

CHAPTER 8

8.0 NON-COMPLIANCE IN ONCOLOGY SCREENING AND TREATMENT

8.1 Cancer Screening

Cancer Screening is an aspect of non-compliance in cancer that has inspired a great deal of research. As is well known, late diagnosis of any cancer can gravely affect the prognosis (Obermair, Hanzal, Schreiner-Frech, Buxbaum, Bancher-Todesca, Thoma, Kurz, Vaura, Gitsch and Sevelde, 1996).

Various cultural and minority groups have beliefs and distortions about cancer. Carter (1999) found that cancer misperceptions or non-scientific cancer beliefs exist within the minority populations and as a result, should be an essential part of any cancer intervention and should not be dismissed as merely folklore, as has been seen in the previous chapters.

Hill (1978) wrote that both primary and secondary prevention have great potential (when) calculated on the assumption that everyone takes the education and advice and that it is presupposed that people will respond rationally to guard against cancer once the steps they should take have been explained. However, behaviours which are rational from a public health viewpoint are not necessarily compelling from an individual point of view . He suggests that greater account should be taken of the irrational side of human nature. He talks about fear and anxiety suggesting that the fear of cancer induces some people to employ psychological

defenses that might relieve their anxiety but divert them from medical care, a crucial point in the present research.

"For some people the undiagnosed disease like the unknown sound, does not exist.

Psychologically these people begin to consider themselves 'sick' only after a formal diagnosis of illness has been made. It follows that if one can delay the formal diagnosis (and therefore the admission of illness) one can postpone or circumvent the illness itself" (people can treat themselves and delay) Oncologists are particularly concerned about the psychological games people play with themselves." (Kastenbaum and Aisenberg 1976 p.342)

People who have had personal or vicarious experience of cancer, and have seen cancer statistics in the media, often are extremely afraid of a potential diagnosis of cancer. They delay going to the doctor, even though most warning signs turn out not to be cancer, these feelings of fear lead to avoidant behaviours which can be both dangerous and foolhardy. As many people now know, a cancer diagnosed in the early stages is usually curable (Holland and Lewis 2001), which should , theoretically at least, motivate people to confirm their cancer status by screening.

However Wakefield (1972) points out that fear of cancer remains a major barrier to the earlier diagnosis and few people who have had any real experience of cancer have any doubt that earlier diagnosis leads to better treatment.

The word 'cancer' has different meanings for different people. In general it is synonymous

with fatality, either imminent or in the foreseeable future. When faced with death there is a flight into defense mechanisms such as denial and avoidance of anything to do with the threatening situation (Levy 1999).

8.1.1 Breast cancer

Breast cancer has been increasing at an alarming rate and is considered to be of epidemic proportions in the US, with current estimates indicating that approximately 270 thousand new cases of breast cancer in women will occur in 2005 and that in spite of the advances in technology to improve early diagnosis and an increased emphasis on education to promote awareness of early detection, an estimate of 40,410 women will die (American Cancer Society, 2005). . A significant number of these losses could be prevented through risk reduction measures, yet many women do not practice breast self-examination (BSE) or receive adequate clinical screening (George, 2000).

Despite impressive scientific advances that have been made in the diagnosis and treatment of breast cancer, women's regular participation in screening programs, particularly certain sub-groups of women, remains a major concern among health care professionals (Landis, 2001) .

The American Cancer Society recommends a regimen for breast cancer screening that includes mammograms, clinical breast examination, and breast self-examination (Kurtz, Given, Given and Kurtz, 1993); regular screening mammograms for asymptomatic women

being the most effective method for early detection of breast cancer (Stein, Fox, Murata, Morisky, 1992).

8.1.1.1 Breast Self Examination (BSE)

Breast self-examination (BSE) is the first preventive step in the fight against breast cancer for women. Utilization of breast self examination may mean life or death for the women most seriously at-risk. Fulmore (1999) in his study of breast self examination suggests that cognitive distortions and high anxiety levels should be addressed to reduce clinical signs of depression in populations which have a genetic predisposition to breast cancer.

Stevens, Hatcher and Bruce (1994) examined compliance with the three recommended breast self-examination (BSE) positions over a 6-month follow-up period. His results indicated that adherence to all three position types was obtained in only 40% of the exams. Forty-two percent of exams were comprised of only one position, with the supine position being the most frequently practiced exam type.

Devi and Ramaiah (1994) studied teachers' knowledge and practice of breast self examination. Their results showed that although the fear of breast cancer is common, the knowledge and practice of self examination was deficient and not regularly followed. This study accentuates the fact that rational knowledge does not translate into positive behaviours.

8.1.1.2 Mammography

Mammography guidelines recommend that women ages 50-75 years receive screening mammography every 1-2 years. (May, Kiefe, Funkhouser and Fovad, 1999) The risks of not doing this are great. McCarthy, Burns, Freund, Ash, Shwartz, Marwill, Moskowitz (2000) found that older women who were nonusers of mammography were diagnosed with breast cancer at Stage II or greater more often than regular users. Non-users of mammography were at significantly greater risk of dying from their breast cancer than regular users for all women and for women within each age group studied.

Leitch and Garvey (1994)'s studies also highlight the seriousness of neglect of mammography. They point out that mammographic screening has lowered the stage of cancers diagnosed in the screened indigent population. However, a significant percentage of patients were presenting to their hospital with stage III and IV disease. Problems identified in the screening project included non-compliance with recommendations for follow-up of abnormal studies and non-compliance with appointments.

Beaulieu, Beland, Roy, Falardeau and Hebert (1996) found that the strongest predictor of compliance was the number of previous mammograms. Other factors associated with non-compliance were the expression of fear of mammography and the lack of time to take the test . Being a smoker was also negatively associated with compliance, the fact that people who smoke tend to deny smoking is dangerous for their health, is probably a large part of this, smoking itself, being at this time, a type of non-compliance. Bryant (1996) found that, in the

above program, only two thirds of eligible women for whom screening mammography was prescribed obtained a mammogram within the 2-month study period. In other studies this would be considered an excellent result.

Kee, Talford, Donaghy and O'Doherty (1992) did a study on mammography in Northern Ireland. The most frequently cited reasons for non-attendance were related to feelings of indifference or ignorance of screening issues and to fear of pain or embarrassment. Although more non-attenders did not have access to private transport, few women expressed a preference for more accessible clinics. The fact that non-attenders were more likely not to have had a recent cervical smear, adds weight to the notion that attitudes rather than access played the predominant role in influencing uptake in this sample.

Swinker, Arbogast and Murray (1993) went into the question as to why patients decline screening mammography? They had found that physician recommendation may not be sufficient to motivate patients to comply with health maintenance activities. During a physician visit, female patients over age 50 were reminded to schedule mammography, of which more than 10% overtly refused. They found that the refusers had less knowledge of bad experiences with mammograms. Refusers were more likely not to know if their insurance covered screening, and were less likely to recall their physicians recommending screening even though recommendation was documented in the chart. Refusers were less likely to have ever had a mammogram. Haggerty, Tambly, Abrahamowicz, Beaulieu and Kishchuk (1999) found physician mammography referral to be below optimal levels.

8.1.1.3 Emotional and psychological factors

There are many psychological and emotional reasons why women refuse mammography.

Johnson, Bottorff, Balneaves, Grewal, Bhagat, Hilton and Clarke (1999) found that embedded in women's accounts of breast cancer were distinctive, often vivid and fear-provoking images of abnormal growth. Explanations about the causes of breast cancer involved 5 domains of belief. The first domain was of a physical nature and centered on damage to the breast (i.e. damage of self image and loss of femininity). A second domain of contributing explanations was feelings of contamination. This focused on the way this disease could be spread to others. Other women attributed breast cancer to the ways women could "bring it upon yourself," often linking a negative lifestyle with the development of cancer. Many women attributed cancer to being "in the hands of others," explaining the cancer was caused by careless words, curses or divine power.(external locus of control) Finally, breast cancer was seen as something that could be genetically transmitted.

Kash, Holland, Osborne and Millar (1995) found that cognitive deficits, in terms of lack of knowledge, and breast cancer misbeliefs contributed to poor adherence to breast cancer screening. Most important, anxiety or emotional distress interfered with adherence to screening. Fullerton, Kritz-Silverstein, Sadler and Barrett-Connor (1996) found that barriers to mammography usage included fear of pain, fear of radiation, and lack of perceived need.

Van den Heuvel (1978), notes that cancer has a negative image and that feelings of anxiety are provoked by the word cancer. People are often not well motivated to obtain information about cancer, and most do not like to talk about it, nor do they tend to participate in mass screening programmes. Many people would even deny symptoms for some time causing patient delay.

On the other hand, Lagerlund, Hedin, Sparen, Thurfjell and Lambe (2000) found that women who worried most about breast cancer were more likely to attend breast cancer screening than those who worried least. Women with the highest scores of perceived benefits were more likely to attend than women with the lowest ones. Other factors associated with nonattendance were less knowledge about mammography and breast cancer, lack of advice from a health professional to participate, and very poor trust in health care.

8.1.1.4 Breast cancer in the family

Most women from high risk families have witnessed early onset breast cancer in one or more close relatives (Lynch, Conway and Severin, 1994). These cancer experiences usually lead to a sense of high personal cancer risk; they can accentuate psychological problems, such as depression, anger, denial, or bewilderment, but they can also inform patients about breast cancer and motivate them to assertively seek information and treatment (Lynch et.al., 1994). Studies have shown that a majority of women with a family history of breast cancer have exaggerated perceptions of their own risk of this disease and experience excessive anxiety (Lerman, Lustbader, Rimer, Daly, Miller and Sands, 1995).

Huizinga , Visser , Bakker , Owkstra , van der Graaf and Hoekstra-Weebers (2003), studied post-traumatic stress symptoms in children of a parent with cancer. Almost one third of the children reported moderate to severe symptoms of post traumatic stress. Daughters of mothers with cancer appeared the most vulnerable. This could, unfortunately lead to avoidance of screening at a later stage.

Lindberg and Wellisch (2003) assessed women attending the High Risk Clinic for Breast Cancer for traumatic stress reactions. Results suggest that witnessing breast cancer in a close relative, and being genetically vulnerable to this disease, may be as traumatic in terms of feelings of vulnerability and fear, as having the disease.

In an earlier study, Lerman, Daly, Sands, Balshem, Lustbader, Heggan, Goldstein, James and Engstrom (1993), found that breast cancer worries may pose a barrier to mammography adherence among high-risk women, particularly those with less formal education. It seems, therefore, that a certain amount of anxiety can be a motivating factor towards breast cancer treatment but too much can produce avoidance behaviour. Diefenbach, Miller and Daly (1999) found, similarly, that moderate levels of cancer worry facilitated, rather than undermined, adherence.

A new factor has emerged in testing high-risk family members with a few emerging studies. Genetic testing for inherited forms of breast cancer is currently available to individuals who want to learn their genetic status for the BRCA1 and BRCA2 genes. Carter and Hailey (1999) point out that although still largely limited to research programs, widespread commercial

testing and incorporation of genetic testing into primary care practices will occur in the not too distant future.

Hailey, Carter and Burnett (2000) examined attitudes about and perceived risk of breast cancer and screening behavior and interest in genetic testing. Fifty-one 24 to 58 year old women volunteers with or without a first-degree relative with breast cancer and controls were compared on several measures. Results showed that, relative to the comparison group, women in the first degree relative group had more negative attitudes about breast cancer (including more anxiety about breast cancer), viewed their risk for getting breast cancer as greater (although they underestimated the actual risk), and were more likely to engage in appropriate screening behavior. A high percentage of women in both groups stated that they would want to have a genetic test for breast cancer if it were generally available.

An interesting point was brought out by Bleiker, Wigbout , Van Rens , Verhoef , Aaronson and van 't Veer (2003) who found that in the past five years about 35% of those who applied for genetic counseling for cancer did not actually undergo the counseling. This was found to be due to their inability to cope with possible unfavourable test outcomes.

8.1.1.5 Follow up of abnormal results

McCarthy, Yood, Janz, Boohaker, Ward and Johnson (1996) evaluated the factors potentially associated with inadequate follow-up of mammographic abnormalities. This is far more serious as it does not involve random screening but the follow-up of actual problems

discovered. Among the women who had the recommended immediate follow-up, they found that those who reported difficulty in obtaining medical appointments were 4 times more likely to have inadequate follow-up. Among the women with six-month follow-up recommended, those who received fewer mammograms in the past 5 years were more likely to have inadequate follow-up.

Rojas (1996), in his study of Black and Hispanic women of low socioeconomic status with abnormal screening mammograms found that the overall rate of non-compliance with follow-up was 50%. Non-compliers were less likely to state that they had been told to receive follow-up than compliers. Non-compliant subjects were less likely to have suspicious mammography interpretations, and more likely to report barriers to follow-up, such as cost of medical care and no wages, system barriers, or fears, than compliant subjects. He suggests improved communication of results.

8.1.1.6 Interventions for breast cancer screening

Various interventions have been tried with some encouraging but mostly disappointing results. Women avoid screening for various reasons as discussed above and perhaps screening for cancer is seen as visiting a potentially dangerous place where a person's life can be changed forever. As long as the diagnosis does not exist, the illness does not exist, as it were. Other interventions are necessary to encourage screening behaviour (Kastenbaum and Aisenberg, 1976).

Lagerlund et.al. (2000) feel that knowledge of the reasons why people do not participate and comparing them with those of participants in screening for cancer may tell us how best to inform the public.

8.1.1.6.1 Suggested interventions

Andersen, Urban and Etzioni (1999)'s study revealed community of residence to be a significant predictor of individual women's mammography use. Andersen, Yasui, Meischke, Kuniyuki, Etzioni and Urban (2000) discuss the Community Trial of Mammography Promotion which assessed the effectiveness of mammography promotion by community volunteer groups in rural areas. Three interventions were tested. One used an individual counseling strategy and one used a community activities strategy, and a third combined the two strategies. Lauver & Kane (1999) suggest that not only should clinicians offer motivational messages about mammography, but also administrators should address external barriers to maximize mammography among socio-economically disadvantaged groups.

