman, 1999; Riessman, 2000). The researcher was very detailed in her transcription and included paralinguistic expressions such as "uhms" and false starts. She noted in parenthesis silences, pauses, chuckles/laughter, emphasis, tone of voice and other nuances as these also conveyed meaning. Grammatical errors in speech were also not cleaned up. By transcribing the tapes herself, the researcher was able to pick out the various intonations in speech.

The researcher had three electronic versions of the interview transcripts. The original transcript was typed single spaced and this was used as a reference check when needed. A second version where she increased the line spacing to 1.5 for the whole

document. The identifying information was deleted and the researcher included comment boxes and highlighted text. This version was sent to the researcher's advisor and another committee member. The researcher also printed and worked from this adaptation. The third version had the line spacing at 1.5; all the identifying information intact; minus the highlighted text and comment boxes. This one was sent to participants for their review and comments.

The transcriptions were forwarded to two of the committee members for their review as soon as they were typed up. The researcher also included some of her field notes and impressions. Feedback was given via emails and telephone discussions on observations, suggestions and recommendations regarding the interviews, and ways to enhance the data.

The researcher looked at several qualitative sources regarding how to proceed with data analysis and utilized various techniques in analyzing the data. Ollerenshaw and Creswell (2002) reported that analyzing field texts goes beyond description and thematic development located in many qualitative studies. The researcher becomes immersed in the transcript to comprehend the lived experience and then retell the story. The process of restorying involves key features such as time, place, plot, and scene; and the story is rewritten in a chronological sequence. Many individuals leave out the sequence in recounting their stories, or the sequence may be disorganized or not fully developed (Ollerenshaw & Creswell, 2002).

Holland & Kilpatrick (1993) noted that the sequence in stories is not a linear one of cause leading to effect (Marshall & Rossman, 1999). Instead recent experiences are used to give meaning to past ones in a retrospective manner (Holland & Kilpatrick, 1993). In

restorying, the researcher makes the connection among ideas and incorporates rich detail about participants' setting. "This setting in narrative research may be friends, family, workplace, home, [and] social organization" (Ollerenshaw & Creswell, 2002, p. 4). The researcher discovered that some women told aspects of their stories in a chronological way, whereas others jumped back and forth in describing their experiences.

Data analysis involves making sense of the narrative text (Creswell, 2003). First level coding which is a detailed and lengthy process starts when the researcher begins to notice similarities and differences between meaning units [chunks/segments of text] (Tutty et al., 1996). The data are assigned to categories, and codes [labels] are given to the categories. This procedure is called 'constant comparison analysis' (Padgett, 1998; Stiles, 2003; Tutty et al., 1996), whereby data that have the same features are placed in the same category and given the same code (Tutty et al., 1996). The researcher read and re-read typed transcriptions to identify patterns in the interviews. Using a tool in the Microsoft word programme on her computer, meaning units were highlighted in colour in the text. The researcher made notes in the comment boxes on the typed transcriptions which helped to develop categories and initial codes [1st level coding].

Second level coding which is more abstract looks at the similarities and differences between the categories in order to discover relationships (Tutty et al., 1996). Categories are further examined to identify patterns and themes that link them (Crabtree & Miller, 1992). These themes are coded and represent the major findings of the study (Creswell, 2003; Padgett, 1998; Tutty et al., 1996). Fraser (2004) suggested that one way in identifying stories is to peruse each line for beginnings and endings. She also recommended that the researcher should probe the transcripts for commonalities and

differences between and among participants (Fraser, 2004; Riessman & Quinney, 2005; Tutty et al., 1996). This is accomplished through, “comparing and contrasting the content, style, and tone of respective speakers” (Fraser, 2004, p. 194). The researcher began detailed analysis by examining the data line by line and coding the data into categories or themes for each case and across different cases [2nd level coding] (Creswell, 2003; Padgett, 1998; Tutty et al., 1996). She also compared transcripts for commonalities and differences.

The most frequent method used to distinguish concepts found in the data is thematic analysis (Overcash, 2004). Owen (as cited in Overcash, 2004; Overcash, 2004a) used three points of reference in picking out themes in the narrative data. These are: i) *Recurrence* of ideas that have the same meaning, but different wording; ii) *Repetition* where the same ideas and wordings are used; and iii) *Forcefulness* where verbal or nonverbal cues emphasize a concept (Ellingson & Buzzanell, 1999; Overcash, 2004). To analyze the data the researcher used both narrative and thematic analytic techniques. She applied inductive analyses using Owen’s (1984) thematic criteria to identify recurrence, repetition, and forcefulness within and across participants’ interviews.

For example, a participant stated “And that was my biggest fear, being bald” in a forceful manner. According to recurrence the phrase may mean “I’m afraid of being bald.” The participant made reference to hair loss several times during the interview “I just want my hair to grow back” and “My hair starts to grow back.” Each of these phrases indicated how the participant felt about her hair loss. Hence it was deemed to be an important concept and was identified under the theme ‘body image issues.’ Other emerging themes on how women coped with a cancer diagnosis and their jobs were

similarly explored. Analysis focussed on the content as well as the context of the interviews in a holistic manner.

The researcher supplemented Owen's three points of reference with Frank's (1995) three types of illness narratives – restitution, chaos and quest as part of the narrative analysis in understanding women's stories in returning to work with breast cancer. Frank (1995) narratives provided a structure of how illness stories are culturally constructed. Each of Frank's illness narratives was prominent at different phases and stages, and at times overlapped in the participants' stories. For example, some women talked about their physical difficulties with the treatment side effects using a restitution narrative structure that it was temporary. However, in the same narrative chaos can be heard as they shared the debilitating effects this had on them emotionally and psychologically.

The feminist perspective was used in looking at the social context in the women's stories. During interpretation of individual transcripts, the researcher also perused the stories for any emerging contradictions. She searched for the appearance and effects of cultural conventions, popular culture, and social structures. The researcher looked for relationships between the stories and specific discourse to see whether the stories supported, or contradicted relevant discourses (Fraser, 2004). All eight transcripts were scrutinized in the same manner to maintain consistency throughout the data process. Each case was compared to the other cases to help develop the various themes.

The researcher looked for patterns between the various categories and some of the categories were combined and/or renamed to produce general themes. These themes were further reviewed to create seven themes that reflected the participants' experiences and perspectives. The themes were then divided into major [five or more responses by

participants] and minor categories (Overcash, 2004a). The researcher also compared her themes to the relevant literature on women with breast cancer.

In sorting the huge amount of data found in the transcripts the researcher coloured coded participants' comments on a particular theme and portrayed them in a table format. Following this she used the cut and paste feature on her computer to place the participants' comments under the various themes and categories in the text. The researcher realized that although she had rich information in her transcripts she needed to focus only on the data that related to her research questions. This was where the coloured text was used to quickly identify the relevant data. The categories were modified, elaborated or eliminated during the research process (Padulla & Miller, 1999). The printed version of all participants' comments on a particular theme corresponded to the electronic coloured version.

The researcher sent an initial list of the main themes and categories that she identified in the data to her advisor. She further revised the themes and categories as she began to compare and contrast individuals' narratives. Each participant was given a colour that represented her comments. Participants' comments were inserted under the various identified themes and categories to show that their actual words had been interpreted correctly for the various themes.

An initial draft of the findings of all the themes was sent to the researcher's advisor and another committee member for their appraisal, corroboration, and any alternative interpretation. The researcher saw some overlap in a few of the themes and categories. This was confirmed by the two committee members that a few themes could be combined. There were initially 7 broad themes, 3 sub themes and 27 categories. This was further

collapsed to 6 broad themes, 2 sub themes and 18 categories. The demographic and treatment information provided contextual background in this research project. The revised themes and categories are found in Chapter 4 where they are described in detail.

Salmon (forthcoming, as cited in Riessman & Quinney, 2005) sees all narratives as a co-construction between the teller and the audience, whether or not the audience is physically present. The audience heavily influences what is told, the manner in which stories are expressed, what information is acceptable and what requires further expansion (Padgett, 1998; Riessman & Quinney, 2005). It is important however, that the researcher seeks to differentiate participants' versions from hers, and does not allow their versions to be taken over by her analyses (Fraser, 2004). During the interview process, the researcher is constantly being enlightened by participants. Reflectivity allows the researcher to understand how her personal beliefs and biases can influence the results of the study (Creswell, 1998; Padgett, 1998). In her writing, participants' comments for each theme were presented so that the reader could hear the women's voices through their own words and their lived experiences. This was supplemented with a narrative description of the researcher's interpretation of these experiences.

Also during data collection and analysis, the researcher collaborates with the participant to verify certain information conveyed in the story and its meaning (Drisko, 1997; Fraser, 2004; Ollerenshaw & Creswell, 2002; Riessman & Quinney, 2005). This is also in keeping with the feminist perspective and the researcher sent the typed transcripts back to all the participants for their feedback. This was to ensure that the researcher's interpretation of the results did not overshadow the participants' version.

Validation standards

This study used reliability and validity as conceptualized in the qualitative research literature. In qualitative research, “reliability refers to the trustworthiness of observations or data,” and “validity refers to the trustworthiness of interpretations or conclusions” (Stiles, 1993, p. 484). In assessing the trustworthiness of a study a number of strategies are applied. The ones that this author used in her research are: triangulation, member checking, negative case analysis, peer debriefing/support, audit trail, and researcher bias (Creswell, 2003; Padgett, 1998; Rubin & Babbie, 2001; Tutty et al., 1996). Padgett (1998) sees the audit trail as a “metastrategy for enhancing rigor” (p. 10), as it also assesses whether the other strategies have been utilized appropriately (Padgett, 1998; Rubin & Babbie, 2001).

Patton (2003) indicated that triangulation could strengthen a study by incorporating several types of methods or data. Triangulation of data was employed through multiple participants, the data source of the transcripts and the research log. These two methods helped to address any concerns about researcher subjectivity/bias, which made the study more credible.

Member checking helps to verify the researcher’s interpretations of the participant’s reality and increases the study’s overall credibility (Creswell, 2003; Drisko, 1997; Tutty et al., 1996). Exact transcription of a 45 minute interview produces approximately 25 typed pages (Morse & Field, 1995). Therefore, an interview that takes about 1½ hours can produce as much as 50 typed pages. During member checking this is a lot of information for participants to read through. As already mentioned, all the women

in this study were sent their transcripts to review. They conferred that the information was accurate and corrected any words that were not clear to the researcher during transcription.

Some member checking took place during the interviews when the researcher restated participants' perspectives, and asked for clarification on certain issues that were discussed in the interview. Enlightenment was also sought during the debriefed segment. Member checking was done with each of the women to determine that interpretations and conclusions were accurate. There were changes in two women's situation and the content was revised accordingly. These changes are included in this report. This entire process guards against researcher bias and reduce threats to reactivity, and participant bias (Creswell, 2003; Padgett, 1998).

Negative case analysis will be given attention as it is an area that can also enhance the credibility of the study. According to Padgett (1998) negative case analysis, "may reveal cases that disconfirm our interpretations" (p. 98). Every effort was made to look for cases that did not fit the researcher's interpretations of the data. Several examples were elicited and highlighted in the findings.

Peer debriefing/support is a strategy that provides an opportunity to guard against personal bias as well as bias in analyzing the data. The peer debriefer can play devil's advocate, challenge biases and allow the researcher to be more self reflective (Padgett, 1998). This role was undertaken by two committee members. The researcher's documented assumptions and perceptions on the interviews were sent to them. The data analysis, emerging themes and categories were also discussed. The two committee members reviewed the initial results to ensure there was consensual validity.

An audit trail increases the credibility of the researcher's study, and allows other people to confirm the study's results (Miles & Huberman, 1984; Padgett, 1998). Inaccurate documentation can affect the transferability of the findings (Padgett, 1998). The researcher enhanced auditability throughout the study by detailed documentation of interview transcripts, together with raw notes about decisions made during data gathering and analysis. These steps have been clearly outlined under the sampling criteria, data collection process, the rationale for the interview guide, and method of analysis. This accountability will determine whether most or some of the strategies – triangulation, member checking, peer support, and negative case analysis have been implemented.

Researcher's bias.

The researcher's views of cancer and cancer survivors have been moulded by her professional and personal experiences as an oncology social worker for 10 years [1986-1996] at the National Radiotherapy Centre. Since then, she has continued to see cancer survivors both professionally and in a voluntary capacity. The researcher believes her understanding of the emotional experiences of cancer survivors has made her more knowledgeable and sensitive to the challenges, decisions and issues that this clientele face. Despite being a novice researcher, she is of the view that her experience has been an asset with this group of individuals. However, the researcher is aware that her knowledge in this area can bring certain biases to the study.

For example, these biases may influence the way the researcher sees and make sense of the data collected. The researcher began this study from the perspective that the cancer survivor in Trinidad has difficulty in working during treatment. Another bias is that women who stop work lack the necessary supports and informational needs for

returning to the work force. The first year can be a period of frustration, unexpected changes, and challenges for both the survivor and significant others as they adjust to living with the diagnosis. There is also the possibility of biases the researcher has incorporated from the literature review which can also decrease the credibility of her findings.

Every attempt was made to deal with the threats posed by personal biases during the study. 'Disciplined reflection' was used to minimize the researcher's biases. The researcher admits that there were times when she had to mentally remind herself that her role was one of researcher and not counsellor. Perhaps this is why she gave participants control to tell their stories at their pace. Using the same interview schedule with all of the participants also control for researcher bias. The researcher had never met any of the women before the study so had no preconceived notions of their experiences. Researcher bias was also reduced between the researcher and the participant through empathetic listening techniques. Concerns about researcher bias were dealt with by the various criteria that were identified as a means of reinforcing trustworthiness and which were outlined above.

Summary

In this chapter the methodology was outlined. A description of the methods and procedures for recruitment was shown. Data analysis proceeded concurrently with data collection and this was explained in detail. Validation standards were also discussed. The next chapter will present the study findings.

Chapter Four: Results

The findings from the data analysis are presented in this chapter. It is organized according to the six (6) major themes identified in analysing the data. Each theme consisted of several categories which have been developed from merging minor categories or codes. Examples from the various interviews are given to support the main themes and categories that surfaced during data analysis (see Table 3). This section deals with the return to work experiences of employed women with breast cancer in Trinidad. Before discussing the themes some information about the participants' demographics (Table 1) and treatment profile (Table 2) is introduced.

Demographics

Demographical information was elicited from the women during the course of the interview as they recounted their experiences as well as in the debriefing. The eight (8) women's ages ranged from 37 years to 49 years. All the participants were professional women with educational levels from post secondary to graduate. Time spent in their current jobs was from 3 years to 29 years. Four were employed in the public service, three came from the private sector and one worked in a state enterprise. There were variations in their ethnic background and religious affiliation. All the participants were in relationships, six were married and two were divorced and now were engaged to be married again. Six women had children whose ages ranged from four to eighteen years. Table 1 summarises the women's profiles.

Table 1

Participants' Demographics (n = 8)

P	Age	Marital Status	Ethnic Group	Religion	Education	Occupation	Years in Current Job
B1	48	M	Mixed	RC	Bachelor	Bank Official	29
C2	48	M	East Indian	Christian	Bachelor	Clerk	29
A3	37	D, E	East Indian	Hindu	Post Secondary	Admin. Coordinator	6
D4	47	M	Mixed	RC	Post Secondary	Manager	9
E5	45	M	African	Pentecostal	Post Secondary	Admin Assistant	3
F6	49	M	African	Pentecostal	Bachelor	HR Advisor	12
G7	39	D, E	East Indian	RC	Bachelor	Technical Analyst	5
H8	47	M	African	SDA	Graduate	Manager/Asst Professor	5

Note. E = engaged; M = married; D = divorced.

A map of Trinidad and Tobago with the Regional Health Authority (RHA) divisions gives an aerial snapshot of participants' residences (Appendix I). The Ministry of Health decentralized its health care services to the Regional Health Authorities in 1994 (RHAs). However, the Ministry plays a main role ensuring that these services are properly run through policy development, planning, evaluation, regulation, research, and allocation of resources for the Regions. The Ministry has also maintained responsibility for some vertical and national programmes. There are five RHAs, four in Trinidad and one in Tobago. These are: Northwest Regional Health Authority (NWRHA); North Central Regional Health Authority (NCRHA); South West Regional Health Authority (SWRHA);

Eastern Regional Health Authority (ERHA) and Tobago Regional Health Authority (TRHA) (Directorate of Health Policy, Research and Planning, 2006).

All the women dwelled in urban areas; two lived inside the boundaries of the NWRHA. There are two treatment facilities in this Region - The National Radiotherapy Centre (NRC), and the Brian Lara Cancer Treatment Centre (BLCTC). The NWRHA also contains Port of Spain, the capital. Three participants were located in NCRHA, and the other three women resided within the SWRHA. The third treatment facility, The Southern Medical Oncology Centre (SMOC), is found in the SWRHA and the second major city San Fernando, is also situated in this Region.

The participants

The participants interviewed were diagnosed at two different time periods. Four women were diagnosed between 3 - 4 years ago, had lumpectomies only, and received both chemotherapy/radiation treatment. The other four participants' diagnosis ranged from 3 - 11 months ago. In this group, three women also had lumpectomies which were followed by a mastectomy for two participants; another person had a biopsy and then a mastectomy. One has just completed all her treatment and three women are still in treatment. An individual currently having chemotherapy is the only person from this group who is not scheduled for radiation.

All eight participants received their chemotherapy at NRC. Four women got their radiation treatment free of charge from the Ministry of Health at the BLCTC and SMOC. The other two participants paid for their radiation treatment at the BLCTC through their medical insurance. One individual will begin radiation treatment at NRC after chemotherapy finishes. All the women took sick leave for their surgeries and the time

away from work for treatment varied. A more comprehensive breakdown of the treatment profile is found in table 2.

