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**Coping, quality of life and psychological adjustment in men with  
testicular cancer: Evolving changes across the stages of diagnosis,  
treatment and follow-up.**

Thesis submitted in partial fulfilment for the degree of Doctorate in  
Clinical Psychology at the University of Leicester.

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**July 1999**

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## **Acknowledgements**

Firstly I would like to thank Ian Fussey for getting me started; the various consultants who provided access to their patients and all of the men who agreed to take part. I am very grateful to Jane, without whom data collection would have been impossible. I would also like to thank Chris Cordle for her encouragement and flexibility and Aftab Laher for providing academic supervision. Finally, my thanks go to my family and to Richard for his support and enduring belief in the restoration of my sanity.

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**Coping, quality of life and psychological adjustment in men with testicular cancer:  
Evolving changes across the stages of diagnosis, treatment and follow-up.**

**Holly Capey**

**Abstract**

Testicular cancer, the most prevalent cancer in young men, can have a profound impact on coping and psychological adjustment. These effects were investigated in three groups of men at different stages of the illness. Men at diagnosis ( $n=16$ ), receiving treatment ( $n=18$ ) and those at follow-up ( $n=20$ ) were compared in terms of QoL, psychological well-being and coping strategies used in order to deal with their illness. Participants completed a battery of standardised measures assessing these concepts (affect, satisfaction with life, cancer-related quality of life and coping strategies). Overall, well-being was associated with the use of adaptive coping strategies and good quality of life. There was a residual impact on psychosexual functioning and impairment was reported in all three groups at relatively high rates. However, this was unrelated to adjustment. The results showed that at follow up, well-being scores were high, quality of life was perceived to be good and most men used 'adaptive' coping strategies. The diagnosis and treatment groups used more maladaptive coping strategies and had lower well-being scores. Treatment posed the greatest threat to quality of life. Despite the controversy within the literature as to the utility of denial in cancer patients, the present study found that it was associated with lower well-being scores in the diagnosis and treatment groups. With the exception of employment status, contextual factors were not found to have a unique impact upon coping or well-being. However, clinical experience would suggest that these variables should not be ignored. Cross-situational differences in well-being and coping were demonstrated. This lends support for the perception of cancer as a dynamic stressor placing different demands on individuals' coping resources and therefore well-being at different stages. The clinical and theoretical implications of these findings are discussed. Limitations of the present study are acknowledged and ideas for future research are presented.

# **1 Literature review**

## **1.1 Introduction**

Although there is a vast amount of literature pertaining to coping theory and research in the field of health psychology, very little progress in the application of coping theory to clinical work has been made. Previous research has examined how individuals cope with a variety of stresses including acute and chronic illness (Maes, Leventhal and DeRidder, 1996). The prevalence of cancer in the UK is increasing. It affects one in three people, and testicular cancer affects one in five hundred men (Horwich, 1996). However, within the context of clinical psychology, psychosocial oncology is a new and rapidly expanding speciality. Psychology departments are witnessing increasing referrals of cancer patients with a wide variety of associated psychological disturbances.

In many ways, men with testicular cancer represent an ideal group to study. Recent media reports have highlighted the lack of research into issues of men's health. Little is known about how men with testicular cancer cope with, and adjust to the demands of the illness. At the same time, these patients are homogenous with respect to sex and age, prognosis is good and the prevalence is relatively high. Therefore, an examination of the effects of testicular cancer on quality of life, well-being and coping mechanisms at different stages is an important area of study. In the present study, how men cope with the illness will be examined in an attempt to improve our understanding of the process of the illness and its demands on coping resources and quality of life.

The following review will examine literature from a number of areas relevant to coping with testicular cancer. Firstly, a brief history of coping theory is given, with a critique of the various approaches and an emphasis on process models of coping. A definition of coping and measurement is given. The experience of cancer in general and more specifically, testicular cancer, are presented as challenges to coping resources. Studies of quality of life and psychological adjustment in cancer patients will also be discussed.

## **1.2 Coping terminology**

Part of the confusion in coping research stems from the lack of consistent terminology. Compas (1987) distinguishes between coping strategies, styles and resources. Coping strategies are defined as the cognitive, emotional and behavioural actions engaged in by the individual. The term coping style is used in both dispositional and process theories of coping. It refers to the consistent use of a coping strategy either in response to one situation or across a number of situations. Coping resources are a function of both the individual and the environment and they effect coping ability. The term coping implies the presence of a challenging situation or stressor. Lazarus (1993) states that stress refers to the emotions such as anxiety and behaviours such as withdrawal that result in distress. The conceptualisation given above will be used in the present study.

### **1.3 Coping theory**

At grass roots level, coping theory can be divided into the trait and process approaches. The trait or dispositional approach states that certain stable personality characteristics determine the type of coping strategy used regardless of the stressful situation that is facing the individual (Rowland, 1989). The process approach emphasises the interaction between the demands of the situation and the individual's appraisal of those demands and their resources. This appraisal determines choice of coping strategy (Lazarus and Folkman, 1984).

#### **1.3.1 Dispositional coping theories**

Research into individual differences has indicated that our personalities, at least to a certain extent, determine the way we cope with stressful encounters (McCrae and Costa, 1986). The foundations of the trait approach to coping stem from the analytical school of thought. Vaillant (1977 cited in Rowland, 1989) stated that coping refers to unconscious, mature defence mechanisms that act as buffers against psychological distress.

Miller (1987) offers a more contemporary version of the trait approach. He believes that individuals are more or less likely to use a certain coping strategy dependent on their personality traits. The two main styles he describes are 'monitors' and 'blunters', i.e. those who generally seek or those who do not seek information to help them cope with the demands of a stressful situation. Another branch of this approach has focussed on dispositional optimism and its effects on coping outcomes (Scheier and

Carver, 1992). People can be characterised as either pessimists or optimists according to their general view of life. Optimists fair better in coping with a variety of stressors such as illness (Taylor, 1983) and surgery (Caplan, 1981).

This approach is less favoured in health psychology settings as it is now believed that many stressors, especially illnesses, are dynamic in their nature and that individuals adopt different coping strategies as these demands change. Individuals do not consistently use an 'either or approach' (Lazarus, 1993). Furthermore, if the stable trait approach is indicated, it gives far less scope for intervention as it is far easier to alter aspects of behaviour than personality (Rowland, 1989).

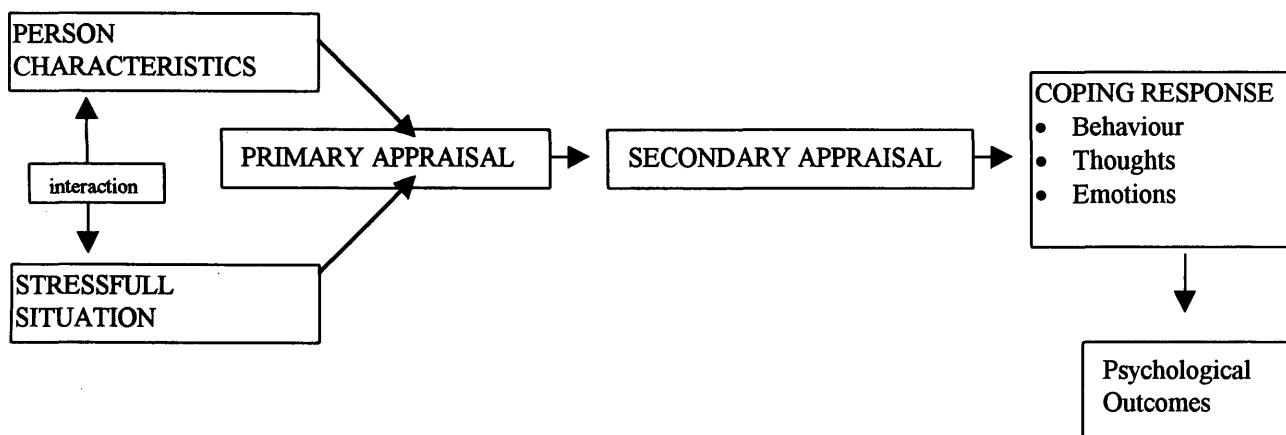
### **1.3.2 The process approach to coping**

Lazarus and Folkman (1984) have been the most influential proponents of coping theory over the past few decades. They developed the process model of coping that is applied across a wide variety of settings and in relation to a vast number of stressors, both acute and chronic. Their model is the foundation of most coping theories to date. Of crucial importance is their assumption that coping is an active, conscious process. Consequently, Lazarus and Folkman's (1984) definition of coping describes a dynamic process where coping changes over time and in response to the situation in which it occurs. Coping is defined as:

'Constantly changing cognitive and behavioural efforts to manage the specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus and Folkman, 1984, p114).