Moorman, Newman, Millkan Tse and Sandler's (1999) report describes factors associated with nonparticipation in a population-based, case-control study of breast cancer and discusses ways to overcome barriers to participation. They found that obstacles to recruitment seemed to differ among race and age subgroups, suggesting that recruitment strategies may need to be tailored to potential participants based upon demographic characteristics.

Sadler, Dong, Ko, Luu and Nguyen (2001), give an insightful and original and very practical

suggestion. With the assistance of key informants, evaluated the social patterns of Asian American women for places where health education interventions might be offered. They came up with the original idea that Asian grocery stores appeared to offer a valuable site for a community-based health education program. They suggest that the best interventions will address the specific needs, culture, and characteristics of the subpopulations within the larger Asian community.

8.1.1.6.2 Practical interventions

By sending a letter of notification when women are not up-to-date on their screening mammography, Maurer (1995) was able to increase the mammography compliance rate from 47% to 72%. This system is designed to supplement the preferred method of recommendations by the primary care physician aided perhaps by a chart reminder system.

Lantz, Stencil, Lippert, Beversdorf, Jaros and Remington (1995) conducted a randomized trial to evaluate the combined impact of a physician reminder letter and a telephone contact on the use of Pap tests and mammograms in a low-income managed care program. Medical claims were reviewed after 6 months to determine intervention effectiveness. The odds of receiving all needed cancer screening tests during follow-up were four times higher in the intervention group. However, women who reported having to take time off from work to see a doctor had lower odds of getting screened. Their results were excellent but from the last statement it appears they were subject to the order which the woman found important (i.e. having to continue working and not jeopardizing the job, a strong factor in a country such as in South

Africa).

Bell, Branston, Newcombe and Barton's (1999) findings showed that translated literature, a GP endorsement letter and language support by link-workers were beneficial. Contrary to what might be expected, the provision of free transport was ineffective and under-utilized. In a similar way Kee et.al., (1992) concluded that investment in flexible mobile screening units could not replace the continued need for delivering effective advocacy to eligible women.

To increase mammography participation, Ludman, Curry, Meyer and Taplin (1999) implemented an outreach intervention translating concepts from expectancy value theory into a motivational interviewing telephone intervention that included the opportunity to schedule a screening appointment. They found that women with prior mammography were more likely to be receptive and to schedule a screening appointment during the calls than were women with no prior experience. In other words, reluctance to go for mammography was on a different level to that addressed.

8.1.1.6.3 Educational and informative interventions

Van den Heuvel (1978), stresses the importance of information and health education motivating most people to participate. There are many educational and informative interventions that have been suggested and used (Schofield, Cockburn, Hill and Reading (1994) found that a personal invitation, a community promotion campaign, informing women of the benefits of early detection and improving access to the screening centre improved

attendance at a screening mammography centre.

ENCOREplus is a health promotion program that provides outreach, education, referral, and other service that facilitate breast and cervical cancer screening for medically underserved women (where?). Fernandez, DeBor, Candreia, Wagner and Stewart (1999) assessed the effectiveness of ENCOREplus in promoting mammography and Pap test screening among women who were non-adherent to screening guidelines, demonstrating that programs implemented through community-based organizations can be successful in increasing mammography and Pap test screening among low-income and minority women.

Brenes (1999) examined the effect of two theoretically based interventions on mammography compliance. In this very interesting study, 73 women watched a video that emphasized the benefits of getting a mammogram and 69 women watched a video that emphasized the risks of not getting a mammogram. He found, contrary to expectation, that the women in the two groups were equally likely to get a mammogram. However perceptions of risk of developing breast cancer if non-compliant were higher in women who viewed the loss-framed message.

An interesting result comes from Schwartz, Lerman and Rimer (2001) who found that standard breast cancer risk counseling could in fact have an adverse impact on the health behaviors of less educated women.

Aiken, West, Woodward and Reno, (1994) worked with two theory-based programs to increase mammography screening rates among asymptomatic women, which were

implemented and evaluated in the community. One program was based on the Health Belief Model (HBM); the second program added exercises adapted from the social psychology of compliance. Program impact on screening was evaluated against an untreated control group over a 6-month period. Programs based on the health belief model as well as the program with additional exercise. Both programs were better than controls and no difference between the two experimental programs were noted.

8.1.1.6.4 Psychological ways of improving compliance

A significant study was done by Kash et. al., (1995), who developed ways for improving screening behaviour. In developing psychological counseling strategies for high-risk women, they focused on the treatment outcomes of reducing emotional distress, decreasing perceived vulnerability, and improving adherence to screening behaviors. They conducted a preliminary study by piloting a group psycho-educational intervention for 6 consecutive weeks. This intervention was found to significantly reduce perception of risk and to increase adherence to screening behaviors .

Champion (1992) used the health belief model to identify potential variables related to intention or compliance with mammography guidelines. Intent to complete mammography was related to having a family history of breast cancer, perceived barriers to mammography, and perceived control over breast cancer. Compliance with mammography was influenced by general health motivation and perceived susceptibility to and seriousness of breast cancer, benefits, and control over breast cancer. In addition, knowledge about breast cancer and

breast cancer detection, age, having a health care provider suggest mammography, having symptoms of breast cancer and socioeconomic status were significantly related to actual compliance with mammography.

A further study by Champion (1994) found that for women 50 years and older, compliance in the year prior to the study was significantly predicted with logistic regression. What was found to be important was believing that breast cancer was serious, having had mammography suggested by a health professional, having had regular check-ups, having higher education and higher socio-economic status, and having heard recently about mammography.

A significant study was done by Champion and Huster (1995) on a probability sample of 405 women ages 40-88 years, without a prior history of breast cancer, which was randomly assigned to groups. Subjects in the intervention group received individually tailored messages to alter beliefs or provider information related to mammography screening. Women in the combined belief/information group were over two times more likely to have been compliant with mammography 1 year post-intervention than those in the control group. In addition, groups who received the belief intervention had significantly more women that went from a lower to a higher stage of mammography adoption.

8.1.1.7 Quality of the physician-patient relationship

The importance of the physician and his/her interest in having his/her patients screened for breast cancer cannot be underestimated. Friedman, Woodruff, Lane, Weinberg, Cooper and

Webb (1995) and May et. al., (1999) found that perceived barriers to and physician recommendation of mammography were the strongest predictors of both breast cancer screening behaviors and intentions. Their results suggest that physicians play a key role in motivating women to comply with breast cancer screening.

Schapira, Pamies, Kumar, Herald, Van Durme, Woodward and Roetzheim (1993) found that when physicians recommended cancer screening tests, the compliance among patients was relatively high. They concluded that primary care physicians could take the opportunity to recommend cancer screening tests during routine patient visits, and this strategy may well increase cancer screening rates in the population. They have an important role to play in recommending breast cancer screening to patients in the target age group (Bryant 1996).

Roberts and Birch, (2001) and Sharp, Peters, Bartholomew and Shaw (1996) concluded that the most important determinant of using preventative screening is the relationship between patients and their healthcare provider.

8.1.1.8 Input of other health workers

An interesting result was found by Crump, Mayberry, Taylor, Barefield and Thomas (2000) who found that low-income African-American women referred for mammography by a physician's assistant or nurse practitioner were less likely to miss their appointments than women referred by a physician. Embarrassment, lack of breast symptoms, and forgetfulness also contributed to non-compliance. Therefore not only the physician but other members of the team can be extremely important. This is important in the South African context where

patients attending primary health care clinics may not see general practitioners but primary health nurses instead.

Margolis, Lurie, McGovern, Tyrrell and Slater (1998) found that breast and cervical cancer screening rates were improved in women attending non-primary-care outpatient clinics by using lay health advisers and a nurse practitioner to perform screening. The effect was strongest in women in greatest need of screening.

8.1.2 Testicular cancer

Testicular self examination (TSE) is recommended for the early detection of testicular cancer. However, as Wardle, Steptoe, Burckhardt, Vogele, Vila and Zarczynski (1994) evidence from North America suggests, there is only limited public awareness of its importance among the young male population. They studied attitudes toward and practice of testicular self examination outside North America. Attitudes to testicular self examination were evaluated by questionnaire in a sample of 16,486 students. Frequency of testicular self examination practice was reported by the 7,304 men in the sample. Eighty-seven percent of men reported never having practiced testicular self examination. Regular practice (monthly) was reported by only 3% of the sample, with another 10% reporting occasional testicular self examination. Significant differences emerged between countries, ranging from 76% of German men to 98% of Icelandic men reporting no testicular self examination. Wardle et. al. (1994) comment that if a highly educated population group in the increased risk age category is not carrying out the recommendations, it is unlikely that there are higher levels of compliance in other age groups.

They suggest that these results indicate an important role for health education in the early detection of testicular cancer.

A similar study was done by Barling and Lehmann (1999), who surveyed 101 male Australian university students, aged 18-25 years to assess their testicular self-examination practices and knowledge of testicular cancer. Results showed that the majority of men were uninformed or misinformed about testicular cancer and testicular self-examination. Eighty-three per cent of respondents did not perform testicular self-examination once per month as recommended.

Finney, Weist and Friman (1995) evaluated the effects of two health education teaching methods, a pamphlet based on a task-analyzed checklist and two professionally developed films, on the completeness, accuracy, and maintenance of testicular self-examinations (TSE). Subjects (N = 48) were videotaped while performing a testicular self examination after training and at a follow-up visit. Direct observation of the tapes showed that checklist-based training resulted in more complete and longer TSEs . However, adherence to testicular self examination recommendations was high during the study, but declined across the follow-up period. They felt that further study is needed to promote adherence to testicular self examination and to document the effects of early detection on morbidity and mortality of testicular cancer. It seems that the men involved were alarmed and motivated by the initial flood of information but as soon as the direct motivating stimulus had been removed they discontinued testicular self examination, and adopted an avoidance approach.

8.1.3 Prostate cancer

Weinrich, Ellison, Boyd, Hudson, Bradford and Weinrich (2000) points out that lower-income men are less likely to participate in prostate cancer screening and more likely to be diagnosed with advanced stages of prostate cancer which leads to poorer prognosis.

O'Dell, Volk, Cass and Spann (1999) found that aside from college graduates, most patients could not identify the principal advantages and disadvantages of prostate-specific antigen (PSA) testing for prostate cancer.

However Schapira and Van Ruiswyk (2000) found that when used in a primary care setting, an illustrated pamphlet decision-aid was effective in increasing knowledge of prostate cancer screening tests but did not, in fact, change the use of these tests (Volk and Spann, 2000)

In contrast, Varenhorst, Carlsson, Capik, Lofman and Pederson (1992) had good results. They worked with repeated screening for carcinoma of the prostate by digital rectal examination in a randomly selected population. Of the selected persons, 78% accepted the invitation to the first screening round and 70% to the second one. They conclude that screening for carcinoma of the prostate by digital rectal examination can be organised with a high population acceptance, and at a reasonable cost.

8.1.4 Colorectal cancer

Screening to detect and prevent colorectal cancer (CRC) is well below optimal, contributing to needless CRC-related morbidity and mortality (Weitzman, Zapka, Estabrook and Valentine-Gains 2001). Beeker, Kraft, Southwell and Jorgensen (2000) and Thomas, Whit, Mah and Geisser's (1995) findings suggest that public education campaigns, decision aids, and targeted interventions are urgently needed to increase compliance.

In Olynyk, Aquilia, Fletcher and Dickinson's (1996) study of flexible sigmoidoscopy screening for colorectal cancer in average-risk subjects, a community-based pilot project, subject compliance emerged as a major issue, common reasons for non-attendance being a lack of interest or a lack of time, mainly due to work commitments. On a scale of important commitments it reverts to a place of lower priority. McCarthy & Moskowitz (1993) did a similar study with the same findings.

Powe (1995) saw the goal of increasing participation in fecal occult blood testing (FOBT) for elderly African Americans as a national priority. He saw fatalism (i.e. in this context, the belief that death is inevitable when cancer is present) as a barrier to colorectal cancer screening among this group. Using his own fatalism model he found that these people were significantly more fatalistic than elderly white participants and less likely to participate in FOBT. Not only was fatalism a significant predictor of FOBT, but it remained the only significant predictor of FOBT. Furthermore it remained the only significant predictor even when factors such as age, poverty, and education were controlled.

Hart, Wicks & Mayberry (1995) in their study of colorectal cancer screening in asymptomatic populations, found that there were many reasons for non-compliance including lack of appreciation of the concept of asymptomatic illness and fear of the screening tests and cancer itself. This is in spite of the fact that colorectal cancer screening is relatively cheap compared with breast and cervical cancer screening.

In screening for colorectal cancer with an immunological faecal occult blood test, Robinson, Bush, von Korff, Katon, Lin, Simon and Wlaker (1996) found that compliance for testing over one day was significantly better than that over three days. Myers, Bralow, Goldstein, Jacobs, Wolf and Engstrom (1993) conducted a study in order to assess prospective adherence to surveillance colonoscopy and fecal occult blood testing (FOBT) at 1 year following treatment for an index lesion among colorectal cancer and polyp patients. Their findings indicated that adherence to surveillance, even in this high risk group, was low, and that for both men and women, adherence was influenced strongly by the extent to which the behavior was judged to make sense in everyday life.

8.1.5 Pap smear

Research indicates that up to 60% of college women may be infected with human papillomavirus (HPV), a sexually transmitted disease (STD) attributed to be the primary cause of cervical cancer. The Pap smear is the currently accepted means to detect cervical cancer. However, the clinical compliance literature indicates that many women do not adhere to recommended guidelines for regular screenings, nor are they aware of the risk factors for

cervical cancer. Harris' (2001) study indicates that in pap smear behaviours, women operate under socially constructed paradigms as much as cognitive-based decision models.

As with other screening programmes, Fernandez et. al. (1999) pointed out that minority women and women with low income levels are significantly less likely to practice appropriate mammography and Pap test screening.

Winkler, Anderson, Fields, Runowicz, De Victoria and Goldberg (1999) did a retrospective review of 262 women with cervical cancer. Of the 166 patients studied, 61 (36.7%) did not have a Pap test within 3 years.

Wilson and Fazey (1995) found that fear, worry, and embarrassment were negatively correlated with the decision to have a cervical smear test. Respondents seemed to have higher self-esteem and better relationships with their husbands than non-respondents.