Table 2

Participants' Treatment Profile (n = 8)

P	Time Since Diagnosis	Treatment	Time off During Treatment	Health Coverage
B1	4 years	Lumpectomy, Chemo (4 cycles) – NRC Radiation – BLCTC	Odd day 2 weeks' sick leave for surgery	Yes
C2	4 years	Lumpectomy, Chemo (6 cycles) – NRC. Tamoxifen Radiation – BLCTC	Yes 6 months including 1 month vacation	Yes
A3	9 months	Lumpectomy, Mastectomy Finished chemo (8 cycles) – NRC. Tamoxifen To start Radiation BLCTC	Yes 5-10 days each cycle. One month off for surgery	Yes
D4	3 months	Lumpectomy. On Chemo (6 cycles) – NRC. Tamoxifen To start Radiation after chemo treatment	Yes Took 3 months' vacation after 2 nd chemo	No
E5	11 months	Lumpectomy, Mastectomy On Chemo (8 cycles)	Odd day. 2 & 3 weeks' sick leave for surgeries	Critical illness policy
F6	10 months	Mastectomy Finished Chemo (6 cycles) – NRC. Tamoxifen Completed radiation 2 wks ago – SMOC	Yes 3 months (included surgery & 4 cycles chemo) Worked for 2 cycles chemo & radiation	Yes
G7	4 years	Lumpectomy, Chemo (6 cycles) – NRC. Tamoxifen Radiation – BLCTC	Yes 5-7 days for each cycle	Yes
H8	3 years	Lumpectomy, Chemo -NRC Radiation – BLCTC	Yes While on chemo. Worked during radiation	Yes

Table 3

Themes and Categories

MT1: Finding Out About the Diagnosis

C1: Reactions to receiving the news

C2: Perceptions about cancer

MT2: Coping and Social Support

ST1: Coping Skills

C3: Spirituality and prayer

C4: Humour

C5: Reaching out to others

ST2: Social Support

C6: Disclosure and support at work

C7: Support from health care professionals

MT3: Work Adjustments While on Treatment and After Treatment Has Ended

C8: Reasonable accommodation on the job

C9: Challenges on the job

MT4: Attitude Towards Work After a Cancer Diagnosis

C10: How women viewed their jobs

C11: Reasons women remained with current employer

C12: Work support in educating employees about breast cancer

MT5: Cancer Impact on Self Image

C13: Body Image issues

C14: Intimacy issues

MT6: Lessons Learnt From Cancer

C15: Changes in lifestyle to prevent recurrence

C16: Exploring the cause and search for meaning

C17: Life perspectives changed

C18: Relationships improved

Finding Out About the Diagnosis

All the women started their story with how they were diagnosed with breast cancer and gave detailed accounts of the steps leading up to their medical treatment. Two categories identified under this general theme were reactions to receiving the news and perceptions about cancer.

Reactions to receiving the news.

Most participants believed when they discovered the lump that it would be either a cyst, a growth, or benign. Despite their initial feelings of shock, disbelief, fear, panic, numbness, and confusion, five women acted with a sense of urgency. Two from the five said that the reality hit home when they began their chemotherapy treatment. The other three participants had delays based on a number of factors, which included being told to monitor the lump, diagnostic tests that indicated it was benign, and one wanted time to go on herbal treatment.

The following two examples highlighted the women's feelings and the emotional chaos they experienced in finding the lump and having the diagnosis confirmed.

And I, I check myself regularly, had a shower and all of a sudden there it was. I just couldn't believe what I was feeling, an absolute panic (emphasis) just took over me. And I kept thinking this is, this is not what it is, no. I literally wanted to start screaming in the shower, but I said okay, I'm going to wake up tomorrow it's going to be gone. And um, it was still there, and I was like "oh my goodness this is not happening." (D4)

And um, and he said, "its' cancer." Um, I was shocked I remembered I felt like if I was slapped in the face. Me, cancer, (chuckles) don't go together, you know. So I think that, the whole shock of that (emphasis) was the first of many. But that was the first one that remained in my mind. The shock, because I was telling myself all along well we just testing and, you know its just, if it's a lump we will just take it out it's benign or whatever. But when it came back that it was cancer, it was shocking. (H8)

Perceptions about cancer.

In this category, the women expressed their perceptions' about cancer as well as other people's beliefs regarding cancer. Four participants related that their lifestyle had been a healthy one, with a nutritious diet and exercise and they had difficulty in understanding how they had got cancer. The women realized that doing what they thought was right healthwise offered no guarantee that they would not end up being ill. Their views are depicted in the following excerpt:

As you mentioned that I want to tell you one of the things that, um I was angry about and even now, up to now. When I was diagnosed and I would go by any doctor. When I went by Dr. [name deleted] or Dr. [name deleted] wherever, they gave you a sheet to fill out. Do you smoke, no; do you drink, no. So I remember telling Dr. [name deleted], I say is best that I'd smoking and drink and thing, (humour in voice) you know. Because I, my lifestyle was such I didn't use to eat KFC, I wouldn't drink Coke, I. So where this come from, you know. (C2)

There is a cultural narrative that cancer is a death sentence. Seven women voiced this outlook and felt that their lifespan was now shortened as a result.

...and then you'll give the emotions as well in terms of whether you will live, alright. Life is now shortened, your lifespan has now shortened, alright. Is it that, (pauses). Well life goes on after me, kinda of thing. So that's really the main um, kind of emotions I supposed that I would have gone through, at the time. (B1)

They also encountered this belief among relatives, friends, speaking with others, and in the workplace. As A3 stated, "Well my father every night he cries, and um, he said he don't want me to die before him."

Five women were quite open in sharing their diagnosis on the job and acknowledged that other people also reacted with disbelief, concern and sadness. The other three women told only people close to them, and at their workplace, informed only those who needed to know, such as their department heads. Their reasons were that they did not want to be treated differently, or pitied.

I don't want to be treated any differently because of (B does not finish sentence). Hence the reason why I would not tell everybody because I don't want them to think I want you to treat me in any particular way. (B1)

Yeah um, I'm a private person to an extent and I know. I, I think the thing is you don't want people feeling sorry for you. And I think sometimes you don't know how people will react. I just don't want to have to be carrying people, I done have to carry myself. So I don't want all this additional thing that not every body could handle, you know. (E5)

Um, (pauses) I, I try to stay positive and I think in general I'm a positive person. But when you see the fear you, you think of death you think of you know, and I didn't want to, I didn't want to look at that side of things....Yeah, and I don't want to be seen as a sick person when people have to come and visit. I didn't want that. (C2)

One participant, F6, is a third generation cancer survivor and does not see cancer as a death sentence. Her mother who is still alive at 80 years, gives her hope.

I mean, yes we knew it was possible because my mom is also, was also a breast cancer victim. But she's a survivor too, twenty something, yeah 25 years. So I know the prognosis, you know I'm not one of those who think of it as a death sentence. (F6)

There is also the myth that people with cancer look a certain way. Some women noted that individuals were surprised by how well they looked as evidenced by the following example.

And you know the, the thing a lot of people, especially with workers, and the people I work with and so on. The, the thing they tell me is, "you don't look like you have it." So I asked them well "what I'm supposed to look like, you know?" I, I guess they expected somebody sickly and drawn, I don't know, I don't know what. (D4)

Coping and Social Support

Coping and social support referred to the various strategies and supports that the women used to manage the cancer experience in all aspects of their lives from diagnosis to recovery. This theme is divided into two sub-themes, coping skills and social support.

Three categories fell under this first sub-theme: Spirituality and prayer, humour and reaching out to others.

Coping skills.

The participants all described how the treatment disrupted their ability to perform their various roles in the home as well as at work. Some tried to make the necessary adjustments to normalize their own and their families' lives while others had difficulty coping. It was during these times that they sought and got the instrumental support from the people closest to them. According to B1:

Um, the only, only way, area I sort of sought help was from um my sister to help me with the housework kind of thing. But other than that I think life went on for me. I just continued in what I could have done once I was up, to doing it. Because I wasn't sick, sicky at the time of actually doing the chemo. (B1)

C2 discussed how the harrowing effects of the chemotherapy limited her ability to run her home. She lamented over bodily difficulties and not being there for her family.

And (pauses), it was, I used to be sick for a whole week, a whole week. To be sick, I cannot eat, I can't turn a pot, see the children you know. So all that used to worry me and um, so I couldn't prepare the meals and all that. But I couldn't eat for a week...And then even to go to the bathroom they had to put a chair. It hit me real hard, real hard. (C2)

Although family and friends were supportive, all the women still experienced a sense of helplessness and anxiety in their daily functioning. The participants used a number of avenues to cope during this time in an effort to normalize their lives. This ranged from continuing with regular activities when they were up to it, family and friends taking them out, talking about the illness, being occupied and doing things they enjoyed, holding on to their faith, having a positive outlook, and humour, to help mitigate this stressful period.

For instance, D4 who was diagnosed 3 months prior to being interviewed is taking a positive approach to the illness. She commented:

Yeah, so they like “you’re so positive, you have a good, a good aura, you know. How you so positive?” And I’m like because as far as I’m concerned it is gone. They have cut it out of me, the parameters were clear. So as, as I tell everybody “I had cancer.” So I’m now in preventive as far as I’m concerned. And this is what I have to go through and by the end of the year I’m going to be fine. So why should I fuss. (D4)

Spirituality and prayer.

All the women except G7 spoke about their spirituality, which helped them to endure the treatment process. Some attested that it was their faith that made them stronger during the illness. As B1 said, “*Yeah, I was always a spiritual person, but yes it was part of the um, it was more so at the time, kind of thing.*” A3 admitted that “*I’m a little lackadaisical, but I do pray, I do.*” She indicated that it is her faith that is sustaining her. “*And I, I, I, don’t worry, you know because I know one day, my prayers will be answered even though I’m not a devout Hindu, you know. I still try (chuckles).*” E5’s strong faith has assisted her to cope over the past few months with her surgeries and treatment. She is grateful to God that despite her reactions to chemotherapy she is still able to continue with her life.

I had, actually I had surgery what Tuesday and I was in church the Sunday....Not, I was back, normal (laughs) into, into everything. And um, I would credit that to, I would think to, to, to say it in God’s hand, I really would to be very honest....And I could safely say that it had to be God carrying me, it ain’t have no other way. (E5)

F6 also recounted her deep belief in God and learning to keep Him in the forefront of her life.

I’m a Christian and there is a strong belief (emphasis) in God. I think what it has taught me, it has taught me to trust him more. Because it’s a little situation where it is a challenge and, you know....Going into the, the whole, um, going into the, into the surgery, you know there are, you know, you just felt as though He was always

holding your hand....But this is just another way to show, another aspect of your faith growing in it, you know. And um, continue to trust because I mean He's really, He is the healer. And even after this whole, all the therapies and everything, He is the One who has to keep. (F6)

Humour.

Humour has been known to be a great stress reliever and it can ease many awkward situations. In reflecting on their stories the women were at times able to laugh at themselves. Some in irony, others chuckled/laughed during their own discomfort in relating the stressful and intense feelings/reactions to their experiences. In their stories, four participants mentioned how humour helped to relieve the situation for them and their loved ones. For example, C2 who still gets emotional in reliving the events, recalled:

And um, the father is baldhead so he shaved his head and I, you know I was bald at that time. So my son used to sit between us and he would tap one and tap the next one to see which one sounded more hollow you know that kind of thing, that kind of thing (whole demeanour was relaxed, chuckling as she reminisced over this part of her story). (C2)

D4 described how her two boy children saw the funny side to the situation after she had her lumpectomy and also when her hair began to drop.

I just couldn't put my arm down so I looked funny. My, my son thought it was hysterical because I had my hand on my hip. I go to the grocery hand on my hip, and he's like, "Mom, you looking like a runway model." So you know I walked in the grocery and they will walk me behind me going, "Work it mom, work it," you know, so (both chuckle). (D4)

Reaching out to others.

Seven women reported how they took the initiative to reach out to other survivors including family and friends for support. They also educated others about the cancer experience. C2 has a cousin who was diagnosed a year after her, and shared that in assisting her cousin their relationship became closer. She also felt validated because she was able to give her cousin support.

But for her, um I couldn't um, I couldn't seem discouraged or anything, I had to keep it upbeat and thing, ah you know....Or if I find she's getting depressed or all that. I will say no, I will talk her out of it you know, we have life whatever, whatever. So I, I think, in just helping one person, you know, being able to help one person is enough. (C2)

Most participants interacted with fellow survivors from various walks of life and social status. They found themselves comparing their experiences to other survivors, and realized how fortunate they were in their support systems and in having the necessary financial resources. D4, who had her surgery privately, related another survivor's challenge in the long wait time for her surgery, which caused a progression of the cancer.

And I'm listening to this lady this morning, and I'm thinking she didn't have it, you know. And look at where she is now, she's now stage III, triple b whatever. And my mass was 2 cm when they got it. So I said, well how, how was yours? "13 point something," and I'm thinking, holy crap, that's a big thing! you know. And I'm thinking she's saying you know, I wanted to get it done, but every time, they put it off, and the doctor, and the electricity and everything got pushed back and three months later. And then they decided you know what, go straight into chemo because it was just growing. (D4)

G7 acknowledged that because of her own social background she recognized "And I was literally living with blinders on, literally." It appeared that going to NRC has kept her grounded when she communicates with others and hears of their unique experiences in trying to manage the cancer.

But what NRC offers me is a reality check. I like to sit there and be awed by the different kind of people that I meet. And I just like to talk to them....I've met a lot of people who just not too savvy with what's going on....I, I met a woman who said she doesn't have cancer. Her doctor just sent her here and they took out everything and, doctor just send her here. And I'm trying to say to her, you are at NRC, (emphasis) you know (ironic tone with a chuckle)....And again that, that is a reality check the kind of people you meet. (G7)

F6 described an encounter at NRC with a man whose wife has cancer and his uncertainty and fear that she may die. F6 was sensitive and understanding of this man's fear. She listened to his concerns, encouraged him to go into the doctor's office with his

wife and asked the questions he wanted answered. It also made F6 aware of the differences in other people's approach to the illness.

So it was me kind of sharing with him how to cater him, you know....But there are other people out there who really don't know. I mean they come from rural areas and stuff and they really don't know. (F6)

Facilitating this gentleman also boosted her morale. *"I mean, you know just talking to him alone was, you know. You know you felt as though well, I mean, oh gosh at least I helping somebody."* Most participants felt that by reaching out to others they were making a contribution to their own lives as well as to the people they assisted.

Social support.

This second sub-theme consisted of two categories, 'disclosure and support at work,' and 'support from health care professionals.' The women identified a number of people who provided social support, namely, family members, friends and other significant people. However, there was always one special person who was their main support. B1 and C2 informed that it was their respective sisters; D4, E5, F6, and H8 stated it was their spouses; G7 specified her mother and A3 spoke of family and friends. All gave examples of emotional, instrumental and appraisal support in their personal and work lives. As H8 succinctly summed it up:

(Big sigh) They all had a different function. So in the medical, I would say Dr. [name deleted]. In the home care, I would say my mother. In the emotional support, my husband. In, there were different people about and each had a different role. In the spiritual, the pastor came and he has been checking on me, every 3 weeks he calls me. (H8)

Disclosure and support at work.

The literature showed that while the majority of cancer survivors shared their diagnosis there were others who preferred not to disclose. The relationship between

survivors and their employers/co-workers influenced this decision. In this study all the women told someone on the job about the diagnosis. B1 continued working during treatment and although it has been 4 years, she still has not shared openly with more people on her job.

The five participants who were candid on their jobs about the cancer were given support. C2 was impressed and touched by the encouragement people from all levels in the organization offered her. She realized that the outpouring of support had to do with how she lived. This made an easier transition for her reintegration at work.

The supervisor, my boss. We, we like a family, everybody close and she knows that I doh have a problem, people knowing. It's just that I couldn't talk about it....And um, they bought um, vitamins and tonic and thing. They did their research and the Diamite products and they bought whatever. And they came home, and (pauses) and then they were giving me money and I say no, I say, "What is this?" I say no, and she said your fan club keep coming and asking, "What we doing for [C's name deleted], and what we doing for [C's name deleted]?" And I said, "No tell them no" (amazement in her tone). So they bought 2 sets of um, the products for me and insisted that I take all the vitamins and thing. So Dr. [name deleted] had told me yes go ahead and take it....and when I returned to work, they had a surprise brunch for me. (C2)

D4 kept her management committee involved every step of the way about what was happening to her.

And my bosses have said you know, we know you are going through a rough patch right now. And we are not going to um; it's not all going to be over until possibly, closer to the end of the year. And you have to kind of heal, get yourself back up, you know. You are not going to be all back to normal unless it's done. And they are like, well we will see what happens next year. You know when you come back next year, bigger better things. So they are, they are very positive for me, you know. They are like you can do this, we know you are very positive about it. And I'm, we know you need to take the time to, you know see about yourself and we totally understand that. And um, we will get you back up to scratch next year. (D4)

H8 revealed her diagnosis to everyone on the job and got full support. When she went out to work during her radiation therapy she was able to make the necessary work arrangements, which helped her to cope on the job.

So at work they were very supportive. And when I had to go off I would tell them in advance. And we worked around meetings with me and we would work around when I had to leave. And um, ah, some of the responsibilities I didn't have as much. Or I delegated and people understood why I had to delegate. (H8)

Support from health care professionals.

In this final category, the women reported the support or lack of support from health care professionals who attended to them privately, at NRC, and at the other two private treatment facilities. Some participants described a few negative incidents that took place during their treatment. Despite these setbacks, they were all still pleased by the quality of care they got from the medical team at NRC. A3 conveyed, *“And I got the best treatment, the nurses were nice, the doctors were nice, they very helpful. And I would recommend anybody to go there.”* The women all agreed that their oncologist or the house officers gave them information on the treatment side effects. Some participants felt this was insufficient and did further research on their own about these effects, the cancer and nutrition.

G7 did research on the stage her illness had reached and based on another survivor's experience, she made suggestions about the procedure to her surgeon, who agreed to it. Thus, she was part of the decision-making process where her health was concerned.

So I read up on the Internet because I'm a nerd (laughs). That um, he could do an open, um open section where they leave you opened. They biopsy it and then depending on what they find they do it. And I said [doctor's name deleted] can I do that, you know just in case. He said, “Well they only offer that at [name of private facility deleted] because the hospital is right there.” He will make the um,

appointment with the pathologist at General and they will work it out, all out to time. (G7)

Two women discussed that their private physicians were unsympathetic when they were first diagnosed. G7's doctor was "a little nonchalant about it." She further noted that "I um, I had shoddy health care. And then I went to the other extreme where I had like, wow beyond this world health care." C2 was upset by the pragmatic manner in which her private physician broke the news to her and his insensitivity when she began to cry. Although she had confidence in him, she found his reaction odd. She commented that a fellow survivor also had a similar experience.