Therefore, coping is concerned with the thoughts and actions a person makes in response to a stressful situation. The individual's coping response is determined by their appraisal of the demands of the situation (primary appraisal) and the resources they have available to act on them (secondary appraisal). The concept of appraisal as a mediating force between a person's environment and their coping behaviour is central to the concept of coping as a process. This process model is presented in Figure 1.3.2 below. Ultimately the subjective experience of stress is a balance between primary and secondary appraisal. When harm and threat are high and coping ability is perceived to be low, substantial stress is felt. When coping ability is high, stress may be minimal. The stresses experienced by an individual impact upon individual psychological and physical well-being via coping.

**Figure1.3.2:** Diagrammatic representation of the process model of coping (Lazarus and Folkman (1984).



## **1.4 The function of coping strategies**

In order to measure coping strategies, it is necessary to classify the various functions of coping. A categorical distinction is that made between problem-focussed and emotion-focussed strategies. Problem-focussed coping strategies are those which alter the nature of the stress-provoking relationship between the environment and the individual. Therefore, when using problem-focussed strategies, the individual takes direct action to alter either aspects of themselves or the stressful situation.

Conversely, emotion-focussed coping refers to changing our perception of the stressful situation. At another level, it facilitates either vigilance to or avoidance of the stressor. These will be discussed in more detail with respect to coping with cancer.

The uses of both of these dimensions vary as a function of the situation and the individual. The following discussion also illustrates that most stressful encounters demand the use of both types of coping and that none are universally adaptive or maladaptive.

## **1.5 Assessment of coping strategies**

In order to make a study of coping, three variables must be taken into account, the nature of the stressful situation, the coping response made to that situation and the characteristics of the individual who is in that situation (Lazarus, 1993). As indicated in Figure 1.3.2, it is the interaction of the variables of the situation and the person which determines coping response via the person's appraisal of the event and their coping resources. Any research must specify exactly which aspects of the situation the

individual finds stressful. The most commonly used method of identifying coping strategies is through self-report.

Folkman and Lazarus, (1988) developed the Ways of Coping Questionnaire in order to assess coping strategies. It has acted as the bench mark for all subsequent coping questionnaires. The measure consists of a series of statements, each of which portrays a coping thought or action that people sometimes engage in when under stress. Embedded within this scale is the distinction between problem-focussed and emotion-focussed coping. Most stressors elicit both types of coping response. However, problem-focussed strategies tend to be used when people feel that something constructive can be done about the stressor and emotion-focussed strategies are used when people feel that the stressor is something that must be endured.

Lazarus (1993) calls for the repeated use of process coping measurements across both time and different stressful encounters within the same population. Only then can researchers begin to understand the dynamic nature of coping. To illustrate the value of repeated testing, Folkman and Lazarus (1985) studied emotion and coping in 108 undergraduate students at three stages of an examination, anticipating the test, waiting for the results and following the results. A stress questionnaire including fifteen different emotions was used to assess emotions felt at each stage and the Ways of Coping questionnaire was used to assess coping. The results of the study showed that problem-focussed coping and emphasising the positive were more salient during the anticipatory stage and distancing was more prominent during waiting for the results. The study also showed individual differences across situations with each individual

coping differently at each stage. These results support the view that coping is a process as it changes in response to different events and individuals do not show general coping styles.

Psychological well-being is often used as a measure of the success or relative 'adaptiveness' of the coping strategy used. However, Lazarus (1993) stresses the danger of declaring some strategies as universally adaptive or maladaptive. What may be maladaptive in one situation may be adaptive in another. For example, in adjusting to illness, denial may be more effectual than resigned acceptance in promoting a 'fighting spirit' attitude that has been shown to predict psychological well-being (Moorey and Greer, 1989). Thus the term 'coping' is used regardless of whether the process is successful or unsuccessful.

## **1.6 Recent advances in the assessment of coping strategies**

Measures of coping strategies are rife with problems. All measures are slightly different although none can proclaim that they measure all relevant areas of coping. There is a lack of clear focus of many of the items in the various scales (Carver, Sheier and Weintraub, 1989). Often single items combine conceptually distinct qualities, which results in ambiguity about what the item measures. Finally, the majority of scales have been derived empirically using statistical techniques rather than drawing on well established theory. DeRidder (1997), argues that the Lazarus and Folkman (1984), model of stress and coping is more of a frame of reference than a theory. The model conceptualises coping as a reaction to a stressful encounter, but it neglects other determinants of coping such as personal and social resources. One of

the major strengths of the Ways of Coping questionnaire is that it specifies a stressful situation for each individual. However, this is inadequate for applied analyses of adaptation as even in homogenous samples this approach results in a diverse pool of nominated stressors making analysis complicated. Finally, the Ways of Coping questionnaire has low internal consistencies and there is a lack of test-retest data (DeRidder, 1997).

Carver, Sheier and Weintraub (1989), considered the theory of motivated action (renewed efforts vs. giving up) in their assessment of coping strategies. Their instrument, the COPE, incorporates 13 conceptually distinct sub-scales that assess the whole range of coping strategies that individuals use. This was developed to help clarify and separate the broad factors under emotion- and problem-focussed coping strategies.

Problem-focussed strategies incorporate the following: (a) Active coping is the process of taking steps to try to remove or circumvent the stressor or to ameliorate its effects; (b) Planning is thinking about how to cope with a stressor. It occurs during secondary appraisal and is clearly problem-focused; (c) Suppression of competing activities refers to attempts made to deal with the stressor by putting other projects aside. It allows us to concentrate more fully on the stress at hand; (d) Restraint coping refers to the strategy used to prevent any premature action; (e) Seeking social support for instrumental reasons such as for advice or information is also considered to be problem-focused strategy.

Alternatively, seeking social support for emotional reasons is viewed as an Emotion focused coping strategy. It involves getting moral support, sympathy or understanding. Similarly, focusing on and venting of emotions is a process of focussing on the distress caused by a particular stressor and letting those emotions out. This may be adaptive in some situations and maladaptive in others. Other separately classified emotion-focussed strategies include acceptance, denial, positive reinterpretation and growth and alcohol and drug use.

Carver, Scheier and Weintraub (1989), administered the COPE to 117 students who were asked to recall and think about their most stressful experience in the last two months. After describing the event, they completed a number of ratings indicating the extent to which they had engaged in each of the coping strategies. The results showed that most students used a variety of coping strategies in order to deal with the stressor. More females than males sought social support for instrumental and emotional reasons. They also reported focussing on and venting their feelings significantly more. Males reported significantly more alcohol use than females. They concluded that active coping strategies are used when the stressor is perceived to be controllable. They also argued that planning, suppression of competing activities and seeking out instrumental social support are also used in more controllable than uncontrollable situations. Finally, they stated that the more the situation matters to an individual, the more they report focussing on and venting of emotions, engaging in denial and seeking out social support.