Lee, Parsons & Gentleman (1998) found that one in four women aged 18 to 69 had either never had a Pap test or had not had one in three years. Notably, older women who are at the greatest risk for cervical cancer are less compliant with screening guidelines than younger women.

Hancock, Sanson-Fisher, Perkins, Corkrey, Burton and Reid's (2001) results indicated that a community action program can positively impact cervical cancer screening in rural Australian towns; as did Lanier, Kelly and Holck (1999) in Alaska. Margolis et. al. (1998) found that

breast and cervical cancer screening rates were improved in women attending non-primary-care outpatient clinics by using lay health advisers and a nurse practitioner to perform screening.

8.1.5.1 Compliance with further screening for an abnormal pap smear

Another more serious factor is the follow up visit after the Pap smear where abnormal or even potentially malignant results have been found. Lester & Wilson (1999) reported that many women referred to outpatient colposcopy clinics fail to attend for their appointments. Yabroff, Kerner and Mandelblatt (2000) performed a qualitative meta-analysis of interventions designed to improve follow-up after an abnormal Pap smear. Cognitive interventions utilizing interactive telephone counseling were the most effective, improving compliance by 24-31%. Behavioral interventions, such as patient reminders, were also effective, increasing follow-up by up to 18%.

Kavanagh and Simpson (1996) did a retrospective cohort study of women who were recommended for further assessment or treatment after their first visit to a gynaecologist for an abnormal Pap smear. After adjusting for age and the degree of abnormality on presenting smear, women without private health insurance and women who had had treatment were less likely to continue attending, a strong economic factor involved here.

McKee, Luna, Marantz, Burton and Mulvihill (1999) in his study of factors predictive of failure to return for colposcopy among women with significant abnormalities on Pap smears in

a high-risk clinical population concluded that effective communication of results is the most important factor related to follow-up.

Women have to be shown the importance of making this a priority as on their list of tasks.

Stewart, Buchegger, Lickrish and Sierra,(1994), found that women with abnormal Papanicolaou smears who received educational brochures at the initial booking for colposcopy had more completed treatment and follow-up compliance (75.4%) than did those who did not receive the brochure (45.8%). Paskett, Phillips & Miller (1995) found that a motivational brochure could enhance adherence to treatment recommendations among women with abnormal Pap smears.

In these cases it is important to gauge the level of traumatic stress and avoidant behaviour the potential diagnosis evoked.

Funke and Nicholson (1993) explored the relationship between health beliefs, health locus of control and diagnosis with Human papillomavirus and compliance with medical recommendations for an abnormal Pap test, using a survey in a sample 272 women. Two items from the health belief scale were statistically significant. Women who agree with the statement, "The uncertainty about my Pap test makes me nervous," were four times as likely to comply with the medical recommendations as compared to women who disagreed with the statement. Women who agreed with the statement, "I have not been able to cope with my abnormal pap test," were three times as likely to not comply with the recommendations as compared to women who disagreed.

Lacey, Witfield, De White, Ansell, Whitman, Chen and Phillips' (1993) report describes adherence to follow-up appointments for suspected breast and cervical malignancies in a population of low-income black women who participated in a highly successful community-based nurse-managed screening program. Components of the program that were part of the intervention included the following: a consistent referral mechanism augmented by a computerized tickler system; education of women about the importance of follow-up; and active nurse assistance in the follow-up process.

As medicine advances and vaccination is on the horizon, Hoover, Carfioli and Moench (2000) evaluated knowledge of human papillomavirus (HPV), attitudes toward HPV vaccination, and willingness to participate in a clinical trial of an HPV vaccine. 60 adolescent and young adult females, (aged 15-28 yrs) completed questionnaires. Results show that subjects displayed limited knowledge of HPV. However, almost all subjects expressed interest in receiving vaccines that prevented cervical cancer and genital warts. It has yet to be seen how compliant they will be.

8.1.6 Other cancers

Campion, Woods and Lemieux (1998) worked with compliance in a screening program for neuroblastoma. The strategies employed to optimize compliance consisted of increasing the awareness of the parents, health professionals, and the public about neuroblastoma and the screening program. The population responded well to this public health measure, with a 91% compliance rate at 3 weeks and a 74% compliance rate at 6 months.

Talamini, Barzan, Franceschi, Caruso, Gasparin and Comoretto (1994) studied an early detection programme for cancer of the head and neck which was conducted in north-eastern Italy, in an area with very high mortality rates for cancers in those sites. An educational message was given to 627 high risk individuals on the health hazards of tobacco and alcohol abuse was delivered together with an invitation to undergo a free ear, nose and throat (ENT) examination at a nearby hospital. Two hundred and twelve individuals (34%) underwent the ENT visit. Female sex and absence of ENT symptoms were associated with a more than two-fold higher lack of compliance. Current smokers, a high risk group, were more than three-fold less likely to accept the invitation to undergo the examination, possibly in fear that they will have to change their smoking habits.

The objective of Pavlik, van Nagell, De Priest, Wheeler, Tatonan, Boone, Sollars, Rayens and Kryscio's (1995) study was to identify factors influencing participation in screening for ovarian cancer using trans-vaginal sonography in a free experimental program. Distance and education correlated with participation. Franco, Belinson, Casey, Plummer, Tamburrino and Tung (2000) explored psychological distress and adherence to health care recommendations among 83 women (aged 24-73 yrs) who perceived themselves to be at risk for ovarian cancer. Interestingly, those who had the highest scores on the Death Anxiety Scale were less likely to comply with the recommendation for a physical/gynaecological examination. This would strengthen the conclusions of this present study that previous experience of medical trauma of fear of death could influence compliance negatively.

"There is an ongoing need for evaluating the effectiveness of skin cancer screening programs

and barriers to obtaining definitive diagnoses and treatments among screen-positive patients."

(Jonna et. al., 1998) Their study confirms the ability of skin cancer screening programs to successfully identify individuals with cutaneous malignancies. They found that patients without a family history of skin cancer were less compliant than those with a history and patients with only one presumptive skin cancer lesion were less compliant than those with additional cancer lesions. Older patients were more compliant than younger. Among 82 patients under 65 years of age, the above factors were important only among men. Also, non-compliance was significantly higher among younger men without health insurance.

8.1.6 Personal and circumstantial barriers to compliance in the health professional

Not all doctors are aware of the importance of their encouragement to their patients in various aspects of cancer screening.

Bekker, Morrison and Marteau (1999) found that 37% of general practitioners they studied reported that their practice has a policy of following-up non-attendees for screening and differed from those who did not in 3 ways: a greater perception of the threat of breast cancer; a greater belief in the importance of general practitioners' role in increasing attendance of women for breast cancer screening; and a less-negative attitude towards breast cancer screening. They suggest that women's attendance for breast cancer screening may be increased by raising ' perceptions of the threat of breast cancer, addressing their concerns about breast cancer screening, and enhancing their views of the importance of the general practitioners' role of primary care in a national screening program.

As was found with other cancers, it is not only the patients who do not comply with screening: Warnakulasuriya and Johnson (1999) studied dentists and oral cancer prevention in the UK: opinions, attitudes and practices to screening for mucosal lesions and to counselling patients on tobacco and alcohol use: baseline data from 1991. The questionnaire was circulated to 15,836 dentists. The response rate of 16% was poor. Disturbingly, it was found that half of the respondents did not enquire about risk habits related to oral cancer and, among the other half who claimed to make such enquiries, and that only 30% routinely provided brief health education advice concerning these.

Wender (1995) discusses barriers to effective skin cancer detection, finding that the major barrier is that skin examination is a low priority for most providers. An additional problem is that the infrequent occurrence of an early melanoma presenting in any one physician's office leads to a lack of positive reward from skin exams as well as deterioration of a provider's skill in correctly identifying lesions.

Austin , Baron and Gates (1993) compared women not complying with the American Cancer Society (ACS) guidelines for pap smears and mammography, with women complying with the guidelines. Non-compliers were found to be twice as likely to be non-white, much more frequently lacked a regular physician or a gynecologist, more commonly lacked insurance paying at least in part for the test, and more frequently reported that physicians visited did not suggest pap smear or mammographic screening. It was also found that almost one-third of 75 responding physicians acknowledged not discussing pap smear and mammographic screening with their patients, a practice most often attributed to "specialization."

8.2 Non-compliance in Oncology Treatment

This present study deals specifically with non-compliance in relation to cancer patients, especially cancer patients with a good prognosis where non-compliance can make the difference between life and death. Though there is some very solid research in this direction, especially in relation to adolescents, it is minimal when compared to the extent and seriousness of the problem.

“Modern medical diagnosis and treatment have made an enormous difference in our ability to survive certain cancers, notably those of the blood and lymphatic systems (lymphomas and leukemias, especially Hodgkin's disease), testicular cancer, and certain childhood cancers, many of which can now be cured. Early detection and vigorous treatment of other more common cancers, such as colon and breast are extending survival time and in a smaller number of cases leading to a cure. While the outlook is less optimistic with such cancers as those of the lungs and pancreas, treatment controls symptoms and may prolong life. What this means is that more people are living with cancer rather than just dying of it. Medically cancer was once thought of as a terminal illness, it is now thought of as a chronic illness, similar to diabetes, arthritis, or heart disease” (Speigel, 1993 p. 46).

"It has been concluded that, in cancer patients, adjuvant radiotherapy and chemotherapy improve survival rates, enhance the quality of life, and reduce the rate of recurrence. In spite of this, many patients refuse or fail to complete treatment" (Simmons and Lindsay, 2001 pg. 355). Although non-compliance has long been recognised in medicine, few studies have

examined this in cancer.

Despite medical advances in cancer treatment, not only do oncology patients 'avoid' screening tests, they also tend in fairly large numbers not to comply with treatment such as chemotherapy (Lebovitis, Strain, Schleifer, Tanaka, Bhardwaj and Messe ,1990)

8.2.1 The extent of the problem

Oncologists have become increasingly aware that their treatment has to take into account the ability (or seeming inability) of the patient to comply to the fullest extent.

Apart from the large body of research done on cancer screening, non compliance studies in oncology came fairly late because though it was recognised in other diseases. It was not considered a possibility in an illness as serious as cancer-. However it is becoming well recognised in this field, even with childhood cancer where the onus for treatment is largely on the parents (Tebbi, 1993; Lansky, Smith, Cairns and Cairns Jr, 1983).

There is significant noncompliance with self-administered medication, especially in chronic conditions such as cancer, obviously, often with devastating results (Gillespie, 1999; Tebbi 1993).

"Although it would empirically seem that compliance in cancer patients would be greater than that of patients with benign disease because cancer is perceived as life-threatening and

because of the necessity for administration of most treatments by skilled personnel, a review of the literature does not support this assumption. Reported non-compliance rates for cancer therapies range from 19% to 50%. Only recently has compliance with cancer treatment regimens and its possible impact on treatment failure been examined." (Berger, Braverman, Sohn, and Morrow, 1988, p. 1455)

"Despite agreement that compliance is an important factor in the outcome of therapy, little is known about treatment compliance by cancer patients, particularly for paediatrics and adolescent patients." (Tebbi, Cummings, Zevon, Smith and Richards , 1986, p. 1184). Tebbi et. al.'s (1986) results indicated that overall, serious and occasional medication non-compliance is found in approximately one-third of children and adolescents with cancer, with greater non-compliance occurring at 20 weeks post-diagnosis

Lebovits et.al. (1990) found that 43% of patients in his study who were receiving self administered cancer chemotherapy, met criteria for non compliance according to both behavioral and dosage definitions.

Neergaard (2004) cites the research on breast cancer of Dr Gary Lyman of the University of Rochester Medical Centre. He received medical records from more than 20,000 breast cancer patients who underwent post-surgery chemotherapy. Lyman found that more than half received less than 85% of the recommended dose intensity that is considered the minimum for optimal treatment.

8.2.1.1 Specific cancers

Urquhart (1996) studied patient compliance with crucial drug regimens in patients with prostate cancer. He pointed out that understanding of patient compliance with these drug regimens had improved markedly since 1986, because of more objective methods for monitoring drug dosing which remove the camouflage that masks many poor compliers. The older methods allowed patients easily to censor evidence for delayed or omitted doses. The new methods showed many more and larger errors of omission in both trials and practice than previously believed. He found that one patient in six was punctually compliant. A modest majority of patients made errors probably too small to affect or modify the actions of all but the most unforgiving medicines. A third of patients delayed or omitted many prescribed doses, thus attenuating or otherwise modifying the actions of the majority of drugs. One patient in six took too little medicine, though he/she was often camouflaged as a good complier

Colls, Harvey, Skelton, Frampton, Thompson, Bennett, Perez, Dady, Forgeson, and Kennedy (1999) did a retractive study of treatment for nonseminoma germ cell testicular tumour. They found poor compliance with surveillance in 12% of patients. Hao, Seidel, Brant, Alexander, Ernst, Summers, Russell and Stewart (1998) evaluated compliance and its effect on the outcome of 76 patients with clinical stage I nonseminomatous germ cell tumour who underwent post-orchietomy surveillance. The surveillance protocol consisted of clinical evaluation, chest x-ray and serum tumour marker measurements monthly in year 1, every 2 months in year 2, every 6 months in years 3 to 5 and yearly in years 6 to 10. Abdomen and pelvic computerized tomography (CT) were scheduled every 2 months in year 1 and every 4

months in year 2. Noncompliance was defined as missing 2 or more consecutive clinic visits, tumour marker measurements or chest x-rays or 1 or more CT scans. Compliance with clinical evaluations was 61.5% in year 1 and 35.5% in year 2, whereas compliance with CT was only 25% and 11.8% in years 1 and 2, respectively.

Howard et. al. (1995) wrote about an unacceptable rate of default in terms of a Scottish national audit of current patterns of management for patients with testicular non-seminomatous germ-cell tumours. Three per cent of patients had a biopsy of the contralateral testis and 27% of patients defaulted from clinic attendance. Fossa, Jacobsen, Aass, Heilo, Stenwig, Kummen, Johannessen, Waaler, OGREID and Borge (1994), however, found that patient with clinical stage 1 non-seminomatous testicular cancer surveillance, non-compliance did not represent a major problem, whereas the regular and adequate performance of necessary CT examinations yielded some administrative difficulties.