(Continues with tears in her voice) But my surgeon was very good. But what struck me is when I started to cry, he um, he looked at me and I don't know if it is a man thing or what, he said um, "What you crying for?" (continues to cry silently)...Um, I wondered if I was over reacting, or what, but, I just didn't know what because, the shock of it to me. But from talking to other people, they tell me the same thing. In church I um, have a girl who is doing treatment now. She told me, she said her doctor ask and she too was shock by it. He ask her um, "Why you crying?" She said, "He asked me why I was crying." (C2)

Some participants had unpleasant experiences pertaining to their health care at NRC. Two women, E5 and H8, observed that the nurses were in a hurry and did not take time regarding their chemotherapy administration. According to E5:

I think it was a [ethnicity deleted] nurse, she did not give me the um, premeds, yeah she did not give me the premeds. Hurry, you know, she did not give me and then, and then I told the doctor after, you know about it. (E5)

G7 also found that some of the doctors at NRC were unconcerned about her issues. She rationalized that others' needs were more pressing than hers.

No, let me tell you something eh, when I. I never discussed brain fuzz because when I discussed the lymphodema they trivialized it. When I say I feel tired all the time they trivialized it. Because and I, I don't blame them because they dealing with people who so sick and dying, and weak, and not sure about what's happening next. That when I come in and I say you know my hand swollen. Is like "and," you know. (G7)

Based on physicians' reactions and responses, survivors would hesitate to ask questions about issues that were worrisome to them.

There were times when survivors grappled with the treatment and what it meant to them and their quality of life. For instance, E5 wanted to stop the chemotherapy treatment, but her doctor laughed at her anxiety.

And he [doctor] wasn't hearing me, I wanted to stop and he just was not (emphasis) hearing me, he was just laughing at me. He said, "Well, we could reduce it you know." So I'm saying, I say "to zero point zero, zero." Yeah, I was that, I went that day I did not want anymore, you know to be very honest. And then I said ok, you know [E's name deleted], it's just 3 more, you done reach this far, I'm telling myself that, eh (in a resigned tone of voice). (E5)

H8 was pleased with her oncologist, but she became upset with him when she had to be hospitalized due to the treatment side effects. She had asked him to change the medication and he would not listen to her.

I told him that, I think he should change the medication. Give me a lower dosage because I'm feeling weaker....And he said, "No, no, we have a 8th week, a 8 session course that you have to take." And he sent the blood for, for checking the hormones. And that didn't come back for awhile....So, we checked Dr. [name deleted], and he said yeah he got back the results, but I was negative. So I'll have to continue on the treatment and it's after that then I got sick....So Dr. [name deleted] came in and he apologized and he said, "Alright I will break down the dosage for you"....So I was upset with him because I was saying, I had to get sick and in hospital and can't breathe, for you to realize what I told you (emphasis). You know, so I wasn't too pleased with him then. And um, when I came out, they had changed the dosage. And um, I had to go once every week, was it, there was about 8 more treatments. And I think it was once a week or something now, but it was not as intense. And, I wasn't feeling as I was feeling just before I got ill. Um, and after that we were fine, that was the lowest I'd been when I ended up in the hospital. (H8)

In the interviews, D4 was the only person who talked about the medical social work services. She learnt about the department when her doctor referred her for diagnostic tests. D4 came to appreciate that social work covers a whole range of services and she now sees social work in a new context.

...just the social workers are just amazing. So I don't think people realize what, what they do, what's really a social worker. And you think, alright they are going to rescue poor abandoned, abused children, that's what they do. But it's a lot more than that, like I said I'm learning, I'm finding out that, they are a huge help (emphasis). And people don't know, you know, you think a social worker and you think, it's not for me, that's for other people, you know. Those people over there. (D4)

When the researcher followed up to verify findings, F6 indicated that she too was referred to the medical social worker. She had been given financial assistance regarding diagnostic tests. However, she was unaware that the department also offered counselling.

I got tests free and paid half for my bone scan. The social worker Ms. [name deleted] was very helpful....I didn't know about the counselling aspect of it. (F6)

E5 related that she would like to see more counselling support. She had dealt with many of her concerns alone or had turned to fellow survivors for support. The researcher enquired whether she was aware that there was a medical social work department. E5 further admitted that although she knew the department existed, she had not accessed the counselling services.

(Big sigh) Hmm, (long pause) um, I wish sometimes that the, the, the counselling support could be more. I don't know, I never really had any counselling per se, I just um, learn to deal with it on my own. And um, I know there are times, sometimes when you have questions you go on the Net. I don't know if all the time that is, correct or appropriate, you know. And you really just look for support with people like, like yourselves. So you form friendships with people who are in the same position like yourself, and we support each other. (E5)

The participants took an active part in securing information about their health care. However, they discovered from interacting with other survivors at NRC that there were women who were passive in this area.

I think it's um, just information, a lot of people um go through the, a lot of, well the ladies I'm meeting they going through the system. And the doctors don't, if you see how many people they have in St. James. They don't have the time, they have to (emphasis) get through this you know. So unless you asked, they don't tell, so I usually go and ask. Go with you know, "I need to ask you this, can I do this, can

this happen if I do this you know.” But I realize that people are in and out, they don’t ask and the information is not offered. So I don’t know if there’s, if um, there is something that could be put in, a desk or something that people could go and asked the questions, without keeping back the doctors. (D4)

A3 remarked that she had not read the radiation literature she got because it was somewhat depressing. However, she has made enquiries about having a PET scan post treatment.

So you know, you need to check up on yourself. So I’m actually a little more aware. I don’t, I read certain things, I had the, even the radiotherapy thing they give me to read, the radiation stuff, I haven’t, read it as yet. Because (tsk) it’s a little depressing, you know, just to, when I ready I will read it....But, they say probably in, after the radiation, a couple of months you have to go and get a PET scan. So, I’ve looked into that, right and it’s in Miami and stuff like that, and what it entails, and you know. (A3)

Work Adjustments While on Treatment and After Treatment Has Ended

This third major theme is represented by two categories, reasonable accommodation on the job and challenges on the job.

Reasonable accommodation on the job.

All the participants were professional women whose jobs were office positions. D4’s job was a combination of both, being in the office and also outdoors liaising with the customers. The treatment phase affected the participants’ ability to function fully at work. There were work disruptions in terms of taking time off to go for their various treatments, sick leave to cope with the treatment side effects, as well as a decrease in productivity level at work. A common symptom the women all raised was being fatigued. Although they experienced this to varying degrees it still hindered their functioning. The majority of participants worked during treatment and returned to work fully after their treatment ended. Three women took sick leave and/or vacation leave in a blocked period for their surgeries and/or treatment.

For example, C2 was on five months' sick leave for her surgery and chemotherapy treatment. She was informed that the effects of chemotherapy could weaken the body, which she subsequently faced. C2 returned to work for one month at the end of her chemotherapy treatment, and then went on vacation for the following month that she was on radiation. F6 was off for three months during which time she had her surgery and four cycles of chemotherapy. She worked for part of the chemotherapy and throughout the radiation treatment.

F6 disclosed that she felt exhausted during this period. She had to manage the long commute to the treatment centre and back to work four times a day. This journey would have been stressful for most people who did not have to contend with a treatment. F6 was given the time off by her supervisor, and her senior position allowed her a measure of flexibility without her having to divulge the type of treatment. The only person she told was her Permanent Secretary who was also a personal friend. F6 put measures in place so that her immediate supervisor and others would not find out about the cancer. She recounted that this gave her the determination to remain on the job once she returned to work.

Yeah, which is why I, I used my head there and got my private surgeon even to submit the medicals, on my behalf, for the um, for when I was doing the chemo. So I was determined that once I went back out I would try to, you know maintain, you know at least try and stay out, it worked. So it was more me not having to divulge, I suppose that gave me the extra will to stay. But it so happens that once I went out the way I would arrange chemo was on a Thursday, so go the hour on a Thursday. Friday I took off and I have the Saturday and Sunday, I have chance to recoup so by the Monday I will be okay. (F6)

D4 took two days for her lumpectomy and continued working until she began three months' vacation leave one week after her second chemotherapy. At the time of the interview for this research study, D4 had started vacation the day before. She stated that

her vacation was actually accumulated leave that she has not taken over the years due to the demands of the job.

The other five women went on sick leave intermittently throughout their treatment. All the participants' organizations afforded them this accommodation. Some women also made their own reasonable accommodation by scheduling their treatment to facilitate time off from work. For instance, B1 organized her chemotherapy for a Friday so she would have the weekend to recuperate and be at her desk on the Monday. She also arranged to have the radiation after work hours. B1 made her own reasonable accommodation to normalize her work life.

Like I said I took it on a Friday so that I would have the weekend to recover and I went back out to work the Monday, kind of thing. So that was the arrangement that I wanted that it will be on a Friday. (B1)

A3 began by taking five days' sick leave after her chemotherapy, but increased it to ten days when she started to feel the ravages of the drugs. She realized that this was still insufficient time for recuperation and said that she would recommend fourteen days to other cancer survivors. A3 reported that she went out to work on some of her sick days to help out when the company was short staffed, and her employer appreciated this gesture.

E5 took five weeks' sick leave for her two surgeries and the odd day off for her chemotherapy or other follow up procedures.

I went about my business as normal. I didn't even, the only time I stayed home was for my surgeries. And after that I came back out. The days that I have chemo itself, I stay home that day, the other days I come. If I'm really, really not well unless I have the pains with the joints and unless I really can't make, well then I stay home. But on a scale of 1 to 10, I'm here most days, you know. (E5)

G7 expressed that she used up all her sick leave, which she claimed was fifteen days, for her first three chemotherapy treatments, and then had to apply for extended sick

leave. She acknowledged that although she did not want to stay home, it was difficult to work while being on chemotherapy. H8's position in her organization, and the nature of her job gave her the flexibility to work from home on her computer during the chemotherapy. She went out to work while on radiation.

Um, so during chemo I was working from home, but the radiotherapy I was just, um it was one, one hour for 21 straight days. So that um, I could go to work in [place deleted] after getting it. (H8)

During the verification of findings phase, the researcher enquired of six women if they had discussed working and being on treatment with their oncologists. B1 said that there was no dialogue with her doctor *"because I never stopped work."* C2 and G7 recalled that they made the decision on their own; their doctor gave them as much sick leave as they requested. A3, E5, and F6 asked their oncologists who informed them that they could work, but left the decision up to them. As F6 summarized it, her doctor advised *"depends on how you feel, it is an individual decision. As long as I could cope."*

Challenges on the job.

As already seen the majority of participants had disruptions in their normal work schedules. Despite support from their colleagues, four women also had various challenges they encountered on the job. One of their dilemmas was inability to fully perform their roles although they were given reasonable accommodation. This created a level of anxiety for the women. For example, D4 talked about the difficulties she experienced in having a demanding job and being fatigued, which affected her both physically and cognitively.

This was her reason for taking all her vacation leave at this time.

Yeah, there have been, um there are times when I, it, it has me so tired that you trying to, minimize your way, your time away from work. So you go and by 2 o'clock, I am just no use to anybody, I have to, I can't function. I can't even think, you know, so that has been a challenge. (D4)

G7 commented on two major challenges, one was in reference to a project where she could not lead her team because of being too sick and frequently missing work. G7 believed that she was penalized for this in her yearly performance evaluation. Although disappointed, she was able to put her evaluation rating into perspective. G7 admitted that she had already been diagnosed when she was given her performance plan. Another issue for G7 is “*brain fuzz*” as a result of the chemotherapy. She observed that this still continues four years later causing her increasing difficulty in learning new things. She justified it by telling herself that she was getting older.

There are days when you get brain fuzz. I think I still get it and I researched it, and they said you know sometimes after chemo you do get (emphasis) brain fuzz. I mean, I'm, it's not like I'm not on top of things, I'm on top of things because when I went to the [place deleted] I was already a qualified DBA (Data Base Administrator)....And for new things I find like, my, my learning curve is a little steeper. For things that were there already that's on top of my head....But the capacity, I don't know, it could also be I tell myself because I'm older. Because you know your learning curve is a little hotter when you in your 20's and your teens compared to when you are close to 40. I don't know, but sometimes I feel like I have severe (emphasis) brain fuzz. (G7)

Two participants who did not openly disclose on the job had challenges in trying to maintain their privacy, and the resultant impact, which also aroused anxious feelings. E5 noted that the organizational culture was one where people gossip and there was a lack of confidentiality. She was hurt and disappointed by the insensitive attitude of her superior and the Human Resources department, when in her ignorance she took more sick leave than she should. This made her feel like leaving the job “*I, I, I cried to be very honest, I did cry coming back to work, I didn't even want to come back, you know after that.*” This situation was eventually resolved to E5's satisfaction. Her CEO's changed attitude allowed E5 to be more open about the illness, and the CEO also shared that she was a

fellow survivor. The CEO became more accommodating regarding E5's needs and she was happy for that support.

Another predicament for E5 is that she has a 'floating' position at work because of organizational restructuring. Her CEO has since left the organization, and with her current work arrangements more people has to be told when she needs time off for treatment. She was unsure how many people may be spreading this information around.

Now you don't know how much of these people, them people talking to. I don't, I just don't want, at least for me, everybody different. I know it have people with cancer, the marish, the parish know, and they all right with that. I'm not comfortable with that. (E5)

Regarding her functional abilities, F6 mentioned that she was a workaholic.

Although her supervisor was accommodating, he changed her work schedule without telling her. F6 remarked that her supervisor's actions made her feel "cheated."

Um, in terms of the capacity to work, I guess I'm a workaholic which is bad because I just delved right back into the work. Initially at first because my boss was, he was though, I think he was kind of, I don't know if it is his caring way or his skeptical way. Because he might have guessed it might have been something really serious. Um, it might have been a bit of both, I don't know. But he had kinda, I realized now had kind of just, kind of wiped my schedule off. So things, people I was in charge of supervising, he kind of reorganized it so that I didn't have any; I probably had one person to supervise. Um, and he took up a lot of the slack. Um schedules that I was on, he took it away from me. I kind of felt almost as though cheated in a way. Because, you know these were things that I was doing and I was doing them well. (F6)

C2 conveyed that she did not have any challenges on the job. This is understandable as she was away from work for all her treatment, and also received an outpouring of support from colleagues. C2 related that after treatment ended, and even now her supervisor has continued to be accommodating. However, she has not taken advantage of this concession.

Um, no as I said before the supervisors and everybody, everybody there um, (pauses) they were very accommodating, very thing and I was somebody who I don't um, I don't like to, to get favours, I don't like to be treated in any such, you understand. But they always um, so my boss will tell me [C's name deleted] "if you want to, if you want to leave 3:00 o'clock or whatever time you want to leave you go ahead you know." (C2)

Attitude Towards Work After a Cancer Diagnosis

This theme incorporated three categories: How women viewed their jobs, reasons why women remained with current employer, and work support in educating employees about breast cancer.

How women viewed their jobs.

Many people see work as being pivotal in their lives. A cancer diagnosis is a life changing event which can influence individuals' behaviour about their job and the role it plays in their lives. Seven participants expressed that they enjoyed their work; five women explained that although they liked their jobs, cancer has changed their attitude towards work. They were now slowing down and not allowing their jobs to be the centre of their lives. Despite the stressors of work, focussing on their jobs represented a sense of normalcy and control for the participants.

B1's story depicted how her work helped her to cope in dealing with the illness. She has been in the banking sector for 29 years and has moved up into a senior position. She indicated that the stressful part of her work was in managing people. "*But performing (emphasis) my duties I don't think it was, I was affected in any way, kind of thing.*" When asked about her attitude towards her work since the cancer B1 replied:

Well, nobody will know that I have cancer actually, unless I tell them. Right, they wouldn't think that, I'm sure most people, alright except for those that I told unless they went and tell somebody else kind of thing. But, um, the way I would do my work I don't think anybody would realize that I am a cancer patient. (B1)

A3 has been employed six years with a private company. She stated that her role covered two portfolios which have been combined, so she has more responsibilities. This also involved submitting many reports that did not get done until she came out. A3 recounted that she has a different attitude based on her periodic absences from work. She felt that she needed to prove to the company that she was still capable and committed despite cancer.

Um, it has changed meaning that, how I was away from work during that time. I think I had to put an extra effort (emphasis) into um, getting back myself um, involved (emphasis) in the company. Like I felt like I lose out or missed out on something. So I needed to buck up, you know. And um, I showed them and they were very surprised that you know, even though I sick, I still meeting my deadlines and stuff like that. You know, it was a little stressful, but you know at the end of the day, I accomplished certain things, so. It was difficult, but yet it was challenging and I coped well. (A3)

D4 worked for a private company for nine years. She revealed that there were supposed to be three people in her office, but she has been the only person there for the past two years. D4 announced that although she “loved the job” cancer was making her look at her hectic work pace, and her attitude towards the job was shifting.

So, as they say, what all seem important like, my husband can never understand, he says you get up every morning and it's like, I have to get to work, you rush to get ready, you into your job. I call you and I'm like, I have 3 persons in front of me, I can't talk to you right now, I put down the phone, you know. “You into your job,” (emphasis) he says, so. I wake up every morning now and its, do I really need to do this, should I stop and focus on myself, this is going to be there, you know. Why is it so important, that I fly down here and rush my blood to water and, people screaming at me and. Do I really need this, you know. So, it makes you sit back, and sort of assess what really is important. Yes, the job is important; you do need money and those things. But, are you really going to kill out yourself, (emphasis) and stress yourself out and then what. Something happens to you and they say, “oh well poor thing,” send some flowers and hire somebody for, a cheaper rate. (D4)

D4 is now re-evaluating her career path. She is seriously considering opening up her own bakery business and fully pursuing her passion for baking breads which she

currently does as a sideline. D4 reported that she has spoken to other women and heard similar stories from some who changed careers after breast cancer.

And things that you will like to pursue, but sometimes you don't just get the chance to do it. So sometimes you just don't get the chance to do what you really wanted to do. And sometimes this happens and you stop and think ok, maybe this is now the time, to back off doing what they wanted me to do, and start doing what I want to do (smiles)...I want to open a bakery. (D4)

The researcher contacted D4 for verification of findings in September 2011. She commented that she had finished her chemo and was about to begin six weeks of radiation treatment. D4 was due to go back to work at the end of September. Her employers have given her no-pay leave for the rest of the year to recuperate. D4 said that she was about 90% sure of not returning and would make her final decision by mid November.