Subsequent research (Carver and Scheier, 1994) has attempted to examine the prospective effects of coping with specific stressors that do not vary between

individuals. Like Folkman and Lazarus (1985) earlier, the ongoing stressful situation they examined concerned an examination. They administered the COPE to 125 students (57 men and 68 women) at three time points. The first two days before an exam; the second five days after the exam and two days before the results were posted; the third was five days after the results were posted. All participants were those students who had given high ratings to the importance of doing well in the exam.

Results showed that threat and challenge were high initially and fell off when grades were known and this indicates that stressful encounters differ sharply from one stage to another. It supports the argument that coping is a dynamic process and changes as the demands of a stressful encounter change (Lazarus, 1993). Initial coping was problem-focussed on the upcoming exam: active coping, planning, suppression of competing activities, and acceptance predominated. Coping after the exam seemed to be a function of dealing with negative emotions and channelled into dysfunctional avoidance coping and therefore, emotion-focussed. At the final stage, coping reflected the responses to grades received, with subjects who had done poorly reporting higher levels of problem-focussed coping.

### **1.7 Criticisms of Coping Assessment**

Coping has engendered heated critical debate in recent years from both theoretical and applied perspectives. DeRidder (1997) maintains that coping theory is in need of conceptual clarification. This is highlighted by the fact that more than 30 definitions of coping exist. As coping seems to be such a variable concept, it is hard to measure.

The majority of approaches fail to take account of the context of the stressor within an individual's life.

DeRidder (1997), presents six general limitations of coping assessment: (a) There are too many measures of coping; (b) There is no consensus on the level and focus of measurement; (c) In all cases internal consistency is low; (d) Both predictive and construct validity are absent; (e) There is a lack of test-retest data; (f) Finally the majority of research has focussed on retrospective self-reports. She asks 'to what extent are people actually able to reflect on their efforts to deal with stress?' (DeRidder, 1997 p.427).

Other methodological limitations of coping theory will be discussed later in this chapter, in relation to research into coping with cancer.

## 1.8 The impact of cancer on well-being and quality of life

As illustrated in Figure 1.8 below, cancer is not a single stressful life event.

**Figure 1.8:** Multilevel conceptualisation of cancer-related stress (Somerfield, 1997, p.138)

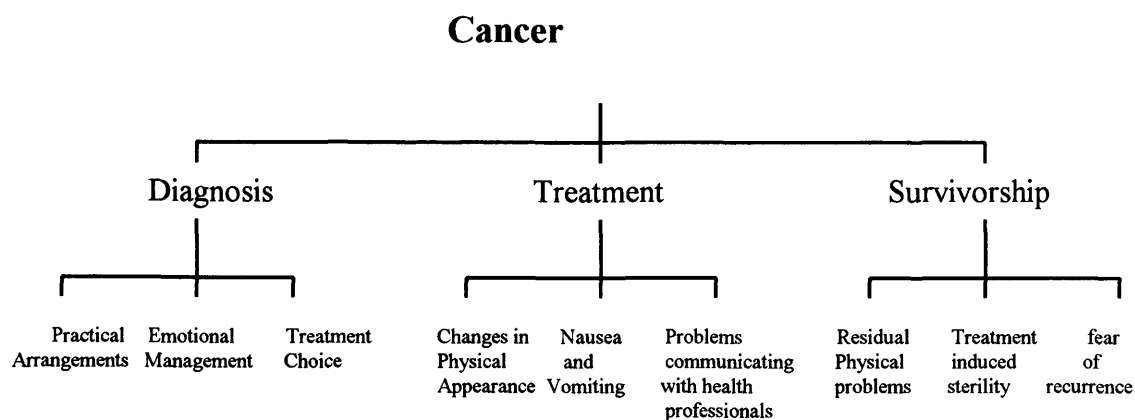


Figure 1.8 allows researchers to organise their thinking around the ever-changing demands of coping with cancer.

There are problems in investigating the prevalence of psychological disorders in cancer patients. Many of the features of anxiety and depression are found in patients with physical illness. Tiredness, apathy, sleep disturbance and weight loss are all effects that can result from the cancer itself or from its treatment. Therefore, reports of the prevalence of psychological distress in cancer patients vary. Responses to a diagnosis of cancer depend upon many variables, including, personality, age, marital status, presence of social support and physical symptoms. After the initial response and the side effects of treatment, the majority of cancer patients cope well. Derogatis, Moorow and Fielding (1983), found that 44% of 215 unselected admissions to three centres in the USA had clinically significant psychiatric disorders. Most of these were adjustment reactions although 18% had pure major depression and 9% a pure anxiety state. Farber, Weinerman and Kuypers (1984), studied 141 patients attending an oncology outpatient clinic and found that 34% had a clinically significant level of psychological distress.

More recent European studies indicate that the prevalence of moderate to severe psychological distress is lower. Watson (1994) studied a large sample of women with recently diagnosed breast cancer, the results suggest that serious disturbance is confined to between 5 and 15% of recently diagnosed patients. Ringdal, Ringdal, Kvinnsland and Gotestam (1994) examined psychological outcomes in 253 cancer patients with mixed diagnoses. They found that the incidence of psychological distress

was comparable with that of the general population (8-15%) and it was not related to physical symptoms or prognosis.

## **1.9 Evaluating coping outcomes – Quality of Life (QoL) and well-being**

Defining successful coping is difficult and controversial with respect to cancer.

Strategies such as denial that are perceived as maladaptive in other situations are often viewed as essential in inducing a fighting spirit in cancer patients (Moynihan, Bliss, Davidson, Burchell and Horwich, 1998). In order to define successful coping, the goals must first be defined. Although there are different models for the goals of coping with serious illness (Caplan, 1981), in general, the goals do tend to reflect the basic areas threatened by the specific illness: psychological organisation, self-esteem, affiliations, body functions, and assumptions about the future.

One way of assessing the efficacy of coping is to examine psychological outcomes (Lazarus, 1993). This can be achieved by using self-report measures of psychopathology such as depression and anxiety scales. However, it is important to distinguish between the physical symptoms and side effects of illness and possible indicators of mood disturbance. For example, both cancer patients undergoing chemotherapy and people suffering from depression frequently report fatigue. More suitable assessments of psychological outcomes focus on self-perceived well-being without implying psychopathology and emphasise quality of life issues.

Health-related quality of life (QoL) refers to the implications or effects of an individual's physical state for their life opportunities and psychosocial functioning (Aaronson, Ahmedzai, Bergman, Bullinger and Cull, 1993). This is an appropriate method of assessing the psychological and physical status of patients with a wide variety of illnesses. The Health-related QoL construct is multidimensional in nature and assesses physical complaints, psychological distress, social interaction, functional status, sexuality and satisfaction with medical care (Fallowfield, 1990).

Functional status refers to the capacity to perform a variety of activities that are normal for most people such as self care and role activities. These can be severely compromised for patients with a wide variety of chronic conditions throughout the duration of their illness (Wright, 1990). Frequently reported disease and treatment related symptoms are also assessed. For cancer patients these include, sleeplessness, nausea and vomiting and fatigue (Holland, 1989). Psychological distress is assessed whilst controlling for direct effects of the illness. As mentioned previously, a number of studies report higher levels of psychological distress among cancer patients than healthy populations (Rowland, 1989). It is also important to assess disruption of social activities. Empirical research points to the importance of social contact and support for cancer patients (Goldberg and Cullens, 1985). Finally, the economic impact of the illness and treatment is potentially devastating. Often long periods of sick leave are required and employers are not always supportive (Moynihan, 1996).