Graupe, Schwenk, Bracht, Kroner-Herwig and Stock (1996) in a prospective study, asked 70 patients after curative resection for colorectal carcinoma about the psychological strain in the follow-up program. Of these patients, 80.1% felt that they did the right thing and 70% were optimistic and confident regarding the follow-up examinations. Only 5 patients (7.1%) had no intention of keeping the follow-up appointment and 12 patients (17.1%) were thinking about recurrence. However patient's intentions are not always carried out. Myers et. al.(1993) assessed surveillance for colorectal neoplasia to see if patient adherence following treatment was, in fact, a problem? This study was conducted in order to assess prospective adherence to surveillance colonoscopy and faecal occult blood testing (FOBT) at 1 year following treatment

for an index lesion among colorectal cancer and polyp patients. Their findings indicated that adherence to surveillance was low.

In head and neck radiation therapy and patient/dentist compliance with recommended dental care. Cacchillo, Barker and Barker (1994) reported a compliance rate of approximately 50%

It is clear from the above studies that non compliance in oncology treatment is a serious and prolific difficulty, undermining progress in good prognostic candidates.

8.2.2 Forms of non-compliance

Hyland, Travis and Pruyser, (1983) described the obstacles to compliance with treatment among cancer patients receiving radiotherapy. Some forms that failure to comply might take included delay in seeking treatment, refusal of treatment recommendations, premature termination of treatment, and loss to follow-up after treatment.

Tebbi (1993) also gives some of the several ways in which non-compliance can be manifested, i.e. failure to fill the prescription, failure to take the prescribed medication, failure to administer the medication with correct frequency and timing, and failure to take correct doses.

Patients can comply or not comply in areas other than for direct cancer treatment. For example, de Wit, van Dam, Hanneman, Zamdbelt, van Buuren, van der Heijden, Leenhouts, Loonstra and Abu-Saad.(1999) evaluated the use of a pain diary in chronic cancer pain

patients at home. They found, with this that patients' compliance was high (86%), even in seriously ill patients.

Potential compliance at times dictates treatment options. Xiao, Sheinfeld and Motzer (1997) explain that two treatment options cure nearly all patients with pathologic stage II testicular nonseminomatous germ cell tumour following a retroperitoneal lymph node dissection. These are (1) two cycles of adjuvant etoposide plus cisplatin (with or without bleomycin) chemotherapy and (2) close surveillance with chemotherapy reserved for relapse. The decision to choose one of these options is dependent on the extent of tumour involvement at surgery and patient compliance (which obviously as to be assessed at this point).

8.2.2.1 Long term follow up

For many patients, the surveillance period is very long.

Sternberg (1998) in discussing the management of stage I testis cancer, finds the main disadvantage to management happens to be the need for long-term follow-up, which is expensive and stressful to the patient. Good patient compliance, mandatory to an observation policy, is often difficult on a long-term basis.

Toma, Palumbo and Rosso (1994) point out that since chemo-preventive treatments in head and neck cancer must be of very long-term duration (even years), and because of apparent 'good health' of treated patients, compliance with treatment needs to be carefully considered.

They stress the vital importance of compliance.

8.2.3 Predictors and reasons for non-compliance

Hill (1978) wrote that both primary and secondary prevention have great potential, calculated on the assumption that everyone takes the education and advice. It is presupposed that people will respond rationally, to guard against cancer once the steps they should take have been explained. However, behaviours which are rational from a public health viewpoint are not necessarily compelling from an individual's . Irrational psychological forces often compete to divert people away from cancer education.” He suggests that greater account should be taken of the irrational side of human nature. He talks about fear and anxiety suggesting that the fear of cancer induces some people to employ psychological -defenses that might relieve their anxiety but divert them from medical care.

The word 'cancer' sends a chill up the spine. It is life threatening and value devastating. Until recent years it ran relentless and unhindered through the bodies of men, women and children. (Vaux 1977) The 'aura of mystery combined with a not too infrequent equation that cancer means death hits at a malevolence , threatening not only the patient but the bystander as well. There is a common myth that even when the cancer has been successfully treated, he (the patient) is still seen as a burden for his fellows, avoided and unclean. (Cohen, Cullin and Martin, 1982)

In the words of Winkler, et. al. (1999, p. 380): "The patient who suspects breast cancer is

handicapped by her social network to the degree that the patient who suspects cardiac disorder is not. The suspected breast cancer patient's friends will tell her not to be silly, not to worry, that there is nothing wrong with her, while the man with chest pains will be encouraged to see his doctor at once."

One of the many misconceptions and distortions which people had, and still have, about cancer is that it is all one illness with a uniform grave prognosis. Goldberg and Tull (1982) point out how important it is for the doctor to enquire into the family and social 'myths' that the patient has about cancer. They cite an example of a patient with a highly curable form of Hodgkins Disease who was refusing adamantly to have any treatment, until it was discovered that he thought his disease was the same as a highly invasive and malignant cancer that had led to radical head and neck surgery in one of his business associates.

Explanatory prospectives regarding compliance often center on the patient's health beliefs, relation with health practitioner, and factors involving medication regimens and cost. Despite a broad spectrum of coverage, like most generalizations, this falls short of encompassing all cases of noncompliance (Tebbi, 1993).

Wakefield (1978) explains that fear of cancer and of cancer diagnosis remains a major barrier to earlier diagnosis and few people who have had any real experience of cancer have any doubt that earlier diagnosis leads to better treatment.

Modern cancer treatments can cure or prolong patients' lives. However, the associated

physical and psychosocial problems can detrimentally affect patients' compliance with treatment and, ultimately, their outcomes. Therefore, oncologists need to recognize the problems experienced by their patients and, when possible, help resolve these problems. Newell et.al., Sanson-Fisher, Girgis and Bonaventura (1998) found that medical oncologists' perceptions may not always accurately reflect their patients' reported physical and psychosocial experiences.

Simmons and Lindsay (2001) did a study examining the characteristics of 158 patients with breast cancer or other cancers, chosen for post-surgical treatment. They completed questionnaires, 32% then failed to complete treatment. The breast cancer patients and patients referred to the local hospital were more likely to complete treatment. Thus, uptake of treatment may be favoured by accessibility and familiarity of its source and by the unique impact in women of breast cancer and the wider public attention given to that illness.

Jacobs, Casiano, Schuller, Pajak, Laramore and al-Sarraf (1994) found that a person who complies with one kind of treatment will usually comply with another. In their research they concluded that compliance with a multi-course adjuvant chemotherapy regimen is predictive of subsequent compliance to radiotherapy in the head and neck cancer population.

8.2.3.1 Side effects

Treatment-related complications, those associated particularly with chemotherapy, have been found to have a negative impact on compliance (Berger, et. al., 1988). Itano, Tanabe and

Lum (1983) noted that patients experiencing severe side effects from chemotherapy have a lower rate of compliance with treatment.

Kaisary (1996) studied compliance with hormonal treatment for prostate cancer. He suggested that, in selecting appropriate therapy, drug-related factors which might influence compliance need to be considered.

8.2.3.2 Psychological reasons for non compliance

Palmer, (2000) points out that depression is highly prevalent in the medically ill, but it is frequently unrecognized and untreated. It may affect quality of life, social functioning, and compliance and the outcome of treatments of medical illness.

Similarly, Berard (2001) noted that depression and anxiety are frequently undiagnosed and untreated in cancer patients, resulting in a significant negative impact on quality of life and disease outcome. He stresses that, depression and anxiety are highly treatable conditions, and that failure to treat them in the cancer patient can have a serious negative impact. He found that as well as compromising quality of life and social support for the cancer patient, depression and anxiety might prolong the duration of hospitalization, negatively influence compliance with treatment, and, this way, ultimately reduce chances of survival. An attitude of helplessness or hopelessness in response to the stress of cancer also has a detrimental effect. When the predominant coping response is a fighting spirit, the cancer patient has better emotional well-being, with less psychological morbidity, and is more likely to adhere to his or

her chemotherapy regimen: (Ballenger, Davidson, Lecrubier and Nutt, 2001)

Tamaroff (1992) assessed 34 oncology adolescents and young adults and used various psychological variables-. The less compliant tended to have less developed concepts of the illness -(causality and prognosis) and higher levels of denial or a psychological defenses. They also had less cohesive future orientations-. In this study the health locus of control was not found to be significant.

Another interesting study comes from Ayres, Hoon, Franzoni, Matheny, Cotanch and Takayanagi, (1994). They did a very comprehensive study on the influence of mood and adjustment to cancer on compliance with chemotherapy among breast cancer patients. They determined that mood variables and attitude toward cancer could predict compliance with IV-administered chemotherapy.

Ayres et.al. (1994) found that factors such as fighting spirit-, anxiety, depression, and vigour scales were associated with greater adherence to a chemotherapy regimen. Guilt and hostility levels predicted lower levels of compliance.

Lesko (1994) felt that in response to their illness, bone marrow transplant oncology patients could develop emotional disturbances of anxiety, depression, agitation, and also become non-compliant.

Andrykowski (1994) studied the psychosocial factors in bone marrow transplantation. The

evolution of bone marrow transplantation (BMT) from an experimental to a conventional form of therapy has been accompanied by an evolution in BMT-related research. While bio-medically-related research continues to be most prominent, research investigating various psychosocial issues raised in the BMT setting has increased in recent years, one of these being compliance.

Pugliese, Garufi, Nisi, Caruso, Nistico, Giunta, Giannarell and Ferzoli (1995) reported an eventual drop in compliance in advanced cancer patients as they realised they are not getting better.

8.2.3.3 Lag time before diagnosis

Green and Roberts (1974) write about a concept which is important in the study of compliance, an action process, or a continuum of action, starting with the first observation of symptoms and continuing through to completion of adequate treatment. This action process is regarded as having continuity and directionality, with each step in the overall process flowing into the next. Critical decisions, not all rational or conscious, are identified. These decision points include observation and interpretation of symptoms; whether to seek advice from others, and from whom; decisions regarding selection, acceptance, rejection, or modification of medical advice. Forces influencing such decisions and the subsequent action are described as internal (e.g., knowledge and attitudes which pertain to breast symptoms suggestive of cancer) and external (e.g., the community climate of opinion) to the individual concerned.

The initial decision is when to react to perceived, disturbing symptoms and there is often a lag time in doing so.

Worden and Weisman (1975) found that the time period between the appearance of the first symptoms of cancer and the diagnosis of cancer, which is usually about 3 months, is significantly dangerous only for breast cancer patients where delay found cancer at a more advanced stage when diagnosed. Fisher (1967) found that subjects who are most autonomous, independent, and self-delineated are likely to delay longest on discovering breast symptoms within themselves.

The purpose of Crane-Okada (2000)'s study was to describe the characteristics of women referred to a public hospital surgical breast clinic for an undiagnosed breast problem, and to test a model of relationships among social-environmental, cognitive-behavioral, and health-related factors, vulnerability to breast problem events (uncertainty and self-efficacy), coping strategies, and psychological distress (anxiety and depression) and diagnostic delay. The average delay from self-discovery of a problem to the first health care visit was 2.1 months. There was no significant difference in anxiety, depression, or delay by age, ethnicity, or income. The only factor significantly associated with decreased patient diagnostic delay was having more relatives nearby.

Gascoigne, Mason and Roberts (1999) undertook a qualitative study with 6 men (aged 20-59 yrs) treated for testicular tumours to ascertain how they interpreted their symptoms and the factors which influenced their decision to consult a physician. Interviews were also conducted

with four wives and one mother. The findings showed that giving men information on testicular cancer may not guarantee early presentation. Symptoms were not generally attributed to cancer and the one patient who practiced self-examination had delayed seeking help for 6 months. The extent to which symptoms affected the patient's lifestyle was also a factor in the decision-making process, as was the checking of symptoms with other family members. Wives were often pivotal in persuading men to seek help. The discovery of testicular symptoms produced emotional responses which included embarrassment and fear of both cancer and castration. There was evidence of strong feelings of masculine identity bound up with the appearance of 'normal' genitals. (This type of cancer is obviously associated with body image, masculine and sexual identification, as well as feelings of shame-). On another level, provider-delay was identified in 4 cases and was associated with mis-attribution of symptoms by physicians and the failure to initiate specialist referral. Delay was under-recorded in the hospital notes in all cases where presentation was not immediate.

Krause (1991) worked on the readiness of cancer patients to report for examination and treatment. He found that 43% of the cancer sufferers he studied had sought advice on the cause of the symptoms within a month of their appearance, (or else their disease had been discovered by accident), and almost three-quarters had done so within three months.

Delay in seeking treatment need not necessarily mean that the patient will be less compliant. Berger et. al. (1988) did a study of compliance to determine whether a medically indigent population with breast carcinoma that has been neglected was an appropriate group for inclusion in an aggressive combined treatment program. Compliance was defined as overall

compliance comprising: the percentage of patients completing the protocol as described; and appointment compliance and the ratio between treatments or appointments attended versus those scheduled. Overall compliance was 75% (21 of 28 patients). They found that compliance did not vary significantly with age, marital status, nationality, the presence of complications, or delay to diagnosis. However, compliance did decrease significantly with time. There was 100% overall compliance at 2 months, 82% at 6 months, and 75% at 1 year. They concluded that although their patients had neglected their disease and were medically indigent, they were highly motivated patients once in therapy.

8.2.4 Childhood and adolescent cancer

Three decades ago, the majority of childhood cancers were incurable, untreatable, and rapidly fatal. It is not surprising, therefore, that early references regarding psychological support for children with malignant diseases addressed themselves, mainly, to issues of death, dying, and terminal care. Owing to the recent renaissance of interest in death and the growth of thanatology as a specialised area of inquiry, such studies have not diminished (Kellerman, 1980). "Simultaneously, however," he says, "the recognition of increased life expectancy in children with many types of cancer, notably acute lymphoblastic leukaemia, Hodgkin's disease, and Wilm's tumour, has led many authors to consider the utility of viewing paediatric cancer from the conceptual viewpoint of chronic disease. This has led to an increased awareness of the importance of identifying problems of adaptation and of developing clinical approaches that the patient and family achieve optimal rehabilitation" (Kellerman, 1980 p. 113).