E5 has been a permanent employee for 3 years in a public health institution. She voiced that the current nature of her department's restructuring has her bored and unchallenged. Although this worked to her advantage with the illness she now feels a sense of dissatisfaction. To manage this E5 has decided to continue with her education which she had started before cancer entered her life.

Cause, um, as I say it works for me in some ways, but then, you know in some ways sometimes you bored. Where you know what I mean you feeling real, you know, um not challenged and that kind of thing....So I think next week I'm going to put back myself, back in classes and do some stuff, you know. (E5)

Regarding her view of work:

My attitude to work has always been the same, I mean if I have work I do, I try, you know....And it is still, well we now starting back with the new Boards, starting to get back....Um, so it's still not as hectic because we now, they now getting projects that were there, off the ground, kind of thing. (E5)

Reasons women remained with current employer.

There are a number of reasons why women would stay with a current employer. There are those who have length of service and look forward to a pension. The job also offered training and opportunities for promotion. All the women were permanently employed except for H8 who left her permanent job two years before her diagnosis, and is on contract with her present employer. Although most participants were married, they were independent women with careers.

G7 raised a concern that women became 'locked into' their present job because of medical insurance. A3 identified two important issues which were the fear of being laid off and medical benefits while on extended sick leave. A3 was worried that her frequent absences would have jeopardized her job. However, the current work policies and support at her job gave her some reassurance.

And um, you know I took time off and you know, I thought it would have affected my job. But when I went to my boss he said, "The law is protecting you, you know." He can't fire me even if he wanted to, because I could take him to court, you know. So to avoid all that, you know, um, he just um, he said "don't worry about anything, you know, just um, go ahead." (A3)

She talked about the delay in receiving medical benefits while on extended sick leave and having to manage on less income during this time.

So um, you know I was a little relieved because you know, you tend to want to know what's happening with your job. If they will fire you; if, if you know, they are accommodating, ok; if the sick leave is finished what will happened. If NIS gonna kick in which, and it did, and it did. I mean it is a little difficult because you are not getting the salary you are, accustom getting. And the NIS takes a little while before they pay you. Um, your work give you how much days you actually work and NIS pay you for whatever days you stay. So it is a little time, you have to wait. I mean I am still waiting on some cheques, but you know, God is good. (A3)

Her company's medical plan covered most of the surgery and other private medical expenses which eased the financial strain to a great extent. A3 observed that people who

needed the money tended to take fewer days off. She found it was difficult even though she had additional financial support from her fiancé. Work provided financial independence and having to depend on others even temporarily was seen as a burden.

So I think that you know, 14 days or 2 weeks is sufficient. Some people I mean, I know some people who need their money would go back to work eh and that's difficult....I'm telling you it was difficult for me even though I have support, financially it was still a burden to me, was still a burden meaning that you know you have to depend on somebody else, right. And I only did that for probably a month or two you know. (A3)

The researcher called A3 about a month after the interview for member checking. She shared that approximately one week after beginning radiation treatment, an incident took place on the job and she was given the option to resign or be terminated. A3 believed that she was being discriminated against and chose for the company to terminate her services. A3 remarked that the incident was used as an excuse to cover the real reason, which was the amount of time she was off the job. *"I think they lost time and labour with me."*

In another follow up telephone contact to verify findings in early October 2011, A3 mentioned that she was now working in her father's business. This was something he had wanted for a long time and she was comfortable. Her response was that *"everything happens for a reason."* A3 also informed that she was in the process of taking her former employers to court for discrimination.

H8 noticed that while she was at home during her sick leave she felt quite contented because she had not had a proper vacation in four years. However, having to pay a mortgage meant that she had to continue working.

So I was you know I could get comfortable with this because I hadn't had a holiday in the 4 years before. So it was always get up, go and so on. Except for the little weekend or holidays. So, would I get accustom to this. Um, but at that

point when I got sick, and was in the hospital we got the mortgage for this house. And then I said," Wow we got to get back to work to pay for house, right (chuckles)." So that I was grateful to have a job. (H8)

G7, a public servant, conveyed that she enjoyed her work as much now as she did when she first started. *"I'm, I'm working with the same enthusiasm that I did 5 years ago, I think (chuckles)." G7 was the only participant who discussed being locked into her job because of the medical insurance. Her reason for remaining with her organization was that it provided security for the present.*

And the other thing is with medical insurance. Um it's like if I leave my job, and I changed companies; they don't cover it, because it's a pre existing condition. And I guess that's insurance being insurance. But I think the whole concept of pre existing condition, it just sucks, you know (ironic chuckle). One of my reasons for staying with the [place deleted] is because of the medical insurance. It's like, the amount of money they spent on me I, I will have to give up, if should (emphasis) my cancer come back. I'm not saying it will, but should it come back and I changed jobs, I have no coverage. And that's, something is wrong with that, because they consider it a pre existing condition for my new company. And I don't get covered....Because I mean I'm, I'm in remission right now; I'm not going to switch jobs. I can't, and that, that sucks. But then again I'm lucky that I have medical insurance, you know what I mean. And then um, even if I want to up my insurance, they going to tell me no, you have had cancer you got to be kidding, you know (chuckles). (G7)

D4 noted that she has no medical coverage with her job or personal insurance, and used her savings to pay her private medical expenses. Therefore, D4 did not feel locked into her job.

Work support in educating employees about breast cancer.

It appeared that some workplace settings afforded an opportunity for other employees to learn from the participants' cancer experience. This was made possible by the women themselves and their openness in disclosing. For instance, A3 described how one of her managers did a survey and advised other women to have screening tests. The women used A3's situation to get themselves checked.

Even at work, after they found out about me, one of my managers she did a um, a survey on the ladies in the office. "When last did you do a pap smear, and when last did you do a mammogram?" And some of them say well you know, they haven't, and she, she say, "Make an appointment and tell me the date." You know, "make sure it's done." And it was done, and they all did their, you know, pap smear and mammograms, everything. And you know, it was, it was a wake up call then. (A3)

G7's bank offered EAP services to its employees and this service was made available to her. However, during the debriefing session she admitted that she did not use the services. Her story was featured in her organization's magazine which provided a forum for her to encourage other women.

There's a girl, she told me that um, she always wanted to talk to me and ask me about it, but we weren't friends, you know. And we ended up going on a conference together and we were sitting in the plane. And she said when the [name deleted] magazine came out, she said, I came from lunch and I just dropped everything and I picked it up and I read the article. And then as I read the article, I realized that you were real cool about it, and you were real open about it. Because I talked about everything you know. And um, she said, "you know, I just wanted to ask you about it. And then it was all there in the article, and um, it was cool." (G7)

As a member of management, H8 took the initiative by conducting a session with employees to share her experiences and educate them at the same time. Many people were grateful for her openness, and this motivated other cancer survivors in her audience to divulge their concerns. H8 understood that preparing others around her could lessen fears about the illness.

And then other people were opening up and there were 4 or 5 people who had experiences with cancer. And just never said anything, you know. They were just gone and then they would return. So a lot of people at work were grateful for me sharing (emphasis). And then they were also, you know having the opportunity to tell others. So that when you see them and, you know they need the time off and so on it's because they are also ill, and didn't know how to share that with people....In that if people don't prepare others around them for how to cope with them and this illness; then you get this fear and reaction about, I don't know what's going on, you know. (H8)

Cancer Impact on Self Image

This theme has two main categories, body image issues and intimacy issues. It centered on how the participants managed the physical changes wrought by the treatment and its influence on their well-being and relationships.

Body image issues.

All the participants had chemo that caused hair loss. The women felt pride in their hair, losing this hair was of major concern to them and affected their self-esteem in varying degrees. For many it was an emotional period when they saw their hair coming off in “clumps.”

And um, but still the hair loss thing it was a, it was, it was a bit, you know emotional. I guess you know you seeing it coming off you know in clumps, it wasn't all coming off neatly; it was coming off in big clumps. (F6)

A3 who is currently bald made reference to her hair several times during the interview. She divulged that her biggest fear was being bald. Her hair seemed to be her crowning glory and the hair loss superseded the other side effects. A3 specified, “...my main concern and you have no idea, I'm not worried about the cancer, I'm not worried about being one breasted. I just want my hair to grow back.” Although she is impatient for the hair to grow she is not self conscious being bald. A3 did not wear her wig for the interview, and related that she has taken it off around friends and co-workers.

The participants revealed that they were not used to wearing wigs and most wore one for the first time to disguise the baldness. They bought wigs in anticipation of the hair loss and explained the challenges in wearing the wigs. Some women got wigs similar to their own hairstyles to look normal in their appearance. Three participants were presently bald and two of them had on their wigs during the interview. A3 and E5 commented on

the discomfort in wearing the wigs, which they found hot and irritating. Despite this, several women stated that because wigs were in style now there was a sense of security.

And then the style around now is wearing wigs, you know, so that it was comfortable. And I remembered thinking, this is nice that, people are comfortable to wear wigs or not, because it's the style now. And it isn't you wearing a wig, so you have cancer, kind of thing. (H8)

The implication is that wearing a wig now does not mean you may have cancer. G7 was the only person who went to work bald and it was well received. *“So I wore scarves maybe for a week and then I rocked the bald head....And then when I was bald, people embraced it.”*

In addition to hair loss, most of the women also lost weight while on treatment. Some lost 15 plus pounds which made a noticeable difference in how their clothes fitted. Two participants had put on weight because they were on steroids. Comments on the job made some women self-conscious, especially the ones who did not openly disclose at work.

I know I lost weight and I might have looked, haggard or whatever the word is....They would say “you lost weight.” And I would know because my clothes would have fit, right so that um, I knew that I did look um, very thin (emphasis) kind of thing. (B1)

Intimacy issues.

Intimate relationships can become strained and even break down if partners do not give each other the reassurance that is needed at such a time. Three women encountered problems in this area. For example, G7's partner at the time appeared to have been overprotective, and made her feel she was still sick. She acknowledged that there were also issues in the relationship, which the cancer brought to the forefront and their

relationship ended after three years. G7 has since met and is engaged to someone who has fully accepted her as a person, which has boosted her self-esteem.

Although they are close, D4's intimate relationship with her husband is now tense due to her low sex drive because of the treatment. Her spouse is experiencing his own frustration in not knowing how to respond to her.

So he doesn't know how to deal with me on that level. And he gets frustrated and he's like, "I don't know what to do, again, you know." He gets frustrated at times, but, and then, you kinda of like then, what do you do? (D4)

Three participants had mastectomies which did not alter their husbands' (in A3's case her fiancé's) feelings toward them and they continued to receive emotional support. It was the women themselves who needed to adjust to this new self image. For example, E5 expressed that her insecurities made it difficult for her to understand how her spouse could still love when she was bald with one breast.

You know because of your own insecurities. The man saying he ain't have a problem, you know and he love you just the way you are, then accept that. Try to accept it, you may not understand it eh, (chuckles) you still mightn't really feel whole, but ok you feeling, you know. But I try not to dwell on it because I don't want it to affect our, relationship. So I'm saying if he don't feel a how, then why should I feel a how. So I walk around naked with my one breast, I not being bothered, (chuckles) you know so. (E5)

F6's husband also accepted the mastectomy. *"And I mean even his whole reaction was like you know, you are the same person."* This boosted her self-esteem and made her feel worthwhile. *"Okay your breast doesn't, my breast doesn't define who you are and that kind of thing. And that was really important, right."* The three women are all contemplating reconstructive surgeries to alleviate their concerns about the way they now have to dress.

I mean, I think I more want to have the reconstruction for my own, you know. Because you are a female and it changes the way you may have dressed before, I

mean the kind of things you have to wear. I was never really one into skimpy stuff so it doesn't, didn't matter in that regard. But more in the kind of support you have to always have something to support, so in case, you know. The, the, um the insert you know should fly off or something like that. You know you think of the worst case scenario. (F6)

Lessons Learnt From Cancer

This final theme has four categories: Changes in lifestyle to prevent recurrence; exploring the cause and search for meaning; life perspectives changed; and relationships improved. The cancer experience has impelled the participants to review their lives and to make necessary accommodations for coping.

Changes in lifestyle to prevent recurrence.

Most women recognized that lifestyle changes included managing the various stressors in their lives. The three participants who said that they had healthy lifestyles in terms of diet and exercise continued this pattern. The other five women made adjustments in their dietary habits. H8 became aware that the foods she used to enjoy did not have much nutritional value. She has maintained this way of eating three years post diagnosis.

So I'm giving them up because not because I want to get better as much as I don't see the point in them. They are not that healthy. So the ice cream, and um, even the bread and the bakes and the pasta and what have you. I gave them up because it's neither here nor there, you know. So I have more fruits now, and um, vegetables well I eat all the right vegetables. (H8)

In their narratives many women gave examples of people they knew who died from cancer. At these times their own lingering fear of recurrence was awakened. Even though they held on to their faith there was still that fear, which is a normal part of the cancer experience. Hence, in making certain lifestyle modifications they hoped to avoid recurrence. B1 recounted that after treatment ended and to deal with her anxiety, she did her screening blood tests every three months as opposed to the recommended six months.

Although she was no longer doing the tests so often, B1 was seeing three physicians in her follow up care.

Alright because I don't know if St. James will miss something, that I have this other doctor who could check me and then that doctor miss something, then I have another doctor who will. You know from that perspective, I just find that the check the follow up, is not really telling me, based on how I'm feeling, I'm ok. And cancer is not something that you could tell from how you feel. Right because I could be feeling very fine, but something is going on inside. So that it's from that perspective I am not always too, really convinced that the follow up treatment is, telling me really that I'm ok. (B1)

B1 still has a concern regarding recurrence "... I mean, it could always come back, right.

We could never know." Therefore, she was doing what she could to "make sure you have it under control (chuckles)."

C2 shared that she recently met a young woman at NRC who has had a recurrence of the cancer. Her words contained her own lingering fear that the cancer could return.

Yes, because Thursday last, um, there was this attractive young lady and um, I was sitting next to her. She has nice features and thing and was very nice, and you wouldn't think that she was ill. And she tell me, she say, she say, "My cancer is back." And I spoke to her first of all and I say, "Don't claim that, that is not yours, don't say my cancer." And she was telling me you know, she has a 9 year old child. And she is a young, she is a young woman she could be late 20s early 30s. And, and you could see the fear, and the tears and everything right behind the eyes. And that, will stay with me for a long time to come. (C2)

Exploring the cause and search for meaning.

Many participants were interested in what could have contributed to their cancer. They have been looking within themselves and reviewing the parts of their lives when there might have been heightened stress. H8 has an interest in knowing the cause of her cancer and in society at large. During the interview she kept referring to the need to find the cause and not just treat the disease. From her research, H8 came up with a theory of what could have created her cancer.

And, but you didn't get a sense that there was a search for what was the cause, you know. So I kept reading on the Internet to find out what is the cause. I think the closest I came for me, because it happened to different people different things. But for me (emphasis) the closest, I got to understanding it, it was that, there was a chemical change going on in my body as I was getting older. (H8)

Many women in reflecting on what could have contributed to the cancer were also looking for the meaning at the same time. Some participants discovered that the uncertainties of life took away the feeling of being in control. This led to the 'why' questions in their search for meaning. C2 realized that there were no guarantees in life, which could change in an instant. Her journey with cancer taught her to be more supportive of others.

(Hmm) It tells me that, (pauses) this life, is, you can never tell what, what could befall you, even though it is so far removed (emphasis) from your thinking, it could happen.Because one day you could be good and the very next day your whole world turn upside down....How to lend support, to other persons and you know at the time when, when, at the time of the treatment and diagnosis and thing, you will ask yourself. And I think it is um, it is normal to ask, "why, why me, why me." And it's afterwards I realized that, if I had not gone through this. I would not, no matter how much I read, how much people tell me, I would not have known how to, how to encourage and lend support to, to other people. (C2)

E5 found out that cancer is no respecter of persons and it also introduced the 'why' question. Her search for meaning has made her more insightful. Cancer brought new friends into her life and she has been able to assist others on their journey.

Yeah (in a resigned tone) I, I think yeah sometimes I think about it and um I ask myself what on earth could be the reason. Um, me of all the millions of people in the world, big point (chuckles). But then again you can still come back and ask why me eh, why not you, you know. What makes you so special that you feel, you know. Um, but I think I have made some friends along the way. And I think I have been able to um, help some people along the way. (E5)

Life perspectives changed.

The women reported that cancer has changed their perspectives on life and they valued themselves more. D4 remarked that she has learned to slow down and is now

making herself a priority. The things that seemed urgent and important before were no longer. F6 conveyed that cancer has reminded her to trust God and keep Him in the forefront of her life. She is also renewing her relationship with God. A3 observed that cancer took her unawares and she now understands that “...*you can never, mustn't take it for granted that I'm ok.*” A3's cancer voyage has been teaching her not only to enjoy life more, but to value what is important. It is also helping her to look deeper than the surface.

Um, I enjoy it more, (chuckles) I am, I, I, um, I don't take things for granted any more, that you know. You know, I mean family is important you know; I tend to visit my parents a little more often now than I use to before. I, I spend my money wisely; I never did spend it bad. I, I, um (pauses) I try not to, not that I ever did, but I try to, get into any kind of negative discussions and become stressed out and stuff like that, you know so....Yes, I am more aware of, of people and their feelings, and you know never take anybody for granted that you know, that everything is ok with them and you know. When they are not, you know. (A3)

E5 has begun putting her feelings about the illness into perspective. She was more accepting of others knowing because she was becoming more comfortable with self, and her own emotional reactions to people's responses.

I think in the beginning, I was more closed, I think I'm getting more, comfortable with me. Yeah, I think you have to reach that place where you kind of comfortable with yourself....And until you reach that stage you don't really want other people to know. So I think I'm getting there, so for now it doesn't really so matter to me if people know or not, you know. (E5)

G7 noted that she has learned to re-evaluate what was important in her life. “*But, life is not about your fancy clothes, and shoes, and your hair. And it teaches you to find more in the inside. It's just so weird that I say that*” (in a high-pitched tone). This has taught her to have a deeper appreciation of the inner person. G7 appeared surprised when she made this statement as if it was a revelation to her. Her insight for the things that were important seemed to have been gradual over the past four years, and not suddenly as she had anticipated/expected. Cancer has made her see life without her “*blindness.*”

And everybody says, you know after cancer your life changes. You suddenly deep and profound, and you see the light and. It never happened you know (laughs). It just doesn't happen that way. I think you just need to like, now look at the difference on how you are, compared to then. Which is what I'm doing, but I never got that premonition....I didn't have a choice eh, because I didn't have the hair anymore. I didn't have the body anymore. I don't have, I can't fit into the clothes anymore. So I have to, basically you have to work with what you have eh. And in working with what you have is when you see different things. Because if it never happened, I guess I'll never be on this side of the table. But I didn't get the premonition; I really didn't (chuckles). (G7)

Relationships improved.