The descriptive application of QoL measures has led to the development of a fuller understanding of the impact of different diseases and assessing the relation between different 'objective' aspects of a disease such as severity and degree of incapacity, and

its effects on the individual. Studies have revealed that QoL is not necessarily related to the severity of an illness since there can be enormous variation between individuals with the same condition (Calais da Silva, 1993). Thus factors such as coping, social support and individual difference factors may be critical in determining QoL outcomes, particularly more psychological aspects.

In summary therefore, the degree of the success of coping efforts, depends on the nature of the stress, the goals dictated, the type of coping responses prompted by the situation, and most importantly, the suitability of the strategies chosen to meet the tasks with minimal cost to the patient. Because this process is dynamic, success in prior coping serves to inspire more rigorous and persistent efforts in subsequent coping. Success of coping efforts can be gauged by examining psychological outcomes and QoL.

### **1.10 Coping with cancer**

‘Although cancer is emotionally experienced differently by each individual it constitutes a threat to life and integrity that must be faced by every patient’ (Rowland, 1989, p44.). Early studies that examined how individuals cope with cancer tended to focus on psychopathology, however, now researchers are concerned with the adaptational aspects in human responses to the experience of cancer.

Serious illness such as cancer places vast demands on the individual’s coping capacity and calls for the use of both defensive and novel coping strategies (Rowland, 1989).

Research into coping with cancer has tended to focus on the process approach to coping. The attraction of this is obvious in applied settings. Firstly, it is easier to change characteristics of an individual's coping strategies than to change an individual's personality. Secondly, achieving a clearer understanding of the value of various coping strategies may lead to the design of more effective medical management and psychological interventions.

Within the oncology literature, there is general consensus as to the influences that determine how patients cope with cancer. Rowland (1989) states, 'of prime importance is the nature of the stress: cancer, and the disease related variables (e.g., site of disease, stage, treatment, and course). Next come individual variables such as when in life the cancer occurs and what emotional and social resources are available. Finally, the socio-cultural climate within which the diagnosis and treatment of cancer occur also contributes to coping' (p. 46). Therefore, the demands that cancer places on coping cannot be viewed as static or unitary.

#### **1.10.1 The nature of cancer and disease related variables**

The effectiveness of coping is highly influenced by the duration and the intensity of the stress. Cancer and its treatment often extend over long periods of time and can deplete psychic and social resources needed to cope effectively. It is also important to bear in mind that the acute life threatening nature of cancer elicits different coping responses than non-life threatening events or chronic problems (Cella, Jacobson and Lesko, 1989). Treatment can include, major surgery, chemotherapy and radiotherapy,

all of which may have a permanent impact on QoL and physical and psychological well-being.

### **1.10.2 Age and Stage of life**

The point at which cancer occurs in an individual's life is a major determinant of coping. With the absence of illness there are various tasks, that throughout life, need to be accomplished (e.g. learning to walk, getting a job). The nature of these tasks varies over time for adults, adolescents and children. To what extent specific tasks are affected by illness affects the ability to cope. In addition, the sophistication of personal skills and cognitive capacity at the outset and over the course of the illness affects an individual's capacity to cope.

### **1.10.3 Values and beliefs**

Values and beliefs also affect coping with cancer. Previous illness experiences have important repercussions for coping in the time of sickness. The individual's specific perception of the illness is what dictates the selection of particular coping strategies. Naturally, a previous experience with cancer influences coping. If a patient knows someone who has recovered from cancer they are more likely to believe that they can succeed in mastering their illness. There is also strong anecdotal support for the

positive impact of religious beliefs and activities on individuals' adjustment to serious illness (Rowland, 1989).

#### **1.10.4 Environmental Factors**

It is now widely recognised that social support contributes significantly to well-being. More specifically, social support has been shown to reduce the negative impact of serious illnesses including cancer (Blanchard and Harper, 1996). The wider socio-cultural context also influences individuals' coping responses. Attitudes of others can also lead to feelings of stigmatisation. For example, many people respond with fear and ignorance to the diagnosis of cancer and still mistakenly believe that it is contagious. Other factors such as relationship status, financial and employment status all impact on an individual's ability to cope with cancer (Blanchard and Harper, 1996 and Moynihan, 1996).

#### **1.11 Research into coping with cancer**

The initial short-term response to cancer may include significant depression, anxiety, and other symptoms of distress and reduced functioning. Yet the majority of individuals adjust well over time and are no different on most psychological outcome

measures from individuals with benign disease (Heidrich, Forsthoft and Ward, 1994).

A number of studies have explored the relationship between coping responses and psychological outcomes to understand how this adaptation occurs and also to identify predictors of individuals at high risk for distress (Lev, 1992).

Weisman and Worden (1976) were the first to systematically examine coping strategies and psychological outcomes in 120 cancer patients during the first three months following diagnosis. By employing clinical interviews and self-report ratings of adjustment to cancer, they evaluated the use of 15 commonly used coping strategies including both defensive and adaptive behaviours. The relative effectiveness of each in resolving predominant concerns was then assessed. The outcome measures that they examined were coping resolution, predominant concerns, vulnerability and total mood disturbance. The results indicated that patients who were 'good copers' (high resolution, low vulnerability, low mood disturbance) used confrontation, redefinition, and compliance with authority. 'Poor copers' employed suppression-passivity and stoic acceptance. Regrets about the past, pessimism, multiple family problems and little expectation of support were associated with high vulnerability.

They concluded that the most effective coping strategies in adjusting to the plight of cancer reflected open acceptance of the cancer followed by responses designed to deal with the illness and current problems according to realistic considerations (e.g. 'take firm action based on current understanding'.) Least effective strategies were those that emphasised retreat, avoidance, passivity, yielding, blaming, acting out and apathy

(e.g. 'trying to forget'.) Their model of coping with illness is presented in table 1.13a at the end of this section.

Although this research was pioneering, it does have limitations. The sample of patients was heterogeneous in terms of diagnosis, sex and age. The design was cross-sectional and finally, it gives no prospective information about how coping strategies may change as the demands of the illness may change.

Gotay (1984), interviewed patients with early stage cervical cancer (n=42) and their partners (n=19) and patients with advanced stage breast or gynaecological cancer (n=31) and their partners (n=20). The most common concern for each of the groups was fear of the cancer itself. Partners were more likely than patients to be concerned about the threat of the women dying. The most frequently used coping strategy was taking firm action and denial was not a predominant coping response. There were differences by stage of disease with the early-stage groups commonly employing information seeking while those patients in the advanced stage of the disease often coped by using their religious faith.

Again, the limitations of this study are similar to those given above. The small number of participants makes generalisations spurious. It also ignores the fact that different diagnoses and sites of cancer have different impacts on coping strategies and QoL.

Dunkel-Schetter, Feinstein, Taylor and Falke (1992) examined the relationship between patterns of coping and emotional distress. They hypothesised that distressed cancer patients would cope differently from less distressed cancer patients. They administered the Ways of Coping with Cancer Scale, Profile of Mood States, and a background questionnaire to 603 cancer patients with heterogeneous diagnoses. Five patterns of coping with cancer were identified: seeking or using social support; focussing on the positive; distancing; cognitive escape-avoidance and behavioural escape avoidance. The results suggested that time since diagnosis, type of cancer and whether a person was in treatment had little or no relationship to the coping pattern used. The specific cancer-related problem was also unrelated to the coping pattern employed, but perception of stressfulness was associated with significantly more coping through seeking and using social support and both cognitive and behavioural escape-avoidance.