With the advent of more successful treatments for childhood and adolescent cancer, the compliance factor is gaining greater importance because therapy currently is given with curative, rather than palliative intent (Tebbi, 1993).

Lansky et. al. (1983), point out that only recently has compliance been recognized as a problem in paediatric oncology. While seen as a serious problem in renal dialysis and transplantation, asthma, diabetes and in bacterial illness prophylaxis, it has been assumed falsely that the onus of cancer and the fear of a fatal outcome would insure compliance.

Dubey, Sengupta, Kaleh and Morewaya.(1998) did a review and analysis of 67 cases of paediatric head and neck lymphomas in Papua New Guinea . Standard therapeutic modalities for lymphomas with multi-drug chemotherapy, surgery and radiotherapy were followed. They felt, however that proper prognostic evaluation following the treatment had not been possible in view of poor patient compliance and lack of follow up.

On a very practical level Hutto and Bratton (1999) discussed the difficulty in administering oral corticosteroids to young children who are required to take these medications as part of their cancer treatment which has been a concern among health care providers for many years. They often cannot tolerate the taste of the medicine, and parents do not force them.

Several researchers have gone into the question of non compliance in children and adolescents with cancer. (Macdougall, McElligot, Ross, Greeff and Poole, 1992; Davies & Lilleyman 1995; Manne, Jacobsen, Gorfinkle, Gerstein and Redd. 1993). In a study done by Smith,

Rosen, Trueworthy and Lowman (1979), it was found that drug non-compliance in children was 33% and 59% in adolescents. They conclude that this striking level of non-compliance strongly suggests that the survival of patients may be threatened by this. Children who fail to take their medication are not receiving optimum amounts of chemotherapy and sub optimal therapy causes a shortened survival. Additionally, an adolescent subpopulation has been identified whose compliance appears markedly lower than the overall patient study group. These data raise the important question of whether the known poor prognosis of adolescents with acute leukaemia is partially caused by their poor drug compliance.

Tebbi et. al. (1986) did research into compliance with paediatric and adolescent cancer patients and they found that the adolescent patients were less compliant than the younger patients. Reasons given for this by the patient or parents were: forgetfulness, busy schedules; and non availability of medications. The researchers also found correlation between non-compliance and a large family-, and comprehension of instructions. They noted that non-compliance may be expected when patients and parents do not agree as to who is responsible for medications and do not communicate well. Also developmentally, adolescent-s are often rebellious and oppositional because they feel a need to assert their autonomy -and they often do so by challenging authority.

Rivera-, Pui, Santana, Hancock, Mahmoud, Sandlund, Ribeiro, Furman and Marina (1993) discuss progress in the treatment of adolescents with acute lymphoblastic leukaemia, concluding that approximately two-thirds of adolescents can be cured when treated with the more modern intensive but tolerable therapy, showing that this form of treatment significantly

has changed the prognosis of adolescents with that disease. He notes, however, that "poor medication compliance has been documented in adolescents with acute lymphoblastic leukaemia, but this factor alone is unlikely to account completely for the observed differences in outcome between children and adolescents." (p. 3404)

Tebbi (1993) points out, 7 years after the previous study quoted above, that the rate of compliance in paediatric and adolescent patients with cancer ranges from 40-60%. Two major factors in any therapy are efficacy of medication and compliance with the treatment according to a schedule known to be most effective. He points out that non-compliance can result in the misjudgment of efficacy of a drug or regimen that may necessitate additional tests, alteration of dose, treatment course and hospitalization. Because currently a significant percentage of cancer treatment in children in the United States is given based on research protocols, and their results, non-compliance can also potentially affect the future therapeutic regimen.

Tebbi (1993) says that beliefs of the patient (more often the parent-, in younger children, as children grow towards adolescence it is a combination of both-) have been found to be related to compliance. These findings have been useful in demonstrating that compliance is due, in large part, to the patient's perceptions rather than the physician's judgements of the disease and its effects. These beliefs have most commonly been studied as components of the Health Belief Model and include the patient's perceptions of the disease, accuracy of diagnosis and efficacy of the prescribed treatment. Attitudes that patients have developed about health and medical care are important in terms of compliance. Compliance is found to be greater if both

the parent and child believe that the medication will be effective in achieving remission, believe that the child's cancer can be cured, are satisfied with the medical care the child receives, and believe that they have some control over the child's health.

Tebbi (1993) again notes that compliance appears to be greater when the parent and child agree on who is to administer the medication. Confusion caused by transfer of responsibility from the parents to the adolescent, which gradually takes place in this stage of life, plays a major role in decreased rate of adherence to the scheduled self-administration of oral therapy. Adherence to treatment regimen is also better in patients who report fewer family problems. He feels that compliance in adolescents should be examined separately because, as outlined previously, as a group their compliance with orally administered medication appears to be exceptionally poor. Little is known about the mechanisms involved in compliance of adolescent patients in general and oncology patients in particular.

Festa, Tamaroff, Chasalow and Lankowsky (1992) conducted studies in this field, with very disturbing results. Outpatient adherence to oral medication regimens was evaluated in 50 adolescents and young adults with cancer. Twenty one patients with acute lymphoblastic leukaemia or Hodgkins Disease were to take prednisone as a component to their chemotherapy regimen and 29 with Hodgkins Disease whose chemotherapy had been discontinued and who was to take penicillin for postplenectomy prophylaxis. Of the 21 patients, 52% were non-adherent to treatment. Of the 29, non-adherence was detected in 48% of the patients.

They felt that more rigorous methods of determining adherence should be performed in adolescence and young adults receiving long term therapy, especially if valid conclusions regarding the efficacy of treatment programs, are to be drawn. In terms of taking medication, non-adherence ranged from a complete failure to take this prescribed medication to the patient's altering of either dosage or duration of therapy. They conclude that it is apparent from these results that non-adherence to oral therapy is a significant problem in about half the adolescents and young adults under care for malignant disease (Festa, et. al., 1992).

A urinary assay was used to measure compliance in 31 acute lymphocytic leukaemia patients under 15 years of age receiving oral prednisone. No patient was found to be 100% compliant. Lansky, et. al. (1983) felt that their behaviour represents a continuum of medication compliance, with some children taking little or no prednisone, some usually taking most or all of their pills, and the remainder complying partially or sporadically. Fully 42% of patients in this study were non-compliant. Lansky, et. al. (1983) felt that because parents are responsible for managing their children's treatment, both the parents and the children's personality profiles were studied. Their results show an interesting pattern of compliance: No patient was found to be 100% compliant. As was expected, psychological test scores were generally within the average range for both parents and children. However the psychological variables related to compliance were very different for boys and girls and their mothers and fathers. A general pattern emerged in which parental variables were tied more closely to patterns of compliance found in boys than in girls. Far more parental variables than children's variables were related to compliance.

Parents saw these boys as emotionally and intellectually vulnerable, but the boys' own feelings and attitudes were not related to their compliance. For girls, the pattern of compliance was very different. Fathers of compliant girls tended to avoid problems, their mothers described themselves as calm, solitary, and in control of their lives. Mothers who were worriers had non-compliant daughters. The compliant girls themselves were anxious. The girls' own state and trait anxiety and increasing age also were associated with compliance. They found, therefore, that compliance with oral prednisone is more closely related to parent's than to the children's personality as evidenced by the large number of parent variables and the small number of child variables correlated with compliance (Lansky, et. al., 1983).

An interesting finding of this study suggests that parental personality characteristics, which usually are considered maladaptive when they are extreme, instead facilitate boys' compliance. These characteristics include anxiety, anger, feelings of helplessness, and other manifestations of the parental stress which has been described previously in families of children with cancer. Of these, anxiety and compulsive tendencies may be the strongest motivating factor. In adult cancer patients, many of these negative personality characteristics have been linked to longer survival. They point out that because cancer treatment is complex and demanding, one must look at psychological characteristics of those who are asked to comply. Parents are inextricably involved in the child's treatment. Their beliefs, attitudes, and personality traits interact in a complex manner with the sex of the child in determining compliance (Lansky, et. al., 1983).

8.2.5 The psychological aspects of cancer

Several writers stress the importance of emotional factors in cancer treatment and compliance: (Ballenger et. al. 2001; Levy, 1999; Holland and Lewis, 2001)

Oncologists often fail to ask patients about their psychological state, sometimes because of skepticism or lack of knowledge about appropriate intervention if they were to detect psychological or psychiatric symptoms. Patients often fail to volunteer any information about their distress, not recognising its importance and wrongly accepting it as an inevitable reaction to their medical condition (Ballenger, et. al. 2001).

Scheier and Carver (2001) see a cancer diagnosis as life-disrupting on many levels, and people react to the diagnosis and treatment of cancer differently. "Although everyone is buffeted by the physical and psychological threats that permeate the experience of the cancer patient, some people negotiate the rapids in fine order, emerging from the ordeal reasonably intact. For others however, the toll is more severe.

"It was just a minor ache or lump that crept into the edge of your awareness, an unwelcome intruder. At first you ignored or minimized it - it couldn't be anything important; there are many things you have to do. But, finally, you went to your doctor, and with just a glance and a few words, your life was changed. You learned that you have a life-threatening illness. Suddenly, everything else seems unimportant. You feel removed from the pleasant everydayness of life. It feels as though your life is over, that you will never be able to enjoy

anything again. You find yourself sailing on uncharted waters in a storm. How can you weather the diagnosis, let alone the illness?" (Spiegel, 1993. p. 14)

"Many cancer patients report a sense of betrayal by their bodies - the old familiar body starts to seem alien, hostile, and treacherous." (Spiegel, 1993, pg. 16)

"This sense of betrayal by your own body is a uniquely threatening aspect of cancer
“(Spiegel, 1993, p. 17).

The word 'cancer' has different meanings for different people. In general, it is synonymous with fatality, either imminent or in the foreseeable future. How each person perceives and attributes meaning to this personal experience, varies according to idiosyncratic factors. These factors are constituted by each individual's unique internal make up and by external influences and it is the combination of the multiplicity of factors that bring about the personal attributions of meaning for each individual (Levy, 1999).

There are many myths, or cognitive distortions surrounding cancer. The less known about cancer the more creative are the myths that are deeply held. (Berkman, Rohan and Sampson, 1994). The primary myth is that cancer is always incurable . This myth exists despite the National Cancer Institute's statement that cancer is the 'most curable' chronic disease in the United States (Berkman, et. al. 1994).

To many, cancer means death , chemotherapy a painful and difficult way of prolonging the

process of dying. Powe (1995) found that elderly African Americans were significantly more fatalistic than elderly white participants and less likely to participate in colorectal cancer screening. (Fatalism in this context refers to the belief that death is inevitable when cancer is present.)

Krause (1991) found that various aspects of treatment were influenced by the person's general emotional state.

Fife and Wright (2000) discussed the effects of the stigma associated with HIV/AIDS and cancer on self-esteem, body image, and personal control. Findings pointed to the dimensionality of stigma and its differential negative impact on particular elements of the self regardless of illness type.

Maguire (1979) considers whether the will to live can influence the length of survival in the cancer patient. He discusses the will to live and the way it may be relinquished in different ways:

First, it may represent a rational decision. Faced with an illness which could cause considerable disruption to his everyday life and prolonged emotional and physical suffering, the patient decides that it is an appropriate time for him to die;

Second, it could be an altruistic decision. The patient elects not to fight in order to avoid burdening his loved ones;

In a third type of case the will to live occurs in the context of a morbidly depressed mood. A person suffering from a depressive illness takes a consistently gloomy view of his/her future, which is out of proportion to the actual situation. He/she feels life is pointless and that there is no hope for him/her.

There is nothing to look forward to and he/she would be better off dead. Since he/she is a burden to others, he/she believes that they also would benefit from his/her death although such views might bear little relationship to the true situation. He/she may become clinically depressed; and

Fourth, a person facing a serious illness who has no symptoms of a depressive illness may simply not bother to fight because any attempt to do so would be futile; that is, he gives in because he feels helpless (cited in Seligman, 1975). Finally patients may just let things take their course since it does not matter if they live or die.

Spiegel (2001) notes that, the idea that having an 'attitude' about cancer makes a difference in its course is a popular but controversial one. Most oncologists and surgeons believe that tumour type and stage, general health, and medical treatment are all that account for the variance in outcome. Many patients and their families believe that having the right attitude makes a difference in the course of disease.

Holland and Lewis (2001) in their popular book written for cancer patients, write very strongly about the "Tyranny of positive thinking". In their epilogue they say, "-Here are some

take home messages I would like to leave with you. First, you should take it with a grain of salt when someone tells you that you brought the cancer on yourself, or worse yet, that you 'wanted the cancer' and that is why it developed. Our over zealous application of mind-body ideas can lead to 'blaming the victim.' (Holland and Lewis, 2001, pg.315)

And further: "Another take-home message is that our society has led us to the belief that there is only one way to cope with cancer - by 'positive thinking'. I call it ' the tyranny of positive thinking'" (Holland and Lewis, 2001, pg.315).

8.2.5.1 Depression and anxiety in cancer

Craig and Abelloff (1974) administered a 90-item symptom checklist to 30 patients admitted consecutively to an oncology research unit. More than half of the patients showed moderate to high levels of depression, and 30% had elevated levels of anxiety. Nearly one quarter had overall symptom patterns virtually identical to those seen in patients admitted to an emergency psychiatric service.

Tucker (1999)'s study -provided preliminary evidence that sleep, fatigue, and affective disturbances relate to one another in cancer patients.

In Bjorck, Hopp and Jones' (1999) study, various significant correlational findings were obtained, revealing that increased helplessness was related to decreased self-esteem, and that increased anxious preoccupation was related to increased depression. Loss appraisals were

related to increased depression and threat appraisals were related to increased anxiety. Finally, optimism was negatively related to increases in both depression and anxiety.

Redeker, Lev and Ruggiero's (2000) results with oncology patients receiving chemotherapy showed that insomnia, fatigue, depression, and anxiety were positively correlated with one another and negatively correlated with quality of life. Females reported more anxiety and fatigue and poorer quality of life than did males. Older age was associated with better quality of life and less insomnia, fatigue, anxiety, and depression.