Four participants informed that their relationships with other people improved. A3 indicated, *"Um, actually um, (pauses) I've become closer with my friends, um, my family, co-workers and um, you know. I, I, talk, I talk freely about it, I don't hide it."* C2 explained that cancer has helped her to become more aware and sympathetic towards people, and to be more patient with self and others. G7 related that she has weeded insensitive/superficial friends out of her life. The positive changes that came out of the cancer experience were the new and deeper relationships she has formed. She also credited the cancer to improving relationships on the job. H8 commented that when she told people about the cancer their behaviour toward her changed. She in turn also altered her approach, which has worked to their mutual benefit.

...my relationships improved with a lot of people. Because I got this kind of sympathy um, approach where people who were not too pleased with me for whatever reason were prepared to bury the hatchet, and say okay let's, let's get past this, you know. And so, and that's how I have been approaching most things with people and so on. That, look I have a second chance at life and I don't (emphasis) have time for the petty things. So if you want to work we can work together. And so I have been having a more positive relationship with the people around. Than previously where there wasn't that element of, "oh gosh she's sick, I shouldn't really be doing this," kind of thing. It's now, you know I have to pull my weight and you know, I shouldn't give her that much stress. So, because of that I'm having a better time with telling people off too in terms of "no I can't do that, I'm so sorry." Um, before I would say "okay, I'll try and," but now it's like, "um that don't fit my schedule, sorry." (H8)

Three women stated that there was no difference in their relationships with family, friends and co-workers. As previously mentioned, D4's relationship with spouse is a close-knit one, but her tiredness from the chemotherapy has affected their sexual relationship. The three participants who did not disclose openly on the job also expressed that there was no change in their relationships with co-workers. The few people at work who had to know did not treat them differently.

Informational Needs and Medical Social Work

Hearing the women's need for information and the researcher's own experience about the available resources, she spoke with two Medical Social Workers at NRC regarding participants' concerns. They confirmed that all new patients are formally referred to the department. They do an intake assessment, counselling is given with follow up appointments, and literature is handed out depending on the issues, such as the type of cancer and treatment information.

However, Ms. Haynes reported that not all patients who are referred go to the department. Some reasons given are: The first day is a long one for the patients - from being registered, seeing the house officer, doing vitals, laboratory work, meeting with the consultant, the medical social worker, and the dietician. Patients may be physically tired after the long wait, some are too ill, and there are those who may be in denial or not ready to talk at that point. Transportation is another cause: The distance patients have to travel, weather conditions, or having to conform to the schedule of the person who is dropping and picking them up.

The Medical Social Work department drove an initiative for a complete information package to give out to new patients on a Monday. They ran out of literature

and arrangements were made for printing more material. It is about one year now and they still have not gotten the material from the Government printery. Ms. Haynes admitted that lack of follow up has created the delay in this area. At present, there is no information package on the various services and cancer literature for new patients.

The Monday morning orientations are not being conducted on a regular basis as they were before. According to Ms. Haynes, this has to do with availability of staff from the various departments including Social Work. Currently, about two orientations are given per month. (V. Haynes, medical social worker, personal communication, October 5, 2011; and S. Perez, Medical Social Worker, personal communication, September 29, 2011).

Summary

This chapter presented the findings that developed from the interviews with the eight study participants. The women's demographics and treatment profile data were given. The six major themes and their sub-categories were discussed in detail illustrated by the participants' own words. The themes were: 1) Finding out about the diagnosis; 2) Coping and social support; 3) Work adjustments while on treatment and after treatment has ended; 4) Attitude towards work after a cancer diagnosis; 5) Cancer impact on self image; and 6) Lessons learnt from cancer. Informational needs and medical social work services were delineated. The next chapter will discuss these findings in relation to Frank's three narrative types, the feminist perspective, the influence of social support, the relevant literature, and the methodological issues.

Chapter Five: Discussion

Introduction

This chapter will discuss the findings as it relates to the following four central questions that guided this inquiry:

- 1) What stories do women recount in coping with their diagnosis?
- 2) What stories do women relate to prepare themselves to return to work?
- 3) What stories do women tell to describe their return to work experiences while on treatment or having completed treatment?
- 4) What stories do women share about the impact of being a cancer survivor and its effects on the various aspects of their lives and their social supports?

The application of Frank's (1995) three illness types – restitution, chaos, and quest, the feminist perspective, plus the two constructs coping and social support will demonstrate how employed women experienced living with cancer. The themes and categories unearthed during the research will be compared to the empirical literature. The methodological issues and limitations of this study will be reviewed.

Themes and Categories

The six themes together with their accompanying categories will drive the discussion.

Finding out about the diagnosis.

As already stated, all the participants began their story of discovering the lump and having the diagnosis confirmed as their most significant memory about the cancer. The women were distraught when they were given the news and experienced a gamut of emotions during this phase. The four participants who considered they had healthy

lifestyles, their feelings of shock and disbelief were more intensified when they were first diagnosed. Other studies also identified shock and disbelief as key reactions for women on hearing they have cancer (Landmark & Wahl, 2002; Lethborg et al., 2000).

The diagnosis brought to the forefront the women's fears and perceptions about cancer. Seven participants saw cancer as a death sentence and their view was reinforced by this overall cultural belief despite medical advancements in cancer treatment. They discovered this perception among their families and other people in their social environment. There is also the dominant discourse that people with cancer are treated in a particular way. This discourse appeared to have influenced the outlook of the three participants who deemed themselves as private individuals.

Lethborg et al. (2000) study found that the coping mechanisms avoidance and diversion were often used to manage this intense period (Gall et al., 2000). Two participants withdrew from certain friends and acquaintances to avoid their fearful responses and expectations that they were now sickly. This coping skill gave the women time to adjust to their feelings about the disease. The participants saw their whole lives changed in an instant from one of normalcy to confusion. Their fear of cancer and what it could do to the body made them vulnerable. In relating their stories during this phase, one can hear the voice of chaos that Frank (1995) talks about. Their chaotic feelings were also interspersed with the desire for restitution that this period was a temporary one.

The women's will to live propelled them into seeking medical attention. Five participants took quick action in having their lumpectomies, while the other three had delays because of the system and/or their uncertainties about the best decision. As C2 put it "*I know it was a fight, I was gearing up for the fight, I, you know I was fighting.*" This

view was also articulated in Landmark and Wahl's (2002) research on women with breast cancer. They discovered that the will to live was seen in the early stages of the illness when their participants focussed resolutely on fighting for life.

Coping and social support.

Cancer threatens an individual's existence and this can lead to fear, anxiety and depression (Rendle, 1997). The women exhibited these reactions as they grappled with the diagnosis and the various treatments. In this theme, the participants used a number of mechanisms for coping to achieve a sense of normalcy and control.

Spirituality and prayer.

Seven women spoke about spirituality and prayer as a major coping skill during this turbulent time. Their faith in God became stronger and they saw Him as the healer. People prayed with them such as their pastor/priest, family members, other individuals, and they continued going to church for spiritual support. The participants attested that their spirituality gave them hope and the strength to manage their surgeries, the complications of the treatment, and in their search for meaning.

This finding is consistent with the literature where breast cancer survivors have remarked that religious faith is a great source of support in managing the illness. Also, having cancer has made them more aware of spiritual issues, which has strengthened their faith (Choumanova et al., 2006; Gall 2000). This coping mechanism is congruent with Holt, Lukwago, and Kreuter (2003) who identified similar themes in their study: God as a healer, God's role in coping, increased in their faith/belief, prayer and meaning making, mortality, and social support. Meraviglia's (2006) study also found that meaning in life

and prayer influenced women's physical and psychological well-being, and recommended that spiritual resources can be beneficial to women dealing with a cancer diagnosis.

Humour.

There is the popular adage that laughter is the best medicine. In this study, four women shared how a sense of humour helped to lighten the situation for them and their families. It centred on their bodies and the changes caused by the surgeries and treatment. Their exuberance was seen as they reminisced and laughed while describing these comic events.

Depending on the treatment regimen each participant would have different side effects, some more debilitating than others. Hence, for some participants chaos stories were more loudly heard based on the treatment side effects. The women who used humour in this study were able to subdue the voice of chaos during this period. In fact, humour stories are another form that can be added to Frank's (1995) illness typologies. It has been known to assist people to weather the storms of life and its therapeutic influence promotes healing. Many cancer survivors have used humour to face the stressful aspects of the illness (Johnson, 2002; Wanda & Moore, 2004). E5 recounted how she looked forward to reaching home after work to remove both her wig and prosthesis, and the possible effect on her spouse.

...if I could take it off from outside, I would, but I know my husband would faint (chuckles)...so I wait until I reached inside....and I reach up in my rooms and my husband seeing me with these two things in my hand (chuckling). And my friends and them they laughed at me; they say [E's real name deleted] "you is a clown, eh." I said, "You think I'm traumatizing my husband? Cause every evening I greet him with the wig in one hand and the breast in the other hand" (chuckling, and very amused by this mental picture). (E5)

Medical research has also demonstrated that humour has a positive impact on the immune system (Johnson, 2002; Wanda & Moore, 2004). Appropriate use of humour can aid to mitigate fear and anxiety, and reduce stress levels (Wanda & Moore, 2004). Johnson's (2002) study found that humour is a part of spiritual coping, and the importance of humour in adjusting to the diagnosis. Her study results are in accordance with the participants in this current study who used humour to cope.

Reaching out to others.

To manage the disruption in their normal activities and roles during the treatment, the women reached out to family members, friends, co-workers, and other survivors for social support. Many participants wanted other people to learn from their experiences. They communicated and educated people in their social environment about the importance of preventive measures, medical/life insurance and other sources of information. Most of the women also enlightened other survivors, and felt validated that they were able to make a difference in someone's life. For example, D4 imparted the knowledge she gathered about good dietary habits to help fellow survivors. In reaching out and educating other survivors, the participants showed an ethic of solidarity and commitment in talking with others as fellow sufferers (Frank, 1995).

From the researcher's practice, many survivors expressed that they learned from other survivors' experiences which made them feel less isolated, and gave them hope. Synder and Pearse (2010) labelled this type of support in their study as experiential support which "arises from a relationship with a person who has experienced a similar health trauma or crisis" (p.415). They further noted that this other form of social support could be added to the person's total social support network (Synder & Pearse, 2010). Six

participants had relatives and/or friends who were diagnosed with cancer and they gave and received experiential support.

Interacting with fellow survivors afforded many women an opportunity to share and listen to people's stories while they were at NRC. Some participants wanted to hear other survivors' experiences with breast cancer which resonated with their feelings. The women seemed to value others' chaos narratives because it helped them to put their own situation into perspective. This finding is also found in Thomas-MacLean's (2004) qualitative study of embodiment after breast cancer, where chaos stories are seen "as opportunities for healing" (p.1654).

Disclosure and support at work.

The five women who told their jobs found their bosses and colleagues to be empathetic which enabled them to adjust while they were on treatment. Colleagues' responsive attitudes boosted their self-esteem at a time when they were dealing with their feelings about the illness, side effects of chemo and changes in their appearance such as weight loss/gain. Having a supportive environment at work contributed to their psychological well-being (Berry, 1993).

Several authors have indicated that individuals who do not disclose their illness do so because of "personal, family, employer or community attitudes" (Allen & Carlson, 2003, p.27). The other three women who did not openly disclose, informed certain people who needed to know and this had to do with getting the necessary time off for appointments. Their reasons for not being more forthcoming, besides being private individuals were based on factors such as level of comfort, the culture of the organization, their experiences in coping with the disease, and their own perceptions of being treated

differently. For instance, F6 discussed the lack of confidentiality and gossip in her unit about a colleague with breast cancer who subsequently died. When she was later diagnosed this reinforced her decision not to reveal the cancer and become a topic for gossip.

One of my co-workers eventually, well died from cancer...I looked at it and I was appalled by how some of my co-workers, kind of comments were made. Even my boss at the time, well he has since left and I was determined never, never. (F6)

This insensitivity and lack of support in organizations would make it difficult for women like F6 to be comfortable on the job during treatment. It can also have a negative impact on how they feel about their workplace. Staley et al. (1987) reported from their study that most cancer survivors considered their colleagues' attitudes as positive (Schultz et al., 2002). However, on their initial return to work during their treatment, some survivors experienced co-workers negative attitudes and behaviours (Berry, 1993; Maunsell et al., 1999; Staley et al., 1987). This was due to physical problems related to the side effects of the treatment (Staley et al., 1987), as well as misinformation, and the stigma associated with the disease (Berry, 1993).

All the participants in this present research who shared the diagnosis had positive responses from people at work. They also did not encounter any negative attitudes by their colleagues to the treatment side effects. At the time of the interview none of the five women stated any signs of discrimination on the job. However, as previously mentioned one participant later experienced discrimination at work.

Kennedy, Haslam, Munir, and Pryce's (2007) study showed that all the participants told their employers at the time of diagnosis to facilitate time off for treatment. Employers and coworkers were sympathetic, and most participants said that the work environment

was very supportive during the time they were away from the job and when they returned. It was this support that made it easier for them to return. Amir, Neary, and Luker's (2008) research results are similar to those of Kennedy et al. (2007). The findings from these two recent studies are consistent with this current research.

Support from health care professionals.

The participants identified a number of needs in managing the breast cancer experience. Although the women were diagnosed during two different time periods some of the concerns were similar across the continuum, whether they were presently on treatment, or 3 - 4 years post diagnosis. The more pronounced needs were seeking information regarding their health care, dietary, counselling, and the need to be listened to.

The participants were seen by various doctors each performing a different role from the time they were diagnosed, the surgeries, and during their chemo and radiation treatment. All the participants commented that their physicians gave them hope that cancer is not a death sentence, and they would be able to beat the disease with the treatment. E5's surgeon informed her, *"He say, I know for sure you won't die from this, you know."* F6's oncologist advised her that she had a very good prognosis based on her *"given age and size of the lump and the whole course of treatment that we have chosen should be about 80% or so. Might have been even more, I think it was 80 or 85 something like that."* All the women acknowledged that their doctors told them about the treatment and its side effects. It appeared that some were given more information than others.

During the phase of making decisions about treatment (including surgery) restitution narratives are more prominent. This was reinforced by their doctors and supported by the women's own research in educating themselves about the disease and the

various treatments. It is here that one sees the intersection of restitution and chaos structures in the participants' stories. For example, being told that the treatment would help to cure them, and their perception of cancer as a death sentence with shortened life spans. Frank (1995) indicated that medicine's focus is on cure and controlling the disease. Thus, alternative stories such as E5's wanting to stop her treatment are not the preferred narratives.

Most women realized that there were fellow survivors and their relatives who were not very knowledgeable about the illness and what to expect. They also recognized that there were women who were passive in accepting that their doctors were the expert in their care. Hence, they saw a need for information about the services and resources to be more readily accessible to them and other survivors. This is congruent with Oxlad's (2008) breast cancer study that existing services should be advertised so people will know how to access them.

The women talked about the different doctors' bedside manner and remarked that some were more supportive than others. Some women had negative experiences at NRC during their treatment and follow up. For instance, a couple of nurses were inattentive during chemotherapy administration and made mistakes. They described a few physicians' insensitivity in not listening to their issues about certain short and long-term side effects from the chemo. The doctors' attitude seemed to stem from the existing medical discourse that physicians give advice, make decisions about their patients' medical care, and in return expect a submissive patient (Docherty & McColl, 2003). This discourse however, maintains the status quo (Ellingson & Buzzanell, 1999) of a hierarchal relationship.

Feminist studies on cancer experiences claim that modern oncology clinics are viewed as “a hi-tech production line” (A Feminist Voice in Cancer Debates, 1998, p. 106), and not much attention is placed on women’s feelings and concerns (A Feminist Voice in Cancer Debates, 1998). The participants conveyed that although they appreciated the challenges at NRC with the huge clinics, it still affected their ability to receive individual attention in dealing with some of their concerns. By not addressing their feelings and needs in a satisfactory manner, physicians’ thoughtless attitudes can also influenced women’s self-concept and confidence.

Breast cancer activism has seen women survivors playing a more assertive role in their illness (A Feminist Voice in Cancer Debates, 1998; Klawiter, 2004). In fact, research has shown that patients’ involvement in decision-making has been associated with better health outcomes (Charles et al., 1998; Hack & Degner, 2004). Studies have also denoted that younger and better-educated women are inclined to be more actively engaged in decision-making (Rottmann, Helmes, & Vogel, 2010). All the women in this current study were young, well educated and participated in the decision making process regarding their surgeries and treatment. They were also proactive in seeking information about their health care issues and passing this information on to less assertive survivors.

The participants’ actions gave them a sense of control over the illness. It also reinforced the restitution narrative of wanting to do all that was possible to overcome cancer which meant survival. A3 was the only person who admitted that reading all the information up front was somewhat depressing for her. This is understandable, as some women need time to process their feelings about what they are going through.

According to Andrist (1997), a main factor in feminist practice is having access to information in a supportive environment. Health care professionals do not always recognize that women with breast cancer require a lot of information to manage the disease process (Andrist, 1997; Oxlad, 2008; Rottmann et al., 2010). The women in this study who were 3-4 post diagnosis also reported less information and support are given when they completed their treatments. Thus, survivors become dissatisfied with the follow up treatment as time increases (Oxlad, 2008). They mentioned that they obtained information through their own investigations and resources.

The other survivors the women met at NRC who did not question the doctors, but relied on their physicians to provide the information suggest a desire to feel secure. Therefore, health care professionals need to be more aware of the individual's preference and tailor their communication accordingly (Lethborg et al., 2000; Rottmann et al., 2010). Despite some of the negative experiences and dissatisfactions, all the participants noted that overall they were still pleased with their health care at NRC.