They also found that individuals with cancer distance themselves from the disease and its adverse effects most of the time. Focussing on the positive was associated with younger age, religion and being employed. It was also associated with less emotional distress. Greater perceived stress was associated with more functional limitations, more frequent worry about cancer and higher levels of education. The use of social support was also associated with greater stress. The uses of cognitive escape-avoidance strategies were more common in those individuals with a recurrent disease, those in treatment and those with more functional limitations. They were strongly associated with more emotional distress.

The study also examined individuals' coping repertoires and found that the majority of participants had no primary coping method and used a number of different coping strategies. They concluded that 'people who have had cancer appear to use a large repertoire of behaviours to cope flexibly with any one threat from the disease rather than adhere rigidly to one coping style' (Dunkel-Schetter *et al.*, 1992 p86).

Although this study used a large sample of cancer patients, they were heterogeneous with respect to diagnosis, sex and age. It was cross-sectional and therefore conclusions are only tentative. Again, it only offers comment on general aspects of coping with cancer rather than specifics of disease site and treatment.

Carver, Pozo, Harris, Noriega and Scheier (1993) investigated the effects of optimism and coping on distress for 59 newly diagnosed breast cancer patients. The study was prospective and examined optimism, coping responses and distress at one day pre surgery, ten days post surgery and at 3, 6 and 12 months follow-up. The results indicated that the distress reported by the patients was not extreme at any point. Mood disturbance was greatest before surgery and it diminished significantly post surgery. Most of the women used a variety of coping strategies throughout the year. Many coping reactions were more prominent in the early stages of assessment and diminished later. These included active coping, planning, social support and denial. Conversely, the use of acceptance increased throughout the duration of the assessment period. They found that optimism was inversely related to distress at each

stage of the time periods studied over 12 months. This relationship held even when prior distress was controlled. Although they investigated flexibility in the use of coping strategies, the results were inconclusive. They concluded that flexibility could facilitate adjustment or it may indicate a lack of effectiveness of the strategies used. Further research is needed to clarify this.

Carver et al.'s (1993) study is among the few that actually showed that coping is related to psychological outcomes. Emotion-focussed rather than problem-focussed strategies were associated with psychological outcomes. This may reflect the fact that cancer is generally perceived as an uncontrollable stressor (Lazarus, 1993). The three strategies that produced beneficial effects and prospectively predicted lower distress were acceptance, positive reframing and the use of humour. The strategies that were found to be harmful were denial and behavioural disengagement.

They concluded that the female cancer patient must accept the reality of her situation in order to adjust to the demands of the illness. The optimist uses an active approach to coping and this combats distress more effectively than the passive approach taken by the pessimist.

Carver et al.'s (1993) study is one of the few prospective studies using a homogenous sample. However, the major limitation is the small number of participants recruited, this limits generalisation of the findings.

## **1.12 Methodological flaws and limitations of the coping with cancer research**

Many of the criticisms of the coping with cancer research reflect the limitations of coping assessment in general. Of crucial importance is the fact that analyses of stress and adaptation have had very little influence on clinical practice (Somerfield, 1997). Some of these limitations will now be discussed.

Psychometric assessments of coping strategies all have flaws. Although they offer a convenient source of quantitative data, they have failed to yield much in the way of clinically meaningful information. Reasons for this include the fact that they were not developed for use with a population of individuals suffering from cancer and therefore have weak validity in this area (Cella et al., 1989). More importantly, researchers cannot agree on what constitutes successful coping as so many of the measures are conceptually different (DeRidder, 1997). Finally, researchers tend to use different scoring methods for the same questionnaires and this can produce very different results. Therefore, generalisations are often spurious.

Within the field of cancer, research has used heterogeneous samples with respect to site of the cancer and prognosis. This also limits the use of generalisations. The majority of research is biased in terms of sex and age. Middle-aged women seem to be the focus of much of the research. Furthermore, there is high situational variability in the type of coping strategies employed and this makes analysis difficult and generalisations impossible (Somerfield and Curbow, 1992).

In the past, several potential powerful influences on appraisal and coping in the health context have been overlooked (Somerfield, 1997). Just because an individual has a diagnosis of cancer does not mean that all other aspects of their life become irrelevant. It seems logical to assume that a cancer patient has the same amount of daily stress and ongoing concerns as a non-cancer patient. It may be that for some individuals, coping with cancer is straightforward in comparison to dealing with the stress of divorce or unemployment. Research has failed to examine the demands of the cancer within the context of an individual's wider system (Blanchard and Harper, 1996).

### **1.13 Summary of research findings**

Although the literature is heterogeneous with respect to site of cancer and samples studied and there does seem to be a lack of consensus on how best to measure coping, some conclusions can be made. Two of the models discussed in the previous section are summarised in Table 1.13a below and illustrate that there are common themes in the research.

**Table 1.13a: Models of coping with cancer**

<b>Weisman and Worden (1976)</b>	<b>Carver <i>et al.</i> (1993)</b>
<b><u>Problem Focused Coping</u></b>	
Seek more information about the situation (rational-intellectual)	Active coping
Seek direction from authority and comply (compliance)	Suppression of competing activities
Take firm action based on present understanding (confrontation)	Restraint coping
Negotiate feasible alternatives	Planning
<b><u>Emotion Focused Coping</u></b>	
Accept but find something favourable	Positive reinterpretation and growth
Try to forget	Denial
Submit to and accept the inevitable	Acceptance
Laugh it off/make light of it (reversal of affect)	Humour
Distraction	Mental disengagement
Blame yourself or someone else	Behavioural disengagement
Drink/drugs (tension reduction)	Alcohol/Drug Use
Talk to others to relieve the distress (shared concern)	Focus on and venting emotions
	Seek out emotional social support

The results of the studies discussed above also give a good indication of predictors of good and poor adjustment to cancer. These are summarised in Table 1.13b below.

**Table 1.13b: Predictors of coping with cancer**

<b><u>Predictors of coping well with cancer</u></b>	<b><u>Predictors of poor coping with cancer</u></b>
Supportive social network- (partner/children)	Social Isolation (perceived or actual)
Employed/high socio-economic status	Unemployed/low socio-economic status
Optimistic outlook on life	Pessimistic philosophy of life
Fighting spirit	Alcohol or drug abuse
Flexibility and openness of coping style	Previous psychiatric history
Fewer obligations	History of recent losses
Previous positive cancer experience (loved one cured).	Inflexibility and rigidity of coping
	Multiple obligations
	Previous negative cancer experience

Despite variations in methodology, measures and research questions, there do seem to be a number of common themes within the literature.

- 1) Strategies that promote active responses to problem solving and coping behaviour are consistently found to be most effective in dealing with daily stressors. (Weisman and Worden, 1976 and Lazarus, 1993).
- 2) When stressful encounters are perceived as amenable to change, active problem-focussed strategies are used, however, when an illness such as cancer has to be endured, emotion-focussed strategies predominate (Carver *et al.*, 1993).

3) Coping with any illness is a dynamic process (Lazarus, 1993; Somerfield, 1997).

Coping changes as a function of the circumstances and of the individual's continuing appraisal of its meaning with respect to his/her survival, future, relationships, self-esteem and achievement of goals.

4) Individuals who exhibit flexibility in their coping efforts are better able to cope (Dunkel-Schetter *et al.*, 1992).

5) Research into coping with cancer (Weisman and Worden, 1976 and Carver *et al.*, 1993), has demonstrated that acceptance, positive reframing and emotion-focussed strategies can be classified as 'adaptive' strategies which facilitate psychological adjustment. Conversely, avoidance, denial, passivity, and disengagement can be classified as 'maladaptive' strategies that interfere with psychological adjustment.