Brewin, Watson, McCarthy, Hyman and Dayson (1998) interviewed 65 depressed cancer patients (aged 24-81 yrs) and 65 non-depressed cancer patients about past life events, particularly experiences of death and illness. Consistent with prediction, depressed subjects reported significantly more intrusive memories than controls, and described memories as typically beginning with or being exacerbated by the onset of depression. Greater numbers of intrusive memories were associated with more maladaptive coping, and greater avoidance with deficits in autobiographical memory functioning.

Akechi, Okamura, Yamawaki and Uchitomi's, (2001) preliminary findings suggest that the severity of major depression and physical functioning are important indicators of suicidal ideation among cancer patients.

There is, of course, the danger of carrying this out and the non-interest in complying with treatment.

Schumacher, Deimling and Kahana's (1999) research suggests that physicians should consider the potential for medical scepticism and psychological distress among their patients who are cancer survivors.

These features, themselves, could cause non-compliance.

8.2.5.1.1 Depression and anxiety related to the symptoms of cancer

Ronson and Razavi (1999) discuss the psychological effects of cancer in patients at all stages of the disease. They point out that diagnosis of depression and anxiety in this population can be difficult and must involve awareness of the symptoms of cancer itself.

It is sometimes cancer therapy, rather than the disease itself, that makes the patient feel worse. (Berard, 2001)

"Cancer patients are vulnerable to depression and anxiety for many reasons: metabolic or endocrine alterations, treatment with debilitating chemotherapy regimens, immune response modifiers, and chronic pain associated with their physical illness. Quite apart from the normal emotional impact of the diagnosis of a life-threatening illness, an estimated 20% to 25% of cancer patients meet diagnostic criteria for major depression or anxiety, treatable psychiatric conditions that have serious detrimental effects on their quality of life." (Berard, 2001, pg. 60)

Ciaramella and Poli (2001) found that patients who were depressed had more metastasis and pain than non-depressed patients.

Passik, Kirsh, Rosenfeld, McDonald and Theobald (2001) assessed cancer patients' fears of side effects of chemotherapy as they began treatment, then re-assessed these fears 3-6 months afterwards for patients who received chemotherapy during that time. Researchers also examined symptom distress at these intervals. Hair loss, vomiting, infection, nausea, and weight loss were the most feared side effects as patients began treatment. Patients beginning chemotherapy reported severe fatigue, worrying about the future, pain, and sleep problems. No differences were found in the reporting of symptoms based on gender, age, or educational level. While changes in symptom distress over the study period were unremarkable, changes in fears about chemotherapy were of interest. The most feared symptoms were re-ordered after the treatment experience. Fears of nausea and vomiting, alopecia, and loss of appetite decreased significantly. Patient education and other effective treatments, such as those that have been developed to treat acute chemotherapy-related emesis, can relieve fears of patients in treatment. The authors found that fears of suffering related to chemotherapy changed in response to adequate management.

Berkman, et. al. (1994) found in the patients they studied that 50% believed that treatment (for cancer) was worse than the disease.

However especially nausea: has been found to cause extreme distress in many patients.

Blasco, Pallares, Alonso and Lopez (2000) examined post-chemotherapy nausea and its relations to cancer patients' anxiety and cancer adaptation. Their findings suggest that psychological factors as well as pharmacological variables are related to nausea intensity.

Roscoe, Hickok and Morrow (2000) found that patients' expectations accounted for unique variance in nausea severity in each study even after controlling for known pharmacological and physiological predictors of nausea. By contrast, the authors found no significant relationships between expectations for vomiting and subsequent vomiting. These results support the view that patients' expectations for nausea affect its subsequent development, indicating the presence of a significant psychological component in treatment-related nausea.

An interesting study was done by Cameron and Diefenbach (2001) examined persistent symptoms of nausea, distress, and vomiting triggered by reminders of cancer treatment in 273 Hodgkin's disease survivors, 1 to 20 years post-treatment. Prevalence rates were high for distress and nausea but low for vomiting.

Pelechano (1999) studied sources of stress in cancer patients treated with chemotherapy. He found that sources of stress included the cancer diagnosis, disease severity, disease or death of a loved one, and changes in occupational, economic, and marital status. Secondary effects of cancer diagnosis and chemotherapy included somatic symptoms, pain, depression, and sexual problems. Patient fears included family dependence, pain, deformities, loss of pleasure, changes in sexual activity, and fear of radiation or chemotherapy effects.

It is not always clear as to the reasons for heightened anxiety. Matthews, Ridgeway, Warren and Britton (2002, p. 417) argue that they had “expected the prognostic category of the cancer would be related to the level of worry elicited for a variety of reasons. Clinicians may transmit a high level of concern to the patient-, patients may be told about potential bad prognosis in response to their questions and the intensity and severity of the treatments given would tend to be greater in the poor prognosis group. Contrary to our expectations, however, severity of malignant disease, did not significantly predict the amount of worry about cancer in patients with malignant disease. Rather the tendency to think more frequently about the initial diagnostic visit was more predictive of later worrying about cancer. This simple assessment of thought frequency alone appears to provide an index of tendency to worry about health concerns that may later find expression following diagnosis. It seems that the trauma of that visit continued to haunt them.”

Lekander (2001) did significant studies to determine whether anticipatory reactions include the immune system. Immune variables from 73 patients treated with immunomodulating chemotherapy for breast or ovarian cancer were studied in a hospital treatment setting and compared with samples obtained in the patients' homes 2 days earlier. The number of white blood cells increased significantly between samples. Increases were also observed in the counts and proportions of granulocytes, while decreases were observed in the counts and proportions of lymphocytes. No changes were observed in a healthy control group. The nervous system executes regulatory effects on the formation and distribution of leukocytes. Such mechanisms render psychological influences on blood samples possible, including samples that form the basis for decisions related to cancer treatment.

8.2.5.1.2 Cancer Stage and Anxiety and Depression

Weisman and Warden, (1977) see existential plight in cancer patients as a poorly recognized but crucial period, commencing with the definite diagnosis and continuing for 2 to 3 months into the illness. The chief signs are the predominance of life/death concerns, even over worries about health or physical symptoms.

Weitzner, Lehninger, Sullivan and Fields (1999) found that patients experience a significant amount of emotional distress during all stages of the bone marrow transplantation (BMT) process.

Cancer patients frequently suffer from fatigue, lack of concentration, sleeplessness, -and loss of appetite, all of which may be signs of depression or anxiety: (Berard, 2001). Berard (2001) feels that irrespective of the type of cancer depression and anxiety can result from the emotional impact of diagnosis, coping with treatment, anxiety regarding relapse, and facing the possibility of death. He mentions other issues that are relatively specific to the field of oncology. For example, cancer may be considered as inevitably terminal, particularly in the elderly.

8.2.5.1.2.1 Diagnosis

"Documented anxiety levels are highest in the phase leading to confirmation of the diagnosis."
(Ballenger, et. al., 2001, p.60)

Petz, Diete, Gordemann and Wallesch (2001) found that the influence of radiation on coping, anxiety, depression and quality of life seemed insignificant in comparison to that of the diagnosis of cancer in patients with malignant glioma.

Matthews, et. al. (2002) have mentioned that the tendency to think more frequently about the initial diagnostic visit was more predictive of later worrying about cancer (than the actual experience).

Hammerlid-, Ahlner-Elmqvist, Bjordal, Biorklund, Evensen, Boysen, Janert, Kaasa, Sullivan and Westin (1999) did a head and neck cancer study which was designed to assess prospectively the levels of mental distress and psychiatric morbidity in a heterogeneous sample of newly diagnosed head and neck cancer patients. Approximately one-third of the patients scored as a possible or probable case of a major mood disorder at each measurement point during the study year. There were new cases of anxiety or depression at each time point. The anxiety level was highest at diagnosis, while depression was most common during treatment.

Among the most commonly studied psychological effects of a cancer diagnosis-, especially soon after treatment, are depression , anxiety, self image and fear of recurrence. (Bloom, Stewart, Chang and Banks, 2004)

8.2.5.1.2.2 During stages of treatment

Pillay (2001) sought to empirically evaluate levels of depression, anxiety and hopelessness in adults recently diagnosed with cancer. Their results showed significantly higher levels of depression, anxiety and hopelessness reported by the cancer subjects.

Heszen-Niejodek, Gottschalk and Januszek, (1999) found that cancer patients manifested high anxiety and relatively low hope in the initial phase, then a decrease in anxiety and an increase in hope.

However, Kausar and Ilyas (2000) examined anxiety experienced by cancer patients before the first 3 administrations of chemotherapy. The findings revealed that anxiety in patients increased over the course of treatment. They felt that their findings highlighted the importance of provision of psychological help for patients receiving chemotherapy.

Jianping, (2000) concluded that anxiety and depression were common in cancer patients, especially before surgery.

Malec, Wolberg, Romsaas and Trump (1988) found that approximately 30% of his breast cancer patients studied some months into their chemo/radiation treatment showed significant distress and a disruption of psychological adjustment clearly severe enough to merit consideration of a mental health referral.

8.2.5.1.2.3 Post treatment studies

Fossa et.al. (1994) found that patient with clinical stage 1 non-seminomatous testicular cancer surveillance, one and 3 years after orchiectomy about 50% of the relapse-free patients had no psychological problems and were satisfied with the surveillance programme, whereas 46% reported minor and 4% major psychological distress.

Ptacek, Pierce, Ptacek and Nogel (1999) obtained information about patients' stress, coping, and support during radiation treatment from 57 male survivors of prostate cancer (mean age 72.4 yrs) and their wives (mean age 69.27 yrs). Their results showed that despite remembering having experienced substantial stress, survivors of prostate cancer were quite well adjusted. However patients and their wives failed to agree on patients' stress experiences, with wives consistently report that their husbands experienced more stress than the husbands themselves reported.

However, an important aspect in stress and in compliance is sexual functioning. Jonker, Van de Wiel, Hoekstra, Sleijfer, Van Driel, Van Basten and Koops (2001) reviewed literature concerning sexual functioning after treatment for testicular cancer from 1975-2000-.

Meta-analysis revealed that ejaculatory dysfunction was reported most frequently and was related to surgery. Erectile dysfunction was related to irradiation, but was reported least frequently. They found that other aspects of sexual functioning are not clearly related to disease- or treatment-related factors and may instead refer to a psychological vulnerability caused by one's confrontation with a life-threatening disease, such as testicular cancer.

8.2.5.1.3 Depression and anxiety in children's and adolescent cancer

Zeltzer (1993) points out that survivors of cancer diagnosed during adolescence and young adulthood have had to muster the resources to cope with cancer treatment while accomplishing the tasks unique to this developmental period. He also mentions that "Treatment-related side effects, such as nausea, vomiting, painful procedures, and radiation burns, were vividly remembered by survivors and were often reported as the worst thing about their cancer."

Kagen (1976) showed case examples that showed prolonged and inappropriate use of denial by adolescents who have undergone innovative surgery for a metal bone replacement. Patterns of denial were shown to occur during several stages of treatment: presurgical trauma, chemotherapy, postoperative ordeal, and homecoming.

Mulhern, Crisco and Camitta (1994) assessed the prognostic views of 25 paediatric patients with leukaemia, their parents, and their physicians and complex and subtle patterns of disagreement and misunderstanding were revealed. They feel that these results suggest that disagreements and misunderstandings may be responsible for seemingly unusual or maladaptive patient and family coping. An important point is that in general, physicians sampled in this study were largely unaware of parental hopefulness or denial in that they attributed prognostic views to the parents which were similar to their own.

Stuber and Kazak (1999) write about the more positive aspects of cancer. They discuss

developmental consequences that are, to some extent, negative, they also point out that there may be some positive benefits to the survivor of childhood or adolescent cancer having to do with an appreciation of life and a different perspective on values. This goes into the concept of post traumatic growth that will be discussed shortly.

8.2.5.1.4 Depression and anxiety in breast cancer

There is a vast body of literature and research on breast cancer and it is dealt with here in a section of its own.

Thorne and Murray (2000), feel that an appreciation of the historical and cultural contexts in which breast cancer imagery has been constructed helps to explain the confusing array of ideologies that confront contemporary women diagnosed with breast cancer.

Greer (1999) points out that for the woman who is living with the reality of breast cancer, the literal diagnosis is a terrifying ordeal.

Siegel, Gluhoski and Gorey (1999) looked at younger women who are diagnosed with breast cancer and their unique issues associated with being a young woman diagnosed with breast cancer.

The predominant stressors they described included:

1. coping with the untimeliness of the diagnosis;
2. concerns about the impact of the illness on their husbands;
3. sadness about lost opportunities for childbearing;
4. a feeling of being different and isolated,
5. uncertainty about their future; and
6. concerns about their children.

Evidence of altered belief systems about themselves and the world ran through their narratives concerning the adaptive challenges their illness posed for them.

Cultural factors have been found to be significant, particularly in breast cancer:

A study conducted by Kiser and Norma (1999) explored the life pattern of ten Native American women experiencing breast cancer. Among other things they found that the women were dealing with the grief of losing one or both of their breasts and the uncertainty of their own future. Most had chemotherapy and radiation following surgery. Hair loss, nausea, vomiting and weakness were troublesome side effects. The diagnosis and treatment of breast cancer was a tumultuous experience for the participants and their families. The women felt a

sense of loss of control with the initial breast cancer diagnosis. They questioned why it had happened to them and were fearful and sad. The women felt vulnerable and isolated with a sense of being different from others. They searched for meaning through speculation as to the origin of their cancer. While in the cancer diagnosis and treatment phase, the women talked about having feelings of shock, fear and depression during which they relied heavily on family, friends and especially their husbands.

Schlebusch and van Oers (1999) assessed 25 Black (mean age 42 yrs) and 25 White (mean age 54 yrs) South African breast cancer patients and compared in terms of their levels of depression, body image dysphoria and styles of psychological adjustment during the course of their post-surgical chemotherapy treatment. Most of the Black subjects experienced greater levels of somatisation, depression and body image dysphoria and tended to utilize less adaptive styles of adjustment to their disease. The only measure on which both groups more closely resembled each other was that of anxiety. They felt that the greater levels of psychological distress reported by most of the Black patient group may be due to traditional cultural reasons which possibly predispose them to suppress emotions or somatise them rather than display these outwardly, and because of a lack of knowledge and of psycho-oncological services for this group. They feel that these patients could be regarded as being at high risk for elevated distress levels requiring psychological intervention.