The women who consulted their physicians about being on treatment and working were told that it depended on the person and how she felt. Other participants who did not have this dialogue with their doctors were given as much sick leave as they required. This finding is consistent with four other studies that reported survivors got limited guidance about return to work issues (Amir et al., 2008; Kennedy et al., 2007; Main et al., 2005; Maunsell et al., 1999). The women in this current study practised self-determination and made individual choices to assist them in managing the treatment phase and being at work.

Work adjustments while on treatment and after treatment has ended.

Working can be viewed as a restitution narrative because it gives the participants a sense of control from being in a familiar environment. By making a contribution and performing their roles, they are on their way to being well again. While returning to work during treatment helped to normalize their lives, frequent absences from the job affected productivity levels and created more stress for some women which was challenging.

Reasonable accommodation on the job.

The women took the necessary time off from their jobs to cope with the severe side effects. Three participants went on sick leave and vacation leave for a fixed period; this ranged from 3 – 6 months. C2 was the only participant who took the longest time off. However, she was able to reintegrate easily in her job because of her close relationships with the people at work. The other five participants went on sick leave cyclically during their treatment. Both A3 and G7 commented that it was difficult to work while on treatment and acknowledged that more time is required. H8's job afforded her the flexibility to work from home during her chemo.

The literature identified that many employers have made reasonable accommodations in working conditions, and flexible work hours to facilitate survivors' adjustment back to work (Greenwald et al., 1989; Mellette, 1985; Peteet, 2000). Such accommodations enabled survivors to take time off for examinations, laboratory work, chemotherapy and/or radiation therapy (Hoffman, 1991). All the women's organizations in this present study granted the required accommodation. Some participants also made their own reasonable accommodation by scheduling their treatment to minimize their time off the job. The four longer-term survivors all returned to their jobs fully after their

treatment ended. Main, Nowels, Cavender, Etschmaier, and Steiner (2005) reported that extensive support from employers and co-workers as well as job accommodations, motivated their participants to keep working or return to work after a temporary absence. Their results are congruent with the women in this current study.

Challenges on the job.

The women had demanding jobs and felt obligated to their organizations for giving them the time. However, having to meet deadlines with intermittent absences also caused more stress during this period. Although, the participants were given reasonable accommodation and were supported by colleagues, there were several challenges that they faced.

Fatigue was a common symptom that all the women specified to varying degrees, and contributed to changes in physical and cognitive abilities (Chapman, 2000; Mock, 1998; Weis et al., 1994). Kennedy et al. (2007) study also cited fatigue as the main symptom that was disruptive and challenging at work. Treatment side effects can last for many years as evidenced by G7 who said that four years later she still has “*brain fuzz.*” Her learning curve for new things has become more difficult. For those who did not openly disclose on the job there was the challenge in trying to protect their privacy, the extra effort to function normally, and the emotional impact which heightened their anxiety. In addition, organizational changes affected one participant’s ability to be more productive. It is during these periods that chaos narratives returned to the foreground in their stories as they struggled with these issues.

Attitude towards work after a cancer diagnosis.

According to Hoffman (2005) many factors influenced a cancer survivor being on the job. This involved age, stage at diagnosis, financial status, education, whether they had health insurance, transportation, and the physical demands of the job. She also stated that survivors whose jobs were more physically laborious, their disability rates were greater than those who had sedentary type work (Greenwald et al., 1989). In addition, survivors who were well educated “have had higher return to work rates than those with less education” (Hoffman, 2005, p. 272).

In the researcher’s study all the women were younger, well educated and were in the most productive years of their work lives. Some participants were still advancing their careers goals. They were professional women who had sedentary type jobs, appeared to have financial stability, and all except one person had medical insurance. Transportation was not an issue for the women and their diagnosis ranged from stages I – III. All these elements would have influenced the women being on the job during treatment, and for those who returned to work fully after their treatment ended.

The participants had been in their present jobs from three years to twenty-nine years. The length of time with current employer gave them an opportunity to build supportive relationships and to understand the organizational culture. All the women seemed committed to their work and this would have given them the incentive to return to their jobs during the treatment.

There is no doubt that the cancer had an impact the women’s work lives. Although seven participants expressed that they enjoyed their jobs, their attitudes changed in several ways. They were now trying to create a better work life balance by reducing their work

pressures and evaluating their career path. Some women were proceeding with their educational goals which were started before the diagnosis. During this time quest narratives especially memoir became evident when the participants described how they viewed their jobs. The findings from this study are also consistent with other recent studies (Amir et al., 2008; Kennedy et al., 2006; Main et al., 2005) that although work is meaningful, many survivors re-evaluated their work life to achieve more balance.

Reasons women remained with current employer.

As already mentioned the majority of women were permanent in their jobs and had medical insurance. Their jobs created opportunities for promotion, training and a pension. Most participants were married with children, and wanted to secure their future. Some had financial commitments such as mortgages and other personal expenses. Also continuing to work provided a certain standard of living.

Employment allows the survivor to have access to medical insurance (McKenna & Togia, 1989). Sanchez (2001) reported that survivors were three times more likely to stay with the pre-cancer employer who offered health insurance. Survivors also feel 'locked into' their jobs because they do not want to lose present insurance coverage or pay higher premiums (Feldman, 1976; Mellette 1985, 1993; Mor, 1987). G7 noted her reason for remaining with the organization was that the medical insurance covered her surgery and treatment. Although she has been in remission for the past four years, her concern was that if she left her job and the cancer returned she would have no coverage.

An underlying issue in the workplace is discrimination which surfaced in this study for one participant. The literature gave mixed views on the incidence of discriminatory practices. Some studies found a low level of discrimination among their participants

(Chapman, 2000; Sanchez, 2001; Schultz et al., 2002). Even with legislation in place such as The Trinidad and Tobago Equal Opportunity Act of 2000, this is still a reality as seen in A3's case. She was already feeling guilty about her frequent absences on the job; being terminated would have increased A3's stress level while she was still on active treatment. A3 was disappointed and hurt by the company's attitude and the good relations that she believed she had with her employers over the years. Her initial fear of being fired eventually became a reality. She lost a permanent job with medical benefits due to discrimination which may not always be overt, but happens nonetheless especially in smaller companies.

Both A3 and D4 related that they had a strong work ethic, enjoyed their jobs, and had a supportive work environment. A3 wanted to prove to her company that she was still capable and committed despite cancer; this opportunity has now been lost to her. In D4's quest narrative, cancer has altered her perspective where her job is concerned, and she has been reassessing what is important in her life. D4 has been re-evaluating her career path and is using her time away from work to implement her plan. She has no medical coverage so she does not feel locked into her job.

Work support in educating employees about breast cancer.

When women are accepted and appreciated they feel valued which creates a supportive work environment. This setting made it possible for many participants to educate their colleagues about the cancer experience. This was done on a one to one basis, in an educational session and via one person telling her story in her organization's magazine. The women recounted how this aided in their coping, facilitated other people to share their concerns, fostered better understanding, and improved relationships. These

positive changes indicate a need for interventions and programmes in the work place for survivors, colleagues and employers. Most of the women worked in organizations that provided EAP services to its employees. This is a channel where educational outreaches would bring more awareness and understanding about cancer, and women's experiences. Although A3's Company did a screening with the women, there is more to screening. Understanding the psychosocial issues of cancer will debunk some of the misperceptions associated with the illness.

Cancer impact on self image.

This theme looks at the self image issues that the participants faced in their cancer experience. The physical changes aroused feelings of anxiety and distress about what cancer meant to them, their relationships and their future. It is during this period that chaos narratives returned to the foreground. All the participants focussed on what losing their hair meant which was a major concern for them (Lethborg et al., 2000). There is an adage that "your hair is your beauty" and the women appeared to live by this dictum. Their hair represented their femininity and being bald affected their self esteem to varying degrees (Lethborg et al., 2000; Oxlad, 2008). The emotional and instrumental support from family and friends assisted them during this time.

We live in a society where appearance matters and people are judged based on how they dress and look. Wearing wigs was a new experience and the majority of participants wore wigs for the first time. Some bought wigs similar to their natural hair so that others would not suspect they were bald. As wigs are in style the women felt a sense of security without the stigma that it could be cancer. G7 defied the dominant discourse that wearing a wig would maintain her femininity and concealed the cancer. She was the only person

who went to work bald and it was well received. Most participants also had noticeable weight loss/gain during their treatment. Remarks by people on the job especially toward the women who did not openly disclose made them self conscious. This created anxious feelings regarding whether colleagues had guessed about the cancer.

There is a cultural belief that women who have mastectomies are no longer seen as being physically attractive (Im, 2000; Thomas-MacLean, 2005). Thus, many women's perception is that losing a breast "is to lose one's identity and sense of self as a woman." (Kasper, 1994, p.264). The three participants who had mastectomies their spouses/fiancé were comfortable with their bodies and continued to give them emotional support. Two women admitted to their own insecurities that the mastectomy reminded them that they were not whole and of being sexually unattractive.

All three participants want reconstructive surgeries as opposed to wearing a breast prosthesis. Their aim is to feel normal once more without the added inconvenience of looking for certain clothes to camouflage the prosthesis. This need to feel complete again with two healthy breasts is driven by social expectations (Davis, 2008) which favour concealment as the preferred discourse (Broom, 2001; Thomas-MacLean, 2005; Wilkinson, 2001). The three women are accepting the code of invisibility (Klawiter, 1999).

Reconstructive surgery is an expensive procedure privately. However, it is now possible for women to have breast reconstruction at the expense of the government of Trinidad and Tobago. The availability of this cosmetic surgery represents a restitution narrative which is the only acceptable story in health care institutions because of medicine's fixation with a cure (Frank, 1995). This resource perpetuates the message that

a disfigured breast is not socially acceptable. Although the other women did not have mastectomies, a few had surrounding tissues removed which also caused some difficulty in dressing and sexuality issues.

Three participants revealed sexuality issues with cancer and its impact on their relationships. This has contributed to a strain in the marital relationship for two women. For instance, B1 explained that she went into menopause which affected her libido. She confessed that it was something that she has not worked on in her relationship with her spouse. *“Because as I said I was dealing with it on my own and he was dealing with it on his own. We never really did deal with it together and talked about it.”* Many participants in this study are still coming to terms with self image issues and this is an area where couple counselling would be beneficial in managing the emotional reactions.

Lessons learnt from cancer.

In this final theme, many women have learned some valuable lessons on their journey thus far with cancer which seemed to have enriched their lives and relationships. In searching for the cause to the cancer, the women were also looking for its meaning. There were shifts in perspectives, as well as the lingering fear that the cancer could recur. Quest narratives are most conspicuous in this theme, along with elements of restitution and chaos. According to Frank (1995) *“Stories have to repair the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going”* (p.53). This experiential viewpoint has allowed the women to reconstruct their experiences which is helping/has led them to create their self-identities (Wilkinson, 2000).

Changes in lifestyle to prevent recurrence.

The women discussed the lifestyle changes they have made or were making to manage various stressors and to prevent recurrence. Some participants indicated that these adjustments were still a challenge. Five women made changes in their dietary habits along with getting into an exercise routine. The other three participants who had a healthy lifestyle before cancer in terms of diet and exercise have kept up this practice.

Many women shared their experiences of people they knew who died from cancer and those with recurrence which left an impression on their lives. It was during these times that their own lingering fear of recurrence surfaced along with an element of chaos in their stories. This fear is a reality for women with breast cancer that becomes more apparent after the treatment has ended, and persists as they begin to move on with their lives. This was seen with the four longer term survivors who are remission. They continued to monitor themselves with follow up tests and clinic appointments to make sure that they had the cancer under control. Other research has also cited the fear of recurrence (Lethborg et al., 2000; Thomas-MacLean, 2004; Stanton et al., 2002). In Oxlad's (2008) study, the women were fearful after treatment ended and were worried about the future when they were no longer on medication such as tamoxifen (Thewes et al., 2004). The results from these former researches are in accordance with the four longer term survivors in this study.

Many participants informed that they were maintaining a positive attitude in fighting the cancer and to avoid the possibility of recurrence. They also used their faith to uphold this view. Their outlook about having a positive mental state is a popular cultural belief that women have been socialized to accept (Charles et al., 1998; Wilkinson, 2001).

This approach however, can deter the participants from effectively dealing with their real fears and concerns. It is only when they have put their feelings into perspective that they can move on with renewed hope. Wilkinson (2001) reinforced this point when she noted, “it seems vital for feminists - and others – to denounce the ‘moral oppression’ of positive thinking in cancer care” (p. 274).

Exploring the cause and search for meaning/ life perspectives changed.

Most participants wanted to know what could have contributed to their getting cancer. H8 saw the cause as a chemical change in her body. She believed more information needed to be disseminated to the general population about the disease and how to address it. Her concern is noteworthy because the people who have cancer have lived through the treatments, and have also seen others die despite treatments. The women have a personal interest in wanting to find a cure because they would no longer have to live with the fear of recurrence on an ongoing basis. The participants also reviewed the parts of their lives when there was increased stress due to either work demands or personal circumstances as a probable cause for the cancer.

In reflecting on the cause the women were also, searching for the meaning to the disease to answer the ‘why’ questions it raised for them (Carlick & Bailey, 2004). Cancer showed all the participants how uncertain life can become in an instant, and stripped away their feelings of being in control of their lives. In searching for meaning their perspectives on life began to transform. They were becoming more aware of what was important in their lives. Several changes the women expressed were they valued themselves more, making their needs a priority, being more helpful in interacting with others, different attitude towards people and stressful situations, re-evaluating life/career goals, renewing

and strengthening faith in God, and looking beyond the physical trappings of the body to the inner person. These findings concur with Oxlad (2008) research where her participants saw benefits to their illness, which included self-change and living life in the present.

For some women this shift in outlook came while they were still on treatment. For others understanding and insightfulness have developed over a period of time. Many participants appeared to be at a more comfortable place in their lives. For example, the two women who used avoidance to cope have learned to be more accepting of other people outside their circle knowing about the cancer. They needed time to internalize what cancer meant to them before they could interact with acquaintances.

Relationships improved.

Many women got positive feedback from their support network which validated and boosted their self esteem. This appraisal support (House, 1981) helped in evaluating their outlook on life, and influenced their relationships with others. Four women talked about the improvements in their dealings with family, friends, and co-workers. They became more compassionate towards people, patient with self and others, and learnt to disassociate from insensitive/superficial friends. The women credited the cancer for enhancing their relationships on the job. Tensions with co-workers disappeared and colleagues were also more sympathetic towards them. The women too made accommodations in how they responded to co-workers. The other three participants who did not openly disclose on the job saw no change in the way colleagues related to them. This is to be expected as they would have done what they could to give the impression that things were 'normal' in their lives.

In this final theme, quest narratives are dominant in the women's stories as they described the various ways in which they have made or are making changes in their lives. Despite having cancer, there is now a deeper appreciation for life and their relationships with the people around them. According to Frank (1995), quest stories permit individuals to see illness as a journey from which there is growth. At times this discovery "is not someone wholly new, but rather 'who I always have been.' This self is not so newly discovered as newly *connected* to its own memory" (p.129).

Frank's Narrative Types

Frank's (1995) typology was new to this researcher and it has been an insightful journey for her. It allowed her to appreciate another way of understanding the meanings behind illness stories within a cultural context. In this study, the researcher was able to discern how the three illness types were interwoven throughout each participant's narrative. She was also able to identify the different intervals when each type became more predominant in the women's story. For instance, medicine emphasis is on curing which denotes a restitution narrative that it is important to become well again. This was seen by the participants' desire for survival in having their surgeries and treatment.

All the women began their stories with a chaos narrative surrounding the confusion and fears of a cancer diagnosis. It also became prominent again during their experiences with the treatment side effects and trying to manage their personal and work lives. Frank (1995) emphasized that it is essential for those who seek to help to hear these stories of "wreckage" (p.110) and not dismiss or thrust people towards restitution narratives. Social workers therefore, are in a better position to really listen to survivors' stories of

“wreckage” and the meaning of the illness for the individual, in order to help them find ways to cope (Frank, 1995; Thomas-MacLean, 2004).

The quest narrative took centre stage in the various lessons the women have learned on their cancer journey. This has altered their perspectives on life and is presented as a positive means for coping. However, with the longer-term survivors the end of treatment does not mean that full restitution is achieved, although it may be the goal of medicine and society. The factor of a fear of recurrence caused chaos features to resurface occasionally. The use of Frank’s illness types in this study provided a better understanding of the connection between dominant cultural discourses, and the women’s experiences with breast cancer (Thomas-MacLean, 2004).

Feminist Perspective

According to feminist experiential writings, dominant discourses have influenced women to hide their distress, anxiety, fears and physical symptoms of breast cancer (Wilkinson, 2001). This was observed in the various women’s narratives as they shared their outlook about the illness, and interactions with the people in their support network. For example, several doctors’ conflicting and patriarchal attitudes made some women feel disempowered where their health issues were concerned. It was also highlighted in limited information being given concerning the disease and ways to cope.

The women’s stories also revealed the cultural discourses that they and others have been socialized to accept. For instance, being bald or having less than perfect breasts is unattractive. Many women sought to conceal the physical changes wrought by their treatments in wearing wigs, a prosthesis and wanting reconstruction surgery. Hence, these commodities maintain the appearance of health. Another cultural norm that emerged was

that positive thinking would prevent a recurrence of the cancer. Many participants used this coping skill to manage their concerns about the illness.

The women's narratives depicted how they struggled with these various issues. This study afforded participants a voice to share their stories and re-story their experiences with breast cancer. According to one individual who has not openly disclosed:

Um, but you know it's good to share. And I said, I remember I was telling my husband just recently as I said, "it's not as though I won't be sharing ever again, you know." ...And I really hope that the research could go one, maybe just one little iota step forward in terms of the provisions here in Trinidad and well beyond of course. (F6)

Social Support

To mitigate their helpless and anxious feelings the women received several types of social support in their journey through the different stages in the cancer trajectory. All the participants spoke about their close-knit relationship with various family members who were also deeply affected. At diagnosis they appreciated the emotional and instrumental support from spouses, family members and significant others. They also got informational support from some spouses who assisted in finding material on the internet about the cancer. During the treatment phase, there was ongoing emotional and instrumental support from these people. For the women who are 3-4 years post diagnosis there has been a continuance of emotional support from family members and significant others in their personal and work lives. The literature suggests that emotional support is a key factor in women's psychological well being (House, 1981; Roberts et al., 1994).