6) The amount and nature of social support available to the individual strongly influences their capacity to cope as do other aspects of the wider environmental system.

#### **1.14 Process Model of coping with cancer**

Blanchard and Harper (1996) have addressed the criticisms of earlier research into coping with cancer. They propose a process model that allows consideration of the three categories of coping responses (Rowland, 1989) described earlier: disease related, individual, and socio-cultural. The model also highlights the importance of studying health-related quality of life domains as separate to psychological outcomes. It incorporates the Lazarus and Folkman (1984) process model of coping.

This model also calls for consideration of length of illness, stage of the cancer and other demographic variables. These variables are all known to influence mode of coping and its success. It allows consideration of the combined influences of cognitive coping strategies, Quality of Life domains and the stress of cancer, whilst considering the functioning of the whole individual. Although the framework has not been tested it has obvious heuristic value and the design of the present study is based upon this model.

#### **1.15 Testicular Cancer**

As previously mentioned, the relatively homogenous population of men with testicular cancer represent an ideal focus for research into coping with cancer and allows exploration of the process model discussed above. Very little is known about how men adapt to cancer in general. Even less is known about how men adjust to testicular cancer.

### **1.15.1 Prevalence, description and aetiology**

The incidence of testicular cancer is increasing and has almost doubled over the last 25 years (Horwich, 1996). The peak incidence of testicular cancer is between the ages of 20 and 34 years, when it is the most common malignancy in men. It strikes men when they are at the peak of their lives in terms of career, family and sexual and social functioning. A British white male has a 1 in 500 chance of developing testicular cancer. Statistics indicate that worldwide, the highest five-year incident rates are in white males from the USA, Scandinavia and Western Europe. Low rates are found in Asians, Africans, Puerto Ricans and Native American Indians.

Due to a revolution in cancer treatment the five-year disease-free survival rate, including relapse, is up to 95% for stage one diagnoses and 80% for all other stages (Fossa, Moynihan and Serbouti, 1993). Therefore, the vast majority of sufferers can expect to be cured either at initial diagnosis or relapse. Despite the good prognosis, there is evidence that the side effects of the disease and its treatment can have long term impacts on health, quality of life and psychosocial well-being (Douchez, Drox, Desclaux, Allain and Fargeot, 1993).

Testicular cancer is a generic name used to describe germ cell cancers that constitute 95 percent of all malignant neoplasms of the testes. Two distinct forms of germ cell cancers exist, Seminoma and Nonseminoma. Painless swelling of one or both of the

testes is usually the earliest symptom of the disease. The diagnosis of testicular cancer is made after an orchidectomy, usually unilateral, has been performed. The tumour is then identified and staged. The stage of the cancer dictates what treatment is needed.

The present model for treatment locally is as follows;

Seminoma stage 1 –	Radiotherapy or Chemotherapy (clinical trial)
Nonseminoma stage 1 –	Low Risk = Surveillance (If relapse, chemotherapy)
	High risk = 2 Cycles of Chemotherapy
Seminoma and Non-seminoma stages 2, 3 and 4	4 cycles of chemotherapy +/- operation to remove secondary tumours

The only consistent risk factor for developing the illness is having an undescended testicle. No other correlates have been found.

### **1.15.2 Demands of testicular cancer on coping resources**

Tross, (1989) states “ Testicular cancer is characterised by a combination of clinical features that make psychological issues critically important even after treatment has been completed” (p240). It befalls young men and although prognosis is good, sexual, reproductive and other long-term treatment effects may pose difficulties in adaptation. Testicular cancer reaches its peak incidence in early adulthood when impact on active work and sexual and social functioning is most likely to be readily manifest. The psychological impact of the disease is greatest in the area of psychosexual integrity, body image, sense of masculinity, sense of generativity, and sexual desire and

performance. Weisman and Worden (1976), describe the heightened risk of anxiety, depression, fear of pain, mutilation and death that accompany the diagnosis of any cancer. Even when cure has been achieved, the survivor may be prone to lingering fears of recurrence, hypersensitivity to somatic complaints, and transient anxiety over losing the protection of treatment and frequent follow-up. Social anxiety is also common, especially in relation to re-entering a non-cancer-related work and leisure life style.

Overall, rates of psychological morbidity are low (Moynihan, 1991). At diagnosis, low rates of psychological morbidity are reported before treatment commences. However, Moorey and Greer (1989), argue that transient states of emotional distress at diagnosis are healthy. Retrospective reports indicate that diagnosis is a time of uncertainty where fear of death is common. Anxiety may also in part be due to unresolved treatment decisions. During treatment, prospective data suggests that levels of anxiety and depression are elevated (Trump *et al.*, 1985). At follow-up men report high levels of both physical and psychological well-being. Often a more positive view of life is indicated (Brodsky, 1995). However, a significant minority do suffer psychological effects even years after treatment has ended (Moynihan *et al.*, 1998).

Infertility may be a problem for the testicular cancer sufferer even before diagnosis. Rates of sub-fertility among newly diagnosed cancer patients is thought to be as high as 70-80% (Tross, 1989). It is an acute phenomenon confined to the few months prior to diagnosis. Although sperm banking is now standard practice, this sub fertility can

seriously limit its usefulness. However, there is no doubt that the option to bank sperm is an important psychological support for the young man facing infertility.

Unilateral orchidectomy, per se does not, increase the risk of infertility. However, if the tumour is not contained then the lymph nodes have to be removed. This operation poses a great risk to fertility due to physical interference with ejaculation. Research into infertility that is related to radiotherapy and chemotherapy indicates that the sperm count may be reduced for several years, if not permanently (Tross, 1989). Sexual dysfunction is separate from infertility. The major areas of impairment described by testicular cancer patients are decreased sexual activity (Rieker, Fitzgerald, Kalish, Richie and Lederman, 1989) and diminished intensity of orgasm (Trump, Romsaas, Cummings and Malec, 1985).

The aggressive therapies for testicular cancer may cause residual dysfunction in non-reproductive organs as well. The side effects of curative therapy can be compared to any cancer treatment. The immediate side effects of radiation therapy are nausea and diarrhoea. Major side effects of chemotherapy treatments include myelosuppression, nephrotoxicity, nausea and vomiting, weight loss, anaemia, ileus, pulmonary toxicity, ototoxicity, peripheral neuropathy, Raynaud's phenomenon, and stomatitis. These side effects can be minimised with proper expertise. Late toxic side effects can include high frequency hearing loss, peripheral nerve damage and hypercholesterolemia (Herr, 1987). These can result in the survivor having diminished stamina and sensory acuity with which to meet standard full-time work demands. Often, this is a source of demoralisation and frustration for the young man at the peak of his working life (Edbril and Rieker, 1989).

Finally, there is evidence to suggest that the testicular cancer survivor is at heightened risk for general psychological distress (Moynihan, 1996 and Tross, 1989). These risks include the delayed physical complications of cancer therapies, the practical complications of having been labelled a cancer patient, and emotional 'fall-out' from having come so close to the prospect of death. Even after cure, the survivor may experience heightened sense of mortality, producing anxiety, depressive mood and ideas, damaged body image and fears of recurrence. This is often heightened when follow-up ceases. However, there is some indication that the cancer experience does not impair the major areas of function of the survivor's life, such as employment, marriage, or economic status (Edbril and Rieker, 1989). Increased subjective distress is observed but for the majority it is subtle and non-impairing. Therefore it is not the cancer per se that leads to psychological distress in some men, but concurrent stressors.

Research into social issues is scarce. Divorce rates in survivors seem to be no different from that of the general population. Indeed, Moynihan (1987) found that marriages were often strengthened by the cancer experience although lover relationships were more likely to become strained. Those men who did report relationship difficulties attributed this to sexual dysfunction and other cancer related anxieties.