Epping, Jordan, Compas, Osowiecki, Oppedisano, Gerhardt, Primo and Krag (1999) examined the process of psychological adjustment to breast cancer at diagnosis and at 3- and 6-month follow-ups in a sample of 80 women with Stage I-Stage IV breast cancer. At diagnosis,

symptoms of anxiety/depression were predicted by low dispositional optimism, and this path was partially mediated by use of emotion-focused disengagement coping. Younger age also was predictive of anxiety/depression symptoms at time of diagnosis and this relationship was fully mediated by magnitude of intrusive thoughts. At 3 months, changes in anxiety/depression symptoms were predicted only by intrusive thoughts. At 6 months, low dispositional optimism reemerged as a significant predictor of changes in anxiety/depression and again was partially mediated by the use of emotion-focused disengagement coping. Independent effects for problem-focused engagement and disengagement and emotion-focused engagement coping were also found at 6 months.

Stein, Hermanson and Spiegel (1993) quoted studies which showed that providing strong social and emotional support to cancer patients was associated with extended survival time. Patients least able to cope with breast cancer had self accusation, release of anger, active avoidance and rebellion (Heim, Augustiny, Schffner and Valach, 1993). Eysenck (1991) found 2 characteristics which were most emphasised in the cancer-prone personality. One was a suppression of emotion-, a lack of outlets for strong feelings and failure to express such emotions. The second was an inability to cope with interpersonal stress leading to feelings of hopelessness and helplessness.

Buick, Petrie, Booth, Probert, Benjamin and Harvey (2000) investigated the psychosocial sequelae of radiotherapy and chemotherapy for primary breast cancer. He found that for the radiotherapy patients' negative affect was greatest when therapy began and declined during therapy, whereas chemotherapy patients' negative affect increased during therapy and lasted

up to 1 mo after therapy ended. The patients' functional, recreational, and home management activities were disrupted, predominantly during the first half of the treatment regimen and their sleep and rest behaviours became more disrupted as they progressed through the course of treatment. The chemotherapy patients' social interactions and alertness declined significantly during therapy.

Savard, Simard, Blanchet, Ives and Morin's (2001) results suggest that insomnia is a prevalent and often chronic problem in breast cancer patients and must be appropriately dealt with.

Bleiker, Pouwer, van der Ploeg, Leer and Ader, (2000) studied 170 women (aged 29-75 yrs) with early-stage breast cancer and found that almost two years after diagnosis, 16% of the women reported a high level of psychological distress as measured by the Intrusion scale.

In Payne, Hoffman, Theodoulou, Dosik and Massie's (1999) study, 275 women (aged 30-90 years) with breast cancer attending ambulatory breast cancer clinics in two sites were evaluated. Their results suggested that significant psychological distress exists in ambulatory women with breast cancer.

"Despite considerable individual vulnerability in breast cancer patients-, it seems possible to identify women who run a high risk of therapy -associated distress-. In these patients psychosocial support is necessary to reduce treatment related anxiety and to stabilise confidence in the medical staff." (Mose, Budischewski, Rahn, Zander-Heinz, Bormeth and Bottcher, 2001)

Vickberg's (2000) study was an in depth-examination of women's fears about the possibility of breast cancer recurrence. There was a wide range in terms of how much women feared the possibility of recurrence. Fears about death and health (including physical health, emotional health, and further treatment) were most common.

As Dunn and Steginga (2000) say that: the diagnosis and treatment of breast cancer is a major life stress that is followed by significant psychological morbidity.

A meaning and purpose to life makes a considerable difference to the cancer patients.

To examine the possibility that an individual's sense of global meaning (i.e., the existential belief that one's life has purpose and order) may moderate the relation between intrusive thoughts and psychological distress, Vickberg, Boubjerg, DuHamel, Currie and Redd (2000) conducted telephone assessments of 61 women (aged 30-81 yrs) who had survived breast cancer. Results confirmed that the frequency of intrusive thoughts was positively related to psychological distress. Global meaning, moreover, moderated the relation between intrusive thoughts and psychological distress consistent with the authors' hypotheses.

Ashing (1999) reports a descriptive study on the quality of life and psychosocial concerns of 117 African-American women (mean age 61.8 yrs) who were long-term survivors of breast cancer. Results showed that the women relied on spiritual faith and family support to cope with their cancer. However, they also reported difficulty talking about the disease on the one hand and lack of adequate emotional and functional support on the other.

A significant study has come from the field of psychoneuroimmunology and the relationship between stress and natural killer cell activity (NKCA) in women before and after the experience of diagnostic breast biopsy. Hooper, (2001) feels that the findings from the study contribute to an increasing empirical database that supports the use of psychological or psychotherapeutic interventions not only to improve cancer patients' quality of life, but also to promote immunocompetence.

8.2.5.1.5 The mastectomy

"For many women, mastectomy for breast cancer not only carries the threat of death due to the disease, but also disfigurement that can shake the very core of a woman's feminine orientation." (Khan, Sehgal, Mitra, Agarwal, Lal and Malik, 2000)

Maguire, Hopwood, Tarrier and Howell (1985) points out that at least 1 in 5 women who undergo mastectomy for breast cancer develop a depressive illness within the first year—A similar proportion suffers from an anxiety state. Unfortunately, few women disclose their problems and most affective disorders remain unrecognised and untreated.

In a study undertaken in the Johannesburg Hospital it has been observed that young black women would rather die of breast cancer at a later date than go through the inevitable rejection by the male once a breast had been removed. (Wellisch, 1996)

Crouch and McKenzie (2000) draw on personal accounts of women's thoughts and feelings

following mastectomy. The analysis of the material obtained in multiple, focused interviews has revealed 2 major themes in these accounts: on the one hand, the loss of bodily symmetry (one of the basic cultural criteria of physical beauty) was deeply felt; and on the other, peace of mind (psychological beauty) was permanently disturbed by the fear of the recurrence of cancer and the possibility of death. While the asymmetrical body is a potentially (socially) visible problem of presentation and representation, the fear of recurrence is a fear of the workings of the body that are not visible and not knowable.

Anllo (2000) points out that the trauma of being diagnosed and treated for breast cancer can impact greatly on women's psychosexual functioning and intimate relationships. Survivors of breast cancer report that issues of body image, sexuality and partner communication rarely are addressed by traditional health care providers. Psychotherapy can help women cope with difficult changes in body image and sexual functioning. There is also evidence that psychotherapy may prolong life.

8.2.5.1.6 Depression and anxiety in vicarious experience of cancer

"Our findings suggest that not only a personal history of cancer-, but also close experience with the disease-, can affect the ways people react to health threats in the future. Any type of experience, personal or vicarious, seems to result in greater vigilance. However, vicarious experience seems to result in lower perceptions of risk and less worry about cancer , and about other health threats." (Benyamini, McClain, Levinthal and Levinthal, 2003, p. 168)

Lindberg and Wellisch (2003) assessed women attending the High Risk Clinic for Breast Cancer for traumatic stress reactions. Their results suggest that witnessing breast cancer in a close relative-, and being genetically vulnerable to this disease , may be as traumatic in terms of feelings of vulnerability and fear, as having the disease.

Huizinga, Visser, Bakker, Owkstra, van der Graaf and Hoekstra-Weebers.(2003) studied Post-traumatic stress symptoms in children of a parent with cancer. Almost one third of the children reported moderate to severe symptoms of post traumatic stress. Daughters of mothers with cancer appeared the most vulnerable.

8.2.5 Interventions

8.2.5.1 Patient-doctor communication

"For whatever doctors are or are not, in the heat of the battle, they become the most important person in the life of a cancer patient." (Bombeck, 1989; p. 31)

"Once a diagnosis of cancer has been made, the need to become a partner with your doctor is critical. A positive doctor-patient relationship can make the cancer treatment - and the whole cancer experience- infinitely easier." (Holland and Lewis, 2001, pg. 10)

Collin (2003) found from a meta-analysis of the published research that "Effective physician-patient communication is one of the central aspects within the treatment of patients with a

cancer diagnosis , which can influence treatment outcomes such as treatment /patient compliance, psychological outcomes and affective states (e.g. anxiety, depression) adjustment to illness, and general satisfaction with medical care."

Ballenger et. al. (2001) also note that the quality of information the patient receives from the health care team also helps to reduce anxiety. In this context, patients perceive their oncologist as the most important person involved in their care and the one person who can supply the information they most need to know about their cancer. In this context, "starting the anticancer treatment prescribed by the oncologist can be seen as a positive step." They note further that "the risk of the patient developing clinical anxiety or depression is reduced considerably by the level of psychosocial support provided by the physician and by the existence of a supportive family network." (Ballenger, et. al., 2001, p. 65)

Mills and -Davidson (2002) studied cancer patients' sources of Information.

Hospital consultants were the primary source of information for the vast majority of patients-. In terms of quality of information, however, they fell to third place. This may be due to conflicting advice or dismissive attitude or no time to discuss problems. Family and friends were the sources of information for 75% of patients and seen as an excellent source by 61% of patients. Often the physiotherapist is seen as the best source. Media sources were not as highly relied on as might be imagined. Reading material was often too difficult for them. The Internet, though used by few patients and depending on computer literacy and accessibility is considered an excellent source. (However, as has been shown in a previous chapter, the Internet can be confusing and at times detrimental to treatment.

Dowsett, Saul, Butow, Dunn, Boyer, Findlow and Dunsmore (2000) examined patients and their relatives/friends' preferences for and satisfaction with patient-cantered and doctor-cantered consulting styles. Their study provided empirical data indicating that subjects preferred a patient-cantered approach to the consultation, particularly when the patient has a poor prognosis.

8.2.5.2 Practical interventions

As has been mentioned, there has been a move towards making the patient a partner with the physician with his/her treatment. Vodermaier, Bauerfeind, Caspari, Kahlert, and Untch (2003) mention that a considerable proportion of women want to be more involved in treatment decisions, and to play an active role. They are using decision boards where 3 therapy options facilitate therapeutic decisions on the patient's side.

Hyland, et. al. (1983) have given some forms that failure to comply might take included delay in seeking treatment, refusal of treatment recommendations, premature termination of treatment, and loss to follow-up after treatment. They considered the possible factors that gave rise to difficulties at each stage and the means by which these difficulties may be prevented or managed, such as patient education and orientation, attention to patient-staff relationships, awareness of the behavioral and psychological changes that seriously ill patients and their families undergo, accessibility of psychiatric intervention, and use of community resources. They discuss typical problems and methods of identifying patients at risk for non-compliance before these problems develop.

Cecil-Smith (2003) speaks about providing information about early breast cancer via tele-conferencing

Howard, et. al. (1995) felt that support, both financial and psychological, may reduce the unacceptable rate of default for patients with testicular non-seminomatous germ-cell tumours.

Borras, Sanchez, Navarro, Martinez, Mendez, Ponton, Espirias and Germa (2001) compared chemotherapy given at home with outpatient treatment in terms of colorectal cancer patients' safety, compliance, use of health services, quality of life, and satisfaction with treatment in a randomised controlled trial at a large teaching hospital. Forty two patients were treated at outpatient clinic and 45 were treated at home. Levels of patient satisfaction were higher in the home treatment group, specifically with regard to information received and nursing care. There were no significant differences in use of health services. They concluded that home chemotherapy seemed an acceptable and safe alternative to hospital treatment for patients with colorectal cancer that may improve compliance and satisfaction with treatment.

Adwok (1994) writing from Kenya, reports how drastic measures have to be used because of the high rate of non-compliance. He points out that the immediate and subsequent morbidity of the operation of total thyroidectomy, in their opinion, overweighs its advantages of improved disease control. This was particularly so when low socio-economic standards lead to lack of compliance with replacement therapy.

Lee, Slade and Lygo (1996), used an 'intelligent' tablet bottle which, unknown to the patient,

electronically records the times of opening, and assessed the compliance of patients with prescribed oral altretamine for ovarian cancer. During the periods of compliance monitoring the physical and mental state of the patients was also monitored by means of self-assessed diary cards. Eleven patients were assessed over 21 monitoring periods, each of 14 days, representing a total of 294 days. In this study they were encouraged to find a high level of compliance.

Waterhouse et. al.(1993) did a study of adherence to oral tamoxifen: a comparison of patient self-report; pill counts; and microelectronic monitoring. They found that- microelectronic adherence monitoring provided both confirmatory and complimentary data regarding adherence behaviour, while also allowing for the evaluation of patterns of non-adherence.

8.2.5.3 Psychiatric interventions

"Depression and anxiety in cancer patients result in reduced quality of life, poor compliance with treatment regimens, prolonged hospital stays, and greater overall disability. Perhaps as a result, cancer patients suffering from depression and anxiety may have poorer survival rates. In this context, the benefit of early intervention for depression and anxiety in oncology is readily apparent." (Berard, 2001, pg. 60)

Passik et. al. (1993) studied women receiving radiation and surgical resection of axillary lymph nodes who were at risk for development of lymphedema of the ipsilateral upper extremity. They found that psychiatric consultation and intervention could be an important part of

rehabilitative efforts aimed at improving the lymphedema itself and the overall psychosocial adjustment of the patient, and also help improve compliance intervention where necessary.

Lydiard (2001) and Berard (2001) suggest that cancer patients are a vulnerable population predisposed to recurrent depression, and could be treated prophylactically.

Hosaka (1999) examined the effect of a structured group and individual psychiatric intervention for Japanese cancer patients to improve their negative emotional status. The results showed that the structured psychiatric intervention was effective for breast cancer patients' emotional improvement.

8.2.5.4 Psychological and psychotherapeutic interventions

Maguire et. al. (1985) discusses a Cognitive Therapy Package which consists of three components, stress management, dispatching and reintegration.

Lepore (2001) points out that cancer diagnosis and treatments can profoundly and, sometimes, irrevocably alter people's lives. Cancer treatments are invasive, painful, and often create long-term negative side effects. Yet despite the dread, discomfort and dysfunction associated with this disease, some individuals are able to maintain or quickly reestablish their pre-cancer emotional equilibrium. They feel that understanding this adjustment process is a primary goal of psychologists and health care providers who conduct psychosocial interventions with cancer patients.