There were different degrees of emotional and informational support given by health care professionals such as doctors, nurses and other members of the health care team. Three women were introduced to the medical social work department. Two

received instrumental support in the form of financial assistance for diagnostic tests.

However, they did not access the counselling aspect of social work. F6 was unaware that the department offered counselling. D4 has not been able to find any support groups for families in learning to deal with cancer.

Yeah, he's not sure um, what to do, how to do it, how to support me, you know. And he keeps asking are there any support groups for the men that have to go through this. And we can't seem to find any, because nobody tells the men, what's going to happen to us. We have to find it out on our, our own, you know. (D4)

The researcher enlightened them on the counselling aspect of social work, and the other support organization on site, The Associates of the Radiotherapy Centre. The women's lack of knowledge reinforces the need for information that is more visible and counselling support.

Social support played a significant role in helping the women in this study to face breast cancer. However, the literature has shown that low levels of support from spouses, family members and friends contribute to greater psychological difficulties. The survivor may see her ability to cope as being ineffective because significant others are not around to encourage her. To manage this stressful period the survivor avoids negative people (Henderson et al., 2003; Manne et al., 2003). Similarly, a spouse who has his own fears and concerns about the illness may exhibit avoidance behaviours toward his wife. This lack of emotional support also affects how she adjusts to the illness (Davis, 2004; Roberts et al., 1994; Sormanti & Kayser, 2000). Holmberg et al. 2001 (as cited in Gonzalez & Lengacher, 2007) research discovered that partners in difficult relationships, the cancer further intensified their challenges which led to a deterioration in relationships. Thus, women in unhealthy unions and those who did not have partners, "were more angry, sad, and hurt due to the lack of emotional support" (p.492).

Pessimism about cancer also impacts interpersonal relationships on the job. Negative attitudes can hinder the survivor in making the necessary adjustments to cope, and impede her reintegrating successfully on the job. Feeling isolated by people in her social network can lead to “further psychological problems” in the survivor (Rendle, 1997, p.406). The literature has stated that psychosocial interventions enhanced survivors’ psychological well being (Davis, 2004; Rendle, 1997; Roberts et al., 1994). Therefore, it is important for health care professionals especially social workers to be available for spouses and significant others to assist them in addressing their own negative concerns. It is also essential for families and significant others to be well informed at all stages in the cancer continuum. Knowing how to support survivors can decrease their distress and isolation (Rendle, 1997; Thewes et al., 2004).

Methodological Issues

This section will discuss the strengths and limitations of the research design.

Strengths.

The literature indicates there are limited studies on the return to work experience of women with breast cancer. This exploratory study is the first that is being conducted in Trinidad and Tobago. It may also be a primary study within the Caribbean region as the researcher has not been able to unearth any similar research in this area. Therefore, it will add a new body of knowledge to the literature.

The researcher believes that the results can make a worthwhile contribution to research, education, patient care and policy development. It can increase social workers’ and other health care professionals’ understanding of the psychosocial effects of cancer on the work lives of breast cancer survivors. The findings can aid to improve social work

services to this clientele, as well as identify specific services/programmes that are required during the transition phases of cancer. Chapter 6 will focus on these respective areas.

The researcher was interested in women at two different time periods in their cancer journey. She wanted to know whether women experienced any long-term challenges on the job in living with cancer. The researcher was able to elicit commonalities and key differences between those on active treatment and women who are in the recovery phase years later. She compared her findings to the literature which led to the resultant conclusions.

The informational interviews enabled the researcher to build rapport with the participants face to face and on the telephone before the actual interviews. Most interviews took place in the women's homes and at work. This allowed the researcher to observe them in their natural settings and she also got glimpses of their support system. The participants gave graphic examples in relating experiences and their perceptions of situations. They also reported that they felt good about sharing. This is probably because the researcher used to be a medical social worker and is familiar with the environments where they had/were having their treatments. The researcher also believed that the women felt validated that someone was interested in hearing their whole story, and that their involvement could enhance services for other women.

Another strength to this study is that a cross section of the three major ethnic groups is represented and there are some variations within religious affiliations. The women did not perceive any problems concerning to cultural or ethnic differences. This may be due to several factors: As already noted all the women were in relationships and had a good social support network. They presented as confident women who valued their

spirituality/religion, commitment to family, and their careers. In addition, they were professional women, had a good work ethic, well educated and some were still advancing higher education. The women were from middle to higher socioeconomic bracket and all lived in urban areas. This study has revealed that irrespective of ethnic and cultural backgrounds breast cancer is still a challenging experience for women and their families.

Limitations.

As discussed in the methodology section several strategies were used to increase the credibility of qualitative findings. However, there are still certain limitations which are part of the research design.

1) A key limitation of this study is the use of a small purposive sample. Creswell (2003) indicated that, “the purposive sampling procedure decreases the generalizability of findings” (p. 148). The results from this study will not be generalizable to other samples of women with cancer who return to work, only to groups that closely represent the participant group. Through purposive selection of 8 participants, the researcher tried to look for the widest cross-section of socio-economic related predictors (e.g. age, ethnicity, work experience, education, and length of time since diagnosis) to increase the study’s credibility.

2) There were certain drawbacks to the short time factor (6 weeks) in securing and interviewing participants who met the study’s criteria. The researcher discovered that many of the women she approached who were willing to be interviewed had stopped work while on treatment. There were some who did not return to work for varied reasons. The long-term survivors took between 6 months – 12 months off. The ones the researcher met currently on treatment had also temporarily stopped work. The researcher found herself

going through a process of elimination. Trying to find women who continued working throughout their treatment was not an easy feat!

Most women in this study went on sick days between their chemo cycles. One of the long-term survivors selected had taken six months off for all her treatment. She went back to work for a month after the chemo ended and before starting radiation. Another participant who was currently on treatment said that she worked throughout. It was not until the interview that the researcher realized that she had been employed for 3 years with her present organization. However, she was not a new employee to the work environment, but had transitioned from one job to the next. So she still fitted into the criteria used regarding work experience.

3) The researcher learnt that her participants were well-educated professional women, in a middle - higher socioeconomic bracket, held sedentary type jobs, and all had partners (married/engaged). Their experiences may be different from other women who fall into a lower socio economic background, are in service type occupations or blue-collar jobs, and did not have partners. An attempt to find women with these elements were not successful during the short time period for data collection. The ones the medical records supervisor chose with these characteristics had stopped work six months plus during treatment and had other medical complications. Having women with these attributes would have given further insight into their unique experiences, and whether they faced greater challenges being on treatment and trying to work.

4) Four participants were interviewed 3-4 years post diagnosis, and there is a possibility of retrospective bias, or recall difficulty. However, the four individuals were still able to describe vividly their lived experience and sense of perspective about the

illness. The researcher sees this as both a limitation and a strength. It is viewed as a strength because the women's experiences can assist those who are presently on treatment to know some of the concerns post treatment.

5) An enhancement to this study would have been the inclusion of a focus group. In qualitative research, focus groups can be used along with individual interviews to strengthen the research design (Linhorst, 2002). They can help participants to express ideas and experiences that may not be fully explored during an individual interview (Kitzinger, 1995). The focus group allows the researcher to see how participants share their experiences; as well as make sense of these experiences (Kitzinger, 1995; Wilkinson, 1998). It can also assist the researcher to observe the process of how meanings are co-constructed. For instance, a story told in a focus group can act as a stimulus for other women to disclose their own stories (Wilkinson, 1998), feel validated, and network with other breast cancer survivors (Ferrell et al., 1997). The use of focus groups was originally plan as part of the data collection. However, it was removed from the study due to meeting ethics requirements and the short time factor to conduct the research.

Despite these limitations, the study findings provided graphic accounts of women's return to work experiences with breast cancer.

Summary

In this chapter, the findings were discussed and compared to the relevant current literature. The results were consistent with several other research studies that helped to strengthen this study. Frank's three narrative types, the feminist perspective, social support, strengths and limitations were delineated. The next chapter will outline the

implications for social work research, education, practice and policy, and will conclude with a summary of the research findings.

Chapter Six: Implications and Conclusion

Introduction

The purpose of this exploratory study was to look at the return to work experiences of employed women with breast cancer in Trinidad. The researcher discovered from her practice in working with cancer survivors that there were women who stopped work because of the illness. While other women who continued working during treatment had difficulties in coping. This led the researcher to pursue the study topic specifically for breast cancer because it is the leading cancer among women in Trinidad and Tobago.

This research was a qualitative, narrative study that used Frank's (1995) three illness types in understanding women's stories in returning to work. A feminist perspective was applied in looking at the social context in the participants' narratives. They provided the structure for the study's design. The two constructs coping and social support were also used to determine employed women's experiences with cancer.

This final chapter will explore the implications for social work research, education, practice, and policy based on the research findings.

Implications for social work research.

This study raises areas for future research on women returning to work after breast cancer:

- 1) The women in this study were in a younger age group and for many still advancing their careers, therefore continuing to work means realizing their goals. An area for future research will be to expand the age range to include women 50 years and over who are still in the workforce. What will be some of the issues they encounter after breast cancer?

2) What factors contributed to other women who took six months and over off the job? What issues do they faced when they return to work after a longer period?

3) Further studies comparing the experiences of women who did not return to work, and those who continued will give a better reflection of work issues with breast cancer. Including a wider range of occupations and other demographics will also help to determine employment concerns. This is an area for both qualitative and quantitative research using different approaches such as grounded theory.

4) There are women with cancer who come from lower socioeconomic backgrounds, have different family structures (e.g. single parents, widowed, single), and may lack a proper social support network. These factors may create some difficulties and influence how well women adjust to working with a cancer diagnosis. This is another area for future research.

Implications for social work education.

The findings from this study have implications for social work education both at the university level and in practice settings.

1) There is a need for social work educators at the local universities to develop courses in health social work that would assist students' knowledge base in practice settings. Presently the only training that students receive in health care is during their practicum placement.

2) Medical social workers in oncology have the experience and can educate social work students in practicum placements at NRC on the biopsychosocial needs of cancer survivors. There is also a need for more awareness among social workers on the role of work in the employed survivors' life. This knowledge can help social workers at all levels

to assist the cancer survivor to make adjustments and advocate for services in the workplace.

3) Develop and deliver training to community-based professionals about cancer, its treatment, impact on the individual/family/significant others and their ability to work.

4) It is important for social workers to seek opportunities for continuing education/conferences, as well as in service training in both general and disease site-specific cancer conditions and outcome. This understanding can help to allay concerns and reinforce the medical team treatment regimen to clients. It is essential to seek out new knowledge about the psychosocial effects of cancer and use that information for edification of self and others. Continuous improvement entails a commitment to learning.

Implications for social work practice.

The findings from this study have given a more in depth understanding of women's psychosocial needs in being diagnosed with cancer and its impact on their work lives. It is clearly evident that the participants required emotional and psychological support soon after diagnosis. Therefore, health care professionals have to be more cognizant of survivors' concerns as they make decisions regarding treatment, self-image issues, and returning to work. To support women in making the emotional adjustments to the cancer experience social workers need to:

1) Provide early intervention to assist survivors and family members in coming to terms with the cancer diagnosis.

2) Ensure survivors understand the information relating to the treatment regimen and support them through the process. This should include educational intervention for family members.

3) Help survivors communicate their concerns to the various medical personnel and their significant others.

4) Educate health care professionals in their patient communication about the biopsychosocial, environmental, spiritual, and cultural factors that impact on cancer care. To emphasize the importance of providing emotional and informational support as this would foster a better health care relationship with the survivor. Medical social workers are called upon to deliver tangibles (financial assistance, procurement of appliances and other needs), and their clinical assessment and therapeutic skills are not fully appreciated by the medical team. Thus, it is necessary to educate the health care team on the diversity of the medical social worker's role in cancer survivorship (all phases of the cancer continuum from prevention to bereavement).

The medical social workers at NRC identified that a team approach is needed for cancer care. Case conferencing among the multidisciplinary team has not been a practice at NRC over the years for a number of reasons. However, according to Ms. Haynes, "Grand Rounds" have been introduced recently, but this occurs only between the doctors (personal communication, November 2, 2011).

5) Evaluate service demands, and the various gaps that the participants perceived such as informational and other needs. To develop programmes and resources to address these requirements. For example:

i) It is important to restart distributing the informational package to new patients. To include also information on community resources and support programmes for survivors and their families. This will offer some level of comfort that there is material

and information on available resources. There are times when survivors feel overwhelmed by all that is happening and are unable to absorb too much information at once.

ii) Re institute and plan a regular orientation programme (despite staff shortages) for new patients.

iii) Help survivors design a return to work schedule while they are on treatment to minimize time off the job.

iv) Collaborate with other disciplines to bring a wide scope of practice skills and innovative methods. For example, to develop linkages with organizations that offer EAP services to address work related issues that survivors may identify.

6) Support survivors and spouses in working through the various issues in their relationships and their coping skills in managing the new reality.

7) Increase awareness to be continually available to support survivors during the recovery phase as they grapple with recurrence issues. The needs of survivors after treatment are not considered important by many in the medical community. To educate and sensitize health care professionals in this area.

8) Utilize a wide range of various skills/techniques in planning therapeutic and other interventions including couple or family therapy, psychotherapy, and group work.

Implications for policy.

The general Health policy thrust in Trinidad and Tobago over the years has been on treatment rather than on care. This is an area where social workers play a vital role because they are responsible for the care aspect. Their role as an integral member of the health team can be reinforced through education and training to health care professionals.

Social workers need to collaborate with members of the health team to improve their patient communication with survivors who want to return to work during treatment. This will make the transition an easier one for the survivor because as a team they can identify the supports/interventions required to help women cope better with the treatment side effects (Chapman, 2000; Main et al., 2005). In addition, the health care professional can act as a liaison and support between employee and organizational needs. This will provide opportunities for health care professionals to create evidence-based interventions that will allow breast cancer survivors to manage their work and personal lives.

The Ministry of Health during past few years has been targeting improved cancer services and control in Trinidad and Tobago. Its goal is that when the new Oncology Centre is built services will be co-coordinated at the national level (Maharaj, 2006). The Ministry has recognized that doctors' work in isolation in their management of cancer patients, and has set up an audit system to develop a multidisciplinary approach to cancer care (Khan, 2011). This action can lead to managed care policies, which will help to determine patient satisfaction with the care and treatment given.

The findings identified that many employers have made reasonable accommodations in facilitating the women in returning to work during and after treatment. However, this raise the question of how sustainable is reasonable accommodation in small private companies that do not have an EAP or wellness programme. One person reported discrimination seven months after she began treatment. Although this is significant, the researcher cannot draw any definite conclusions from this study. However, it is an area for further investigation and suggests that policy makers need to review workplace polices of

both public and private companies. This scrutiny will ensure that there is more consistency in workplace practices regarding the cancer survivor in the workplace.

Returning to work can boost a woman's self-esteem particularly at a time when she feels stressed about the diagnosis and what it means to her life. Most survivors in this study continued to work during treatment and most returned to work after treatment ended. This finding indicates that there is also a need for policies that endorse cancer survivors continuing as well as the ones who return to the workplace. The Trinidad and Tobago Equal Opportunity Act of 2000 has been an important piece of legislation that can help to deter discrimination. However, to be effective this piece of legislation has to be enforced so that the cancer survivor can continue to remain in the workplace.

The results from this study can educate health care professionals, human resource managers, and EAP providers on the importance of workplace support for cancer survivors. EAP services in Trinidad and Tobago have continued to be established in many organizations in both the private and public sector. The EAP professionals can work in conjunction with Human Resource departments and Wellness Programmes to develop services to meet the needs of survivors in the workplace. For example, interventions such as educational outreaches, workplace support groups, and other support programmes, can sensitize employers and co-workers about the fallacies and myths that still surround cancer. It will serve to create a more supportive environment for survivors who hide the cancer to avoid being stigmatized. These initiatives can assist people with cancer; especially women with breast cancer to have a more rewarding and stimulating work life.

The study findings can help the three national cancer organizations to increase their education programmes not only to the general public, but to target workplaces. They

can form alliances with workplaces that do not have an EAP or wellness programmes and have their representatives conduct educational sessions. These organizations can also collaborate and advocate for consultation and networking with government and non-government agencies on work factors that can impede women with cancer.

Conclusion

The data analysis revealed six major themes that led to the following findings. The participants' reactions to the diagnosis were a traumatic period for them which changed their lives from one of normalcy to confusion. This was an emotional time as they began to work through what cancer meant to them, their relationships and their future. The findings revealed that all the women had a good social support network which consisted of family, friends, significant others, and co-workers who helped them through this period. They also reached out to other survivors to give and receive support.

The women in the study reported that they were satisfied with their overall care. However, the results highlighted that more support from health care professionals is needed. Although the participants were at two different time periods in their recovery, their concerns were the same across the continuum. Some areas identified were information regarding their health care in both the short and long term, insensitive attitudes from the medical profession, dietary, counselling, support for families and the need to be heard.

This study showed that health care professionals' role has to be a more responsive one. The findings also identified that counselling support is needed to help women manage the various psychosocial issues across the cancer spectrum. The Medical Social Workers' role in this area is an important one. They have the qualities to build caring and

supportive relationship with clients. The Medical Social Worker in utilizing a wide range of various skills/techniques can also empower women and their families on how to manage the illness, and its impact on their lives.

All the women disclosed the cancer to their employers and were given reasonable accommodations. Five participants openly disclosed on the job and received overwhelming support, which boosted their self-esteem. Supportive relationships on the job appeared to make disclosure easier. This study found that disclosing also improved relationships on the job. Three persons who said they were private individuals told on the job only those who needed to know and there was no change in relationships with colleagues. The findings suggest that workplace interventions such as EAP services, wellness programmes, and developing support groups can help to foster a more supportive work environment. The results from this study are congruent with the literature that coping and social support are instrumental in determining how well the women managed the cancer experience and returning to work.

The majority of participants worked during their treatment. Some went on sick/vacation leave for a blocked period while others took intermittent sick leave between their chemotherapy treatments. The findings indicate that most women found working during treatment challenging. Fatigue was a common symptom that all the participants experienced to varying extents. It contributed to changes in physical and cognitive abilities. One person mentioned cognitive changes four years later.

Despite some of the challenges they faced/are facing on treatment, many women have been successful in returning to work. All the participants 3-4 post diagnosis returned to their same jobs. Two important work related issues came out of this study. One

participant who is 4 years post diagnosis spoke of being locked into her job because of the health insurance. Another individual who was on treatment was dismissed subsequently on a work related incident, and was in the process of suing ex-company for discrimination. These two areas are real concerns that the literature has identified that some people with cancer encounter on the job.