Rieker *et al.* (1989) investigated psychological outcomes in testicular cancer survivors. They found that men with sexual impairment report more psychological symptoms and more areas of negative life functioning such as an inability to be active. Men who were unemployed and feared relapse were significantly more distressed than

those who had retained their jobs or were not anxiously preoccupied with their cancer returning. Psychological distress was also related to financial difficulties, and was more prevalent among lower income groups. When patients were asked to compare their current mental outlook with pre-disease states, 17% reported negative changes that were significantly related to higher levels of psychological distress.

A man's cancer experience does not appear to disrupt his career and work life seriously. A significant minority do experience a negative impact on their work lives. General dissatisfaction, a lack of confidence to handle strenuous work, the psychological stress of a job, an inability to work for long periods, apprehension about making further work plans, general worries about job maintenance and worries about adequate medical benefits all helped to contribute to a negative impact in this area (Edbril and Rieker, 1989).

There is no indication that type of treatment (radiotherapy, chemotherapy or surveillance) is related to long term psychological morbidity (Fossa, Aass and Kaalhus, 1988).

### **1.15.3 Previous research into adjusting to Testicular Cancer**

Unlike cancers that affect the female reproductive system, there is very little research into the strategies that men use to cope with and adjust to the demands of testicular cancer (Gritz, Wellisch, and Landsverk, 1988). Indeed, to the current author's knowledge, no studies that specifically assess coping strategies exist. Although at follow-up patients report good psychological health, there is little information

regarding the rates of distress before diagnosis, at diagnosis and during treatment.

Therefore, the following review will consider more general aspects of adjustment to testicular cancer.

Brodsky (1995) carried out a qualitative study of the psychosocial impact of testicular cancer and its treatment on a group of eleven men in the United States. He argued that there were no first-person accounts of men who had had testicular cancer and specifically examined the impact of survival on men's sense of self. Participants were recruited via advertisements in a local newspaper and through announcements in college classes. Fourteen participants came forward, all had received a diagnosis of nonseminomatous testicular cancer and were at least three years post recovery. The sample was extremely biased, age ranged from 30-35 years, all had at least a college degree, were white and had incomes in excess of \$35,000. Furthermore, all participants were married or in a steady relationship. These statistics clearly do not represent the population suffering from testicular cancer, it is far more varied than the above implies. Credibility was also affected by the retrospective nature of the study, the participants had to recall what it was like for them several years ago.

"Purposeful sampling" was used and interviews ceased when no new information was being found. Participants were briefed, ensured of confidentiality and asked to sign a consent form. The interviews began with open-ended questions, and were then driven by the responses given. Each participant was interviewed once for approximately ninety minutes.

Analysis was based upon a definition of self-esteem, and placed data into four categories, body self, identification self, interpersonal self, and achieving self. This was achieved by transcribing and coding the information. The researcher then made inferences, drew conclusions and proposed a set of understandings about the nature of the impact of testicular cancer on men. The findings were non-specific, for all categories. For the identification and interpersonal self, renewed appreciation of life following the illness, a re-evaluation of priorities, more enriching relationships and emotional growth were reported. These concepts seem to be somewhat vaguely connected to the actual responses given by participants, and it seems unclear as to how the researcher made these conclusions. Perhaps the most interesting finding was regarding "Body self". Most participants reported short-term depression about obvious physical changes to their body, such as hair loss, however, mood returned to normal soon after the hair returned. Two patients suffered psychosexual problems. Although amputation per se was not perceived as distressing, major concerns were expressed about scarring and the fear that disclosure of status as a cancer patient may alter interpersonal relations. Finally, it was found that participants were less ambitious and more realistic concerning their work and career.

In discussion, it was reported that the findings can be summarised as a general tendency for survivors of testicular cancer to focus on enhancing the experience of the moment. These conclusions are far too sweeping and non-specific, the research does not contribute to our understanding of how men cope with the illness at the time and how this process changes with the course of the illness. It tells us very little about the kinds of psychosocial issues raised by the disease or risk factors for disturbance.

Finally, although it does examine changes in sense of self, it makes no reference to the process by which the so-called positive re-evaluation of life takes place.

Rieker et al. (1989) carried out a retrospective study of 223 testicular cancer survivors and 120 matched controls, in an attempt to examine the relative impact of clinical factors on long-term outcomes in the areas of sexual function, relationships, employment, and mental outlook. Participants were at least twelve months post-recovery, were recruited via a hospital patient list, approached via a letter and mailed various self-report questionnaires. These assessed current mood, changes in life functioning since having cancer (mental outlook, relationships, physical abilities and personal satisfactions), tendencies to conceal emotions, social support, employment and sexual functioning. The questionnaires were extremely lengthy (up to 64 items) and produced a huge number of variables to examine.

Analysis involved multivariate comparisons. Again the findings were somewhat vague. For most survivors testicular cancer did not lead to unemployment (4.5%), divorce (6.8%), or disabling psychological problems. The only significant finding was that, predictably, survivors reported more infertility and sexual performance distress than controls. These survivors were more likely to have psychological and relationship problems.

This study is clearly useful, and highlights the relevant issues for survivors of testicular cancer and the impact of the disease upon their lives. However, it is retrospective and incorporated a huge number of variables that increased the error rate and affected the strength of the conclusions that can be drawn. In discussion, the

authors acknowledged the need to assess patients during treatment and follow up to help prevent distress, but did not suggest appropriate ways to go about this.

### **1.16 Summary**

The present review has discussed the relevant issues in adjusting to the demands of testicular cancer. The development and the current status of coping theory have been considered in relation to the original model proposed by Lazarus and Folkman (1984). The distinction between problem-focussed and emotion-focussed strategies has been highlighted. The uses of these strategies have been shown to affect psychological adjustment (Lazarus, 1993). However, the literature has also highlighted gaps in understanding of the effects of coping strategies and methodological flaws in their assessment. The most striking problem is the lack of conceptual clarification.

There is empirical evidence that cancer places huge demands on the coping resources of individuals (Rowland, 1989). The case of cancer adaptation has been discussed in relation to psychological outcomes and QoL. Although reports of psychological distress in cancer patients vary, overall, cancer patients are remarkably robust and successful in dealing with their illness. However, psychological distress has been shown to vary as a function of age, site and stage of the illness, prognosis and the presence of non-cancer-related stressors. Studies indicate that the coping strategies used by cancer patients are varied and change as the demands of the illness change (Somerfield, 1997). There is some evidence to suggest that some strategies such as acceptance are beneficial whereas others such as disengagement are unhelpful (Carver

et al., 1993). Following a review of the literature a process model of cancer adaptation was presented (Blanchard and Harper, 1996).

The increasing prevalence of testicular cancer (Horwich, 1996) and the lack of research into its psychological impact (Moynihan, 1996) warrants further investigation. Previous research has been discussed and indicates that rates of psychological disturbance are low. However, problems have been reported in the areas of relationships (Moynihan, 1987), sexual functioning (Tross, 1989), concerns about fertility and employment (Rieker *et al.*, 1989). Limitations of previous research were discussed and the most important of these concern the use of retrospective self-reports.

### **1.17 Aims of the present study**

The previous discussion has highlighted the lack of consensus regarding how best to measure coping. By examining the coping responses of a homogeneous group of men at different stages of an ongoing stressor, it is hoped that some conceptual clarification will be provided. It is also anticipated that the research will lend empirical support to previous findings. The literature review indicates that little is known about the precise coping strategies that facilitate psychological adjustment for men with testicular cancer. It is important to compare these with other more intensively studied populations of cancer patients. Although there is plenty of information regarding the side effects of treatment and long term adjustment, information is lacking about how the various factors within an individual's personal and environmental system interact to affect coping strategies and adjustment.