Maguire (1979) writes about strengthening the fighting spirit against cancer: "The possible survival value of 'fighting' the cancer has led some workers to actively encourage patient to do so. In one such approach, patients have been actively encouraged to imagine white cells swarming in and destroying the cancer cells in their bodies. Achterberg and Lawlis cited in Holden, 1978) have claimed that the ability to perform such imagery is a much better predictor of survival than either laboratory or clinical investigations."

Jones, Culler, Kask and Calvocoressi (2001) reviewed current understanding of depression and anxiety in cancer and its treatment benefits.

As has been mentioned, Howard et. al. (1995) felt that support, both financial and psychological, may reduce the unacceptable rate of default for patients with testicular non-seminomatous germ-cell tumours.

Both Lydiard (2001) and Berard (2001) suggest behavioural therapy interventions for nausea and vomiting. Also to treat the phobia of coming back to the hospital in people who have had nausea and develop physical symptoms of their condition, become more fearful, and avoid continuing with the treatment.

When administered by a trained professional, guided imagery has proven to be an effective behavioral intervention in terms of reducing cancer chemotherapy patients' anxiety, depression and anticipatory nausea and vomiting: (Helge, 1999).

Edelman, Bell and Kidman (1999) describe a 12-session CBT program that has been developed for delivery to cancer patient groups. Their findings suggest that a group CBT intervention generates greater short-term benefits than a supportive therapy group among primary breast cancer patients.

Nezu, Nezu, Houts,, Friedman, and Faddis: (1999) discuss the relevance of problem-solving therapy, a cognitive-behavioral intervention that has been found to be effective in the treatment of a variety of mental health problems, especially depression, for use with cancer patients. It is placed within the context of a problem-solving model of stress. This model argues that the likelihood that cancer patients will experience significant and long-lasting emotional difficulties and psychological distress is partially a function of their problem-solving abilities.

Miller, Manne and Palevsky (1998) examined the treatment acceptability of behavioral interventions targeting non-compliance in children with cancer.

In discussing the explanation of illness to Native Americans (storytelling), Tom-Orme (2000) suggests that a health care provider may not always need to explain illness to a native person but instead allow the person to unfold his or her views of illness through storytelling. Illness explanation recommendations for health care professionals include the recognition of clients' differing world views, maintaining openness to whatever the client brings to the encounter, and creating the proper environment to receive illness-related stories.

Seigson-Nisenbaum and Reynoso-Erazo (1999) studied the efficacy of a coping strategies program in improving the quality of life of 4 male and 2 female adults with stomach cancer. Their results indicated that relaxation techniques are associated with decreased stress levels.

Evidence is accumulating that psychosocial interventions not only improve quality of life but may also prolong survival in patients with cancer. This may be achieved by means of a number of mechanisms, such as enhanced treatment compliance, better nutrition, a reduction in high-risk behaviours, alterations in coping strategies, improved quality of life, the provision of group or other social support, and direct effects on response to treatments such as chemotherapy. (Walker, Komblith, Fleishman, Zuckerman, Raptis, Hudis, Heys and Eramin, 1999)

Donnelly, Hamilton, Payne, Massie, Notorn and Holland (2000) explored the feasibility of using Interpersonal Psychotherapy (IPT) by telephone to reduce psychological distress and to enhance coping during cancer treatment.

8.2.5.4.1 Group psychotherapy

To meet the specialised needs of the growing population of individuals who have successfully completed their cancer treatment, (Zampini and Ostroff, 1993) developed a support program for cancer survivors to facilitate the optimal adjustment of adult cancer patients and their families.

Zampini and Ostroff (1993) point out that although recent advances in detection and treatment have transformed cancer from a usually fatal to an often curable disease, there is growing evidence that cancer survival may be achieved with substantial risk to general physical health, psychological well-being, occupational security and adequate health and life insurance coverage.

They point out that during the past three years of the program's existence, they have carefully observed and listened to survivors' responses . They found that regardless of the stated subject matter (e.g. title of the seminar) cancer survivors needed to describe their experiences in order to gain a sense of mastery of the many challenges they had faced and continue to deal with.

They note that as patients weave their stories together they build a strong fabric which supports them as individuals and reduces their feelings of isolation and helplessness. The collaborative effort of having former patients, patient-to-patient volunteers, medical, mental health and other professional staff provided, they found, a supportive and caring context in which to evaluate the impact of cancer, reduce feelings of helplessness, and prevent further disruption of life domains." (Zambini and Ostroff, 2003)

Goyer, Bouchard, Dupuis, Coutu, Webster and Domar (1999) studied whether a 9-week behavioral medicine group treatment program could reduce psychological distress in 29 male and female adults (aged 24-71 years) in Canada with different types of cancer at different disease stages. Overall, the results demonstrated reduced psychological distress for cancer patients who participated in the program. The post test group means for the first 3 tests were similar to those obtained in a normal population, a finding that suggests a significant clinical

change.

There are few more universally feared diagnoses than cancer or HIV. As patients grapple with their own anxiety, confusion, and sense of powerlessness, so too do their families and friends. At a time when the patient needs all the support available, the network of equally fearful family and friends may fail. Classen, Diamond and Spiegel: (1999) describe supportive-expressive group therapy for these patients. Their aim in supportive-expressive groups is to create an environment where patients feel safe and free enough to bring out their deepest concerns.

Oncologists are not always ready to refer for psychotherapeutic interventions: Leis, Haines and Pancyr, (1994) examined the beliefs of medical and radiation oncologists regarding psychosocial (PS) groups for patients with cancer. The willingness of oncologists to initiate referrals routinely to such groups was also examined. Although 75% of subjects believed that initiating a (PS) program before a patient had accepted and been shown an oncology treatment plan would be harmful, benefits were expected during treatment and after existing therapies failed. Depression, anxiety, anger, and compliance with treatment were selected as appropriate focuses for (PS) groups.

There are, of course, problems with compliance with group therapy itself. Satisfaction with a group rehabilitation program (GR) was evaluated in a heterogeneous group of cancer patients. The usefulness of the (GR) components were rated in the following descending order: relaxation, physical training, encountering others in the same situation, breathing exercises,

information and cognitive-behavioural skills. Patients were more satisfied with diagnosis-specific group meetings than with those including several diagnoses. Reasons for discontinued participation were given: 'don't want to continue/regret participation', 'too many/difficult questions', 'too tired', 'moved from county' and 'don't believe I have cancer'. (Petersson, Berglund, Brodin, Glimelius and Sjoden., 2000)

8.2.5.4.2 Meditation and music therapy

Bolen (1973) describes the combination of meditation and cobalt radiation therapy in the treatment of cancer. The meditation program, involved relaxation exercises and visualizations of peaceful scenes, were outlined.

Specia, Carlson, Goodey and Angen (2000) assessed the effects of participation in a mindfulness meditation-based stress reduction program on mood disturbance and symptoms of stress in cancer outpatients. They concluded that the program was effective in decreasing mood disturbance and stress symptoms in both male and female patients with a wide variety of cancer diagnoses, stages of illness, and ages.

Young (1999) found that the practice of mindfulness meditation increased the cancer patients' understanding not only of themselves but also of others. In the process, they seemed to feel that they had improved the quality of their lives.

Cai, Qiao, Li, Jiao and Lu (2001) and Xie, Wang, Yin, Liao, Lin, Yu, Liu (2001) studied the

effect of music therapy in clinical application in cancer patients in China. Their results indicate that music therapy is an effective additional therapy in the treatment of cancer.

Robb (2000) examined the effect of therapeutic music interventions on the emotions and behaviour of isolated, hospitalized children, with good results.

8.2.5.4.3 Empowerment techniques

Hoff (2001) did a study on one hundred patients and family members to test the effects of a new education/orientation program, the information being presented in verbal and written form. They measured the program's effect on anxiety, distress, compliance, use of support services, knowledge of radiation therapy, and satisfaction with care. There were no significant differences between the orientation and control groups in their level of anxiety and distress at the end of radiation treatment and no significant differences between groups in the area of compliance. However patients in the orientation group were significantly more satisfied with the care they received in the radiation oncology department than patients in the control group.

Peett and Cox (1996) focused on the development of a programme of self-administration of medicines within an oncology setting. Previous studies which have developed this concept demonstrate that such a programme has a positive impact on a patient's knowledge of his/her illness and treatment. Compliance with drug regimens increases and patients are given back control over one aspect of their lives while in hospital.

Mok-Suen (1999) did research to conceptualize and construct an empowerment instrument, and to apply the model of empowerment in cancer patients in Hong Kong. The research approach combined in-depth interviews, participant-observation and measurement development to capture the empowering aspects of the illness experience in a form which lends itself to quantitative analysis, without excessive loss of the phenomenological meaning of that experience.

Bowen, McTiernan , Baumgartner, Aiello , Bernstein and Malone (2003) concluded that personal growth after a diagnosis of breast cancer , particularly spiritual growth, might be important to overall functioning and suggest that there could be interventions like this to improve functioning.

8.2.6 Media impact

The media can have a profound effect on the distress or the actions of the cancer patient.

A wide range of cancer information resources is available to patients and their relatives, who are increasingly acting as independent learners. In order to examine preferences for different types of information and to establish the appropriateness of providing a Web-based cancer information resource (CancerHelp UK), a questionnaire survey was undertaken by James, James, Davies, Harvey and Tweedle (1999). Of 258 questionnaires distributed to patients attending for oncology outpatient or general practice appointments, 205 (80%) were suitable for analysis. Seventy four percent of the subjects wanted as much information as possible. All

subjects cited people most frequently used as a future source of cancer information. All subjects frequently cited television as a source of both general and cancer-specific information. Despite a lack of computer experience patients were significantly more likely than other groups to say that they would like to use the Web-based resource.

Hoffman-Goetz (1999) evaluated attitudes and beliefs about cancer as presented in magazine cancer stories with a predominant readership of African-American (AA) women. Information was collected on full length cancer stories in *Jet*, *Ebony* and *Essence* from 1987 to 1995. There were 11 personal stories about cancer impact on women in the magazine issues over 9 years. Five themes emerged: religiosity; cancer fatalism; quality of life after diagnosis; interactions with medical personnel; and treatment choices. Negative interactions with the medical system were described in 45% of the stories. The authors feel that mass media contributes to that discourse which shapes women's attitudes about survival from cancer.

Clarke (1999) examined the images of breast cancer in the highest circulating periodicals in the US and Canada over a 20-yr period of time. Both manifest and latent themes are noted and described. The emphasis in the manifest themes is on the medical aspects of the treatment and early detection of breast cancer. The latent themes emphasize the contrast in the ways that women with the disease, as compared to their doctors, are described. Notably, women are portrayed as being "worried about their health" and, in particular, the most feared of their diseases, breast cancer. Breast cancer is said to be caused by everything, especially women's own traitorous bodies. Women are described as isolates, as emotional and preoccupied with their sexual attractiveness. Doctors are described in contrasting ways, as moral truth-seekers,

infused with rationality and intelligence.

Finfgeld (2000) discusses therapeutic groups online. It is felt that although online support groups are apparently popular, little is known about their therapeutic efficacy. Seminal findings suggest that these groups offer some advantages over their traditional face-to-face counterparts; however, disadvantages have also been identified. It is pointed out that additional research is required to better understand what role these groups should play in mental health care.

There is, of course, a wealth of literature even in the medical field, condemning the orthodox treatment of cancer, strengthening and adding to the myths and confusing the patient considerably, adding to the non compliance. e.g. "Wealthy and influential people , heads of governments, film stars and senior members of the medical professions , too, still go on dying of malignancy and the effects of its treatment. That such people continue to die is surely commentary enough on the efficacy of such methods (Richards, 1982).

McDonough, Boyd, Varvares and Maves (1996) studied the relationship between psychological status and compliance in a sample of patients treated for cancer of the head and neck. Thirty patients participated in this study designed to evaluate areas of psychological distress associated with treatment of advanced head and neck cancer. Patients completed a set of questionnaires related to various psychosocial variables including anxiety, depression, social support, health locus of control, adjustment to illness, illness-related behaviours, and compliance. Moderate levels of depression and anxiety, disability, and psychological distress

characterized this sample of patients. Additionally, patient self-report of compliance reveals different variable combinations to be related to overall diet and medication compliance, and different levels of each compliance type were observed. They concluded that head and neck cancer therapy presents a unique set of challenges for patients. Awareness of the impact of the illness and the psychological distress that are experienced should improve patient compliance and medical outcome.

8.2.7 Summary

Screening provides the individual with an opportunity to detect cancer at an early and therefore potentially curable or treatable stage. However, in all types of cancer where screening is available, compliance is relatively low. Again all kinds of reasons are given, one of the overriding ones being that such a procedure, even in high risk patients, is not seen as a priority.

It is a common perception that cancer is linked to death, and a common response is that of avoidance and denial. In the same way, as has been mentioned, individuals, especially in a high risk group, will avoid screening for HIV/AIDS. The reasons for avoidant behaviours include fear of illness contamination, contamination and superstition regarding culpability and judgement resulting from illness as a punishment.

There have been some fairly effective interventions but these appear to be effective only within the momentum of the actual intervention. It is also the case that many of these

interventions would be impossible to practice on a large scale.

As was covered in the previous chapters on non-compliance with various medical conditions, the precipitating causes and reasons for non-compliance was discussed and also the strategies for improving compliance. There are many similarities to other treatment plans, with interventions from reminders to take medicine, and very practical and individualised interventions to complicated psychosocial techniques.

The importance of the doctor-patient relationship is stressed and the psychological impact of the cancer diagnosis and treatment.

Again the 'imp of the perverse', in the patient himself as described by Menninger (1938) stops him/her from ensuring that he/she is cancer-free, or if not free, that a chance of a cure becomes a reality.

8.3 Hypotheses and Purpose of Study

It is the hypothesis of this present study that oncology patients with a good prognosis who are non-compliant will show differences in personality to those who are compliant with chemotherapy.

A further purpose of the present study is to make an assessment of any other factors which might be found which contribute to non-compliance with chemotherapy in the oncology

patient with a good prognosis.

From the above results , a method will be developed for identifying potential non-compliant patients.