Although most women mentioned that they enjoyed their jobs cancer has caused a shift in attitudes. They were now trying to create a better work life balance by reducing work pressures and evaluating their career path. For example, one participant is planning to leave her job and move into full time self-employment. The women have made several lifestyle adjustments to prevent recurrence which is a lingering fear; especially the ones 3-4 years post diagnosis.

Cancer has impacted the women's lives in many ways. Their search for the cause and the meaning to the illness has altered their perspectives on life. For some the changes have been rapid and profound, for others they have been more gradual over time. The participants shared the valuable lessons that cancer has taught them, and is still teaching them on their continuing journey. These lessons seemed to have enriched their lives and relationships.

The women in this study showed not only courage, but resiliency in the way they managed the cancer experience for themselves and in reaching out to others. For example, H8 who was diagnosed three years ago has learned to appreciate the uncertainties of life; the actions she has taken to cope, and how she has begun to value her own life with cancer. Her reflections captured the voices of the other women in their outlook, fears, and the various changes they have made/making to manage the illness.

(Long pause) One of the things that I was grappling with was how unexpected life can be. Because here I am struggling and I'm praying to God one night and I said you know, I want to see blue skies and green grass again. You know and it's the middle of the night. And I say God you know what that mean right (chuckles). And I got a chance to go out and see, blue skies and green grass again when I'm driving along in the buses and so on. And I am thinking this life is precious and I'm on diet and I can do the exercise. And um, you know how I deal with people and so on....And the cancer, I wasn't connecting with the finality of death, before. But with the cancer I'd have to stop and think about it that, you know. But here I am worried about it and being able to do something, as against people who just walk out and a car hit them. Or you know you just happened to be in the wrong place and you get shot or. That kind of thing is going on in Trinidad, and you realized how very fortunate you are and at the same time how very cruel (emphasis) the place is with this, you know. By chance you may be exposed to something and in this case the exposure to the cancer again. But we not sure what causing it and up to now we haven't really addressed that, we have just been treating it. But what is the cause, you know. (H8)



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Appendix A

INFORMED CONSENT

Research Project Title: **Return to work experiences of employed women with breast cancer in Trinidad.**

Researcher: **Maureen Mohammed (MSW student).**

Telephone No: (xxx) xxx-xxxx (c); email: xxxxxxxxxxxxxxx

Faculty Advisor: **Professor Paul Newman, Tel. No: (204) 474-8548**

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you a basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The researcher is a student in the Master of Social Work (MSW) programme at the University of Manitoba, Winnipeg, Canada. This thesis is part of the requirement of her MSW programme. The researcher has chosen to study the "Return to work experiences of employed women with breast cancer in Trinidad." This study is an exploratory one because she has not been able to find any similar research in Trinidad & Tobago. The study is designed to elicit information from eighteen employed female survivors, and will use a narrative approach as its method of inquiry and data collection.

Breast cancer survivors need to be given the opportunity to share their stories which can assist other women who may have concerns about their ability to work during and after treatment. The research can also help those who implement health service delivery and employers to understand the fears, concerns and needs of breast cancer survivors. The results can assist organizations to assess whether there are programmes that make the transition back to work a smooth one. Or what programmes are required to help women manage their work and personal lives.

You are being asked to participate voluntarily and to provide your written consent. You will be involved in one individual interview which will take 1-1 ½ hours. You will be asked to share your personal stories of what it is like having breast cancer, your ability to function on the job with breast cancer, your relationship with others, and what things are different about your life now since the cancer. This interview will be conducted by the researcher and the discussion will be recorded with both pen and paper, and two audiotape recorders.

Subsequently, you will also be contacted to provide feedback on the information elicited from this interview through a process call member checking.

The researcher believes that the risk associated with your participation in this study is minimal. However, in recounting your experiences there is a possibility of some potential risk where you may become overwhelmed by memories due to unresolved feelings about the cancer. If for any reason emotional support is required, you will be given the opportunity to be seen by one of the medical social workers attached to the National Radiotherapy Centre, or another medical social worker off site.

In order to ensure confidentiality, you will be assigned a number which will be used for all data collection and coding. Pseudonyms will also be given to all the participants to protect confidentiality. The researcher is the only one who will know your true identity. The only persons who will have access to the coded data will be my committee members, Professor Paul Newman, Dr. Laura Taylor (Faculty of Social Work, University of Manitoba) and Dr. Godfrey St. Bernard (Sir Arthur Lewis Institute of Social and Economic Studies, The University of the West Indies, St. Augustine, Trinidad and Tobago). Every effort will be made to conceal or disguise your identity on presentation of the data findings. The researcher will keep the information gathered from the study in a file, under lock and key at her home. All written notes and audio recordings will be destroyed under supervision on or before January 31, 2012.

The results of this study will be shared with the professional community through a written summary, and ultimately in conference presentations. A summary of the study results will be provided to you via an e-mail attachment or in a stamped, self-addressed envelope around September 2011. Light refreshments will be served during the interview and a token of appreciation will be given for your participation in this project.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researcher, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your decision not to participate or to withdraw from the study will not affect your health care at NRC. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

This research has been approved by the Psychology/Sociology Research Ethics Board of the University of Manitoba. If you have any concerns or complaints about this study, you may contact any of the above-named persons or the Human Ethics Secretariat at (204) 474-7122, or e-mail Margaret_bowman@umanitoba.ca.

Participant's Signature: _____ Date: _____

Researcher's Signature: _____ Date: _____

Please indicate whether you wish to receive a summary of the study's results and the address to forward the summary



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Appendix B

Interview Schedule Questions

Thank you for meeting with me. How are you today? As I indicated at the prescreening interview when you signed the consent form, the purpose of my research thesis is to look at the “Return to work experiences of employed women with breast cancer in Trinidad.” As you know I will be audio taping our interview which will take about 1-1 ½ hours.

I just want to remind you that it is your right to refuse to answer any questions which make you uncomfortable. If at any time during the interview you wish to stop or take a break we can do so. We can also continue the interview at another time. It is also your right to withdraw from the research if you change your mind about continuing without any consequence for doing so. In other words, your participation is voluntary and if you choose to decline at this point it will not affect your health care at NRC.

I have a number of questions that I will be using as a guide in our conversation as you share with me your experiences. I will also be taking some notes during our conversation. Do you have any questions for me before we start?

1. Tell me about a significant episode, memory or experience that you remember when you first found out about breast cancer?

Probe: What can you tell me about your experiences with breast cancer?

2. What kind of person were you during this stage?
3. Who were the significant people for you during this stage and why?
4. Can you tell me about a time that you had to confront a change in your body due to breast cancer [this illness]?

5. Can you tell me a story about returning to work that shows the challenges that you have faced?
Probe: Can you tell me what it is like working and being on treatment?
Probe: Can you tell me about your ability to function on the job with breast cancer?
6. What can you tell me about your attitude towards your work since being diagnosed with cancer?
7. Can you identify an occasion where your relationships felt threatened by cancer?
Probe: Can you tell me how breast cancer has affected your relationship with others?
Probe: Can you tell me what your relationship is like with others since having cancer?
8. What does having breast cancer tell you about yourself that it is important for you to know?
9. What things are different about your life now since having breast cancer?
10. Is there anything else that you will like to add that we have not discussed regarding your needs in dealing with breast cancer?
11. Do you have any questions for me?

How are you feeling right now? Once again thank you for giving me the opportunity for us to meet to discuss your experiences in returning to work with breast cancer. Will it be okay for me to telephone within the next couple of weeks to clarify any information from the interview? I have some refreshments for you. I will also like to give you this token of my appreciation for your invaluable contribution to my study. Until you hear from me take care.



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Appendix C

Explanation for Potential Participants (Medical Records Supervisor)

(For researcher to telephone)

A project on the “Return to work experiences of employed women with breast cancer” is being conducted by Maureen Mohammed, a social work master’s student at the University of Manitoba, Canada. I am hoping you would be willing to share your experience so we can understand what women need.

If you are interested in hearing about her project, will you give me permission to release your name and phone number to Ms. Mohammed? Ms. Mohammed will call you within the week with more details about her project. You can then decide whether you will like to participate or not.

I will also like to reassure you that whether or not you participate in this study it does not affect your ongoing health care in any way.

Thank you.

(Face to face contact with researcher)

A project on the “Return to work experiences of employed women with breast cancer” is being conducted by Maureen Mohammed, a social work master’s student at the University of Manitoba, Canada. I am hoping you would be willing to share your experience so we can understand what women need

If you are interested in hearing about her project, Ms. Mohammed is currently at the Centre and if you have time you can meet with her today. You can then decide whether you will like to participate or not.

I will also like to reassure you that whether or not you participate in this study it does not affect your ongoing health care in any way.

Thank you.



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Appendix D

Explanation to Potential Participants at The National Radiotherapy Centre or on the Telephone

Good day, my name is Maureen Mohammed. Thank you for allowing me to meet you (or phone you). As the medical records supervisor indicated, I am a social work master's student at the University of Manitoba, Canada. This project is part of the requirement of my MSW programme.

I am looking at the "Return to work experiences of employed women with breast cancer in Trinidad." I am seeking information from eight employed female survivors who will be part of individual interviews.

The interview will involve you sharing your story about being diagnosed with breast cancer, your feelings and concerns at the time of the diagnosis, and the effects the diagnosis has had on your work life. I believe that breast cancer survivors need to be given the opportunity to share their stories which can assist other women who may have concerns about their ability to work during and after treatment.

If you are interested in this project I can set up an informational interview where I will give you more details about my study. You will be given a consent form to sign which indicates your voluntary participation in the project. At the informational interview which should be about 15 minutes long we will set up the date and time for the actual interview. We can also discuss whether you will like us to meet at the NRC or in an office at another location. The individual interview will be approximately 1- 1 ½ hrs long.

Do you have any questions? Are you interested in participating in this project?

Can you give me a date and time now that is convenient for us to meet again? Or if you have the time, will you like us to do the informational interview now?

Thank you for your interest in this project, I look forward to meeting you (or seeing you soon).



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Appendix E

Script for Requesting Verification of Findings

Hello, good evening, this is Maureen Mohammed. At the end of our interview 1-2 weeks ago, I indicated that I will like to call individuals about clarifying/verifying information raised during our discussion in the individual interview. Will you be interested in assisting me to verify the various categories/themes that emerged during my analyses of the data? If you are, I will appreciate if you will review a summary of the findings to ensure that your experiences and needs have been captured by these categories.

I will email you (or mail/drop off) the summary today and will telephone you tomorrow evening for the feedback (or call you in a few days time for the feedback). During our telephone conversation you can let me know if there is anything else that you would like to add. I will take notes on your opinions and reactions about the study's findings.

I wish to reiterate that confidentiality will be maintained as the data will be grouped. Thank you very much you have been most helpful.

I plan to have a post study focus group in order to share my findings with all of the 8 participants. Will it be okay for me to call you at a later date regarding more details about such a group, and to find out whether you would be willing to be a part of this group? If you are, I would let you know the date, time and venue for the meeting. If you are unable to attend or not willing to be a part of a post study focus group, I will forward a copy of the research findings to you around September 2011.

Once again thank you for giving me this opportunity to talk to you about the findings from my study.



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Appendix F

September 15, 2010

Dr. Peter Bovell
Director
National Radiotherapy Centre
112 Western Main Road, St. James
Trinidad, W.I.

Dear Dr. Bovell,

Re: **Permission to conduct research at the National Radiotherapy Centre**

As part of the requirements for my master's degree, I will be undertaking an exploratory, qualitative study titled, "Return to work experiences of employed women with breast cancer in Trinidad." This research aims to explore the various factors that affect women who return to the workplace during treatment and after treatment has ended.

I am requesting your permission to access breast cancer survivors from the National Radiotherapy Centre who fit the research criteria. I am interested in eighteen (18) women between the ages of 30-49 years who are in the workforce. These will be women currently on treatment, as well as women three years post diagnosis who are in remission and attend the Centre for routine follow up visits.

The selection process will be conducted through purposive sampling. Each participant in this study will be interviewed in person by myself. Participation will be voluntary, the nature of the study will be explained to all participants, and they would be asked to sign an informed consent form. All information will be kept strictly confidential, and any identifying information relating to the study's participants will be coded so as to maintain their confidentiality.

I am requesting permission to use the National Radiotherapy Centre as a location for interviewing some or all of the participants in a room that will not disrupt the normal activities of the Centre. The time factor for conducting the actual research should be about six weeks.

I believe that this study can benefit the National Radiotherapy Centre. For instance, understanding the psychosocial effects of cancer on the work lives of breast cancer

survivors can aid to improve social work services to this clientele. This study can also educate health care professionals at the Centre about the importance of work and cancer, and how attitudes can impede the reintegration process.

As you are aware, there are major changes taking place within the country's oncology system which will have a direct influence on the National Radiotherapy Centre. My findings may confirm present limitations within the oncology delivery system; identify further gaps; and offer recommendations for developing more effective and efficient client centered services, especially for cancer survivors who re-enter the workplace.

I thank you in advance for allowing me to conduct my research at the Centre, and will keep you informed of the results of the study.

Yours sincerely,

Maureen Mohammed, BSW, MSW Candidate

Appendix G

Office of the Medical Director
St. James Medical Complex
112 Western Main Road
ST. JAMES
1 868-628-9327



October 18, 2010

Ms. Maureen Mohammed
[REDACTED]
[REDACTED]

Dear Ms. Mohammed,

Re Permission to Conduct Research at the National Radiotherapy Centre

In reference to our discussion concerning your Master's thesis research, '*Return to work experiences of employed women with breast cancer in Trinidad*', permission is granted for you to:

- 1) Select breast cancers patients from the National Radiotherapy Centre who fit your research criteria.
- 2) Interview participants in a room that will not disrupt the normal activities of the Centre.

I believe that your exploratory study is in an important area as younger women are being diagnosed with the disease. This research will add new knowledge that will be beneficial not only to the National Radiotherapy Centre, but can also make a valuable contribution to the field of psychosocial oncology.

I look forward to knowing the outcome of the research and will appreciate a copy of your study's results.

Kind Regards,

Dr. Peter Bovell
Medical Director
St. James Medical Complex.

Appendix H



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APPROVAL CERTIFICATE

May 9, 2011

TO: Maureen Mohammed (Advisor- Paul Newman)
Principal Investigator

FROM: Bruce Tefft, Chair *Bruce Tefft*
Psychology/Sociology Research Ethics Board (PSREB)

Re: Protocol #P2011:012
"Return to Work Experiences of Employed Women with Breast Cancer in Trinidad"

Please be advised that your above-referenced protocol, as revised, has received human ethics approval by the **Psychology/Sociology Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval has been issued based on your agreement with the change(s) to your original protocol required by the PSREB. It is the researcher's responsibility to comply with any copyright requirements. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

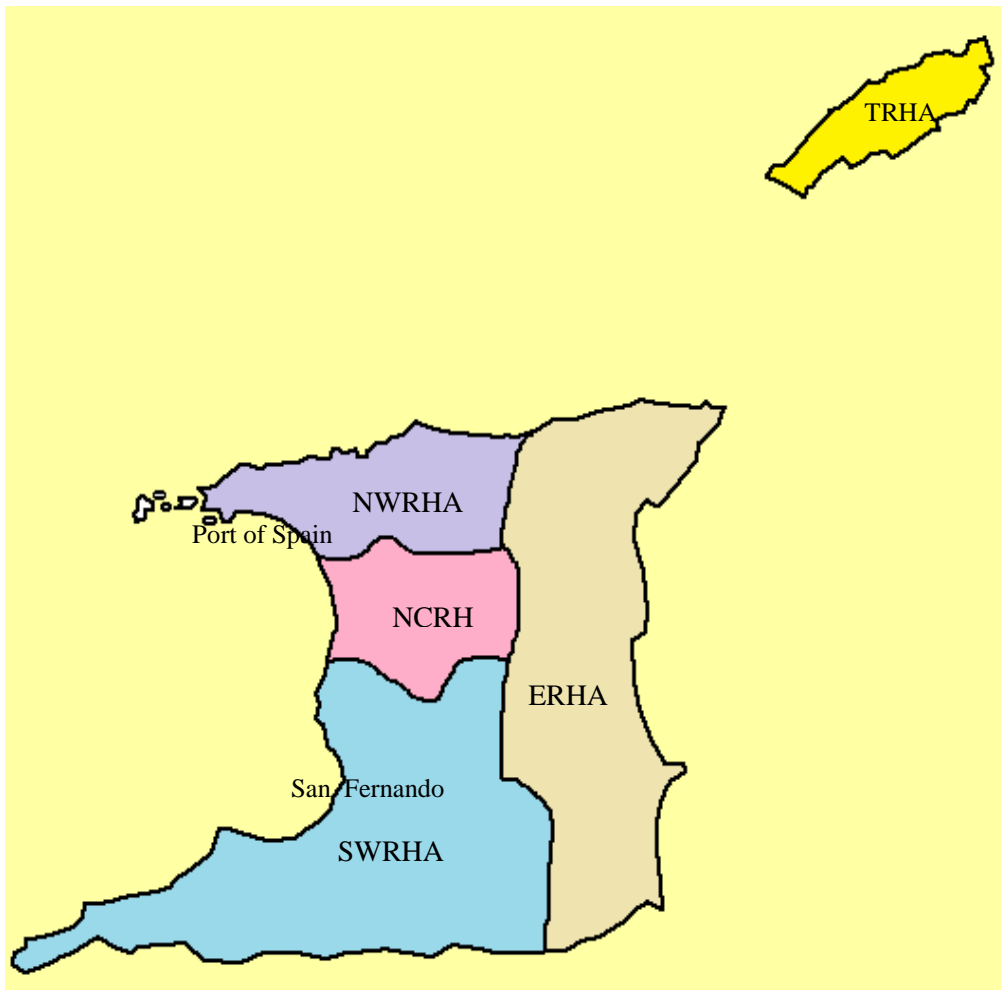
Please note:

- If you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to the Office of Research Services, fax 261-0325 - please include the name of the funding agency and your UM Project number. This must be faxed before your account can be accessed.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Appendix I

Map of Trinidad and Tobago by Regional Health Authorities



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