The present study attempts to lay the foundations for more intensive coping research into this population of men. The study suggests ways in which staff working with these men can work towards predicting those most at risk for psychological disturbance and therefore, facilitate well-being and QoL throughout the course of the illness.

### **1.18 Statement of Hypotheses**

The hypotheses are stated in the order of general predictions to more specific between-group predictions. The hypotheses are presented in bold after a brief justification for each.

Overall the literature indicates that cancer patients are remarkably resilient (Rowland, 1989). Over time, men with testicular cancer generally adjust well to the demands of the illness and its treatment (Tross, 1989 and Moynihan, 1998). Some research (Brodsky, 1995) indicates a heightened sense of well-being. Therefore:

**Hypothesis 1 - There will be no significant difference between the self-perceived psychological well-being of men with testicular cancer at follow-up and normative groups.**

Both common sense and the literature suggest that self-perceived Quality of Life and psychological well-being are related (Blanchard and Harper, 1996). Quality of life here refers to the impact of cancer on all aspects of an individual's life. This relationship has not been directly tested for men with testicular cancer. It will provide further validation for the QoL questionnaire used. Therefore:

**Hypothesis 2 - There will be significant positive correlations between self-perceived global health status/QoL and psychological well-being scores.**

Despite the confusion within the literature, there is evidence that some coping strategies are more adaptive than others in adjusting to the demands of cancer (Carver et al. 1993, Dunkel-Schetter et al., 1992). Therefore:

**Hypothesis 3 - Men with a higher self-perceived psychological well-being will use significantly more adaptive coping strategies than men with a lower self-perceived well-being.**

The evidence suggests that the demands of the illness change throughout its course (Blanchard and Harper, 1996). It is assumed that psychological adaptation varies as a function of the stage of cancer. For example at diagnosis anxiety is common (Rowland, 1989). During treatment psychological well-being is most at risk as there are the added stresses of side effects of the therapies to cope with (Tross, 1989). At follow-up, men often report a higher sense of well-being than before they had the cancer (Brodsky, 1992). Therefore:

**Hypothesis 4 - There will be a significant temporal difference between the self-perceived well-being scores and the global health status/QoL scores at the different stages of the illness, such that treatment<diagnosis<follow-up.**

All of the process models of coping that have been discussed assume that coping responses vary as a function of the dynamic nature of stressful encounters (Lazarus and Folkman, 1984 & Lazarus, 1993). Cancer is a dynamic stressor and the demands it places on the individual changes over time (Blanchard and Harper, 1996). Therefore

coping strategies are thought to vary as a function of the different stages of the illness (Dunkel-Schetter et al., 1992). Previous research suggests that coping efforts are at their maximum during treatment and that at follow-up, less coping efforts are required (Carver et al., 1993). Therefore:

**Hypothesis 5a) – Men in the earlier stages of the illness will report using more coping strategies than men at follow-up such that, treatment>diagnosis>follow-up.**

**Hypothesis 5 b)- There will be a significant difference in the type of coping strategies used between the groups.**

Any systems model of adjustment to illness must take account of both disease related and non-disease-related variables (Rowland, 1989 & Blanchard and Harper, 1996).

By taking the process model into account, this study will examine the predictive power of some of these variables that are considered to be important in adjusting to testicular cancer. Therefore;

**Hypothesis 6 - There will be a significant effect of the following variables upon coping, QoL and psychological outcomes: stage of illness, age, employment, previous cancer experience, relationship status and parental status. Other non-cancer-related stressors such as relationship and work-related stresses will also help to predict coping and psychological outcomes.**

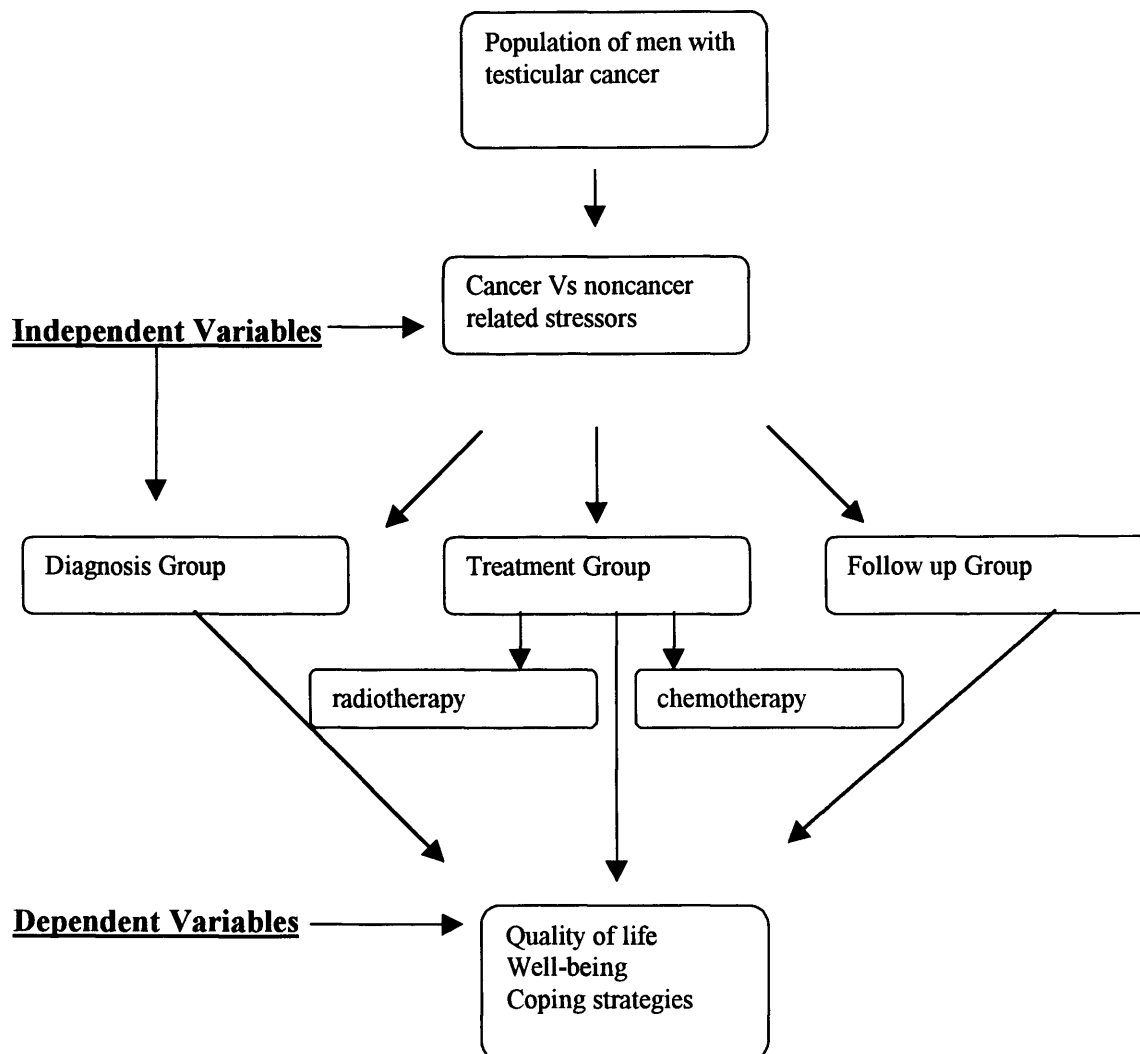
## **2 Method**

### **2.1 Design**

The study was designed to allow both between-group and within-group comparisons as illustrated in Figure 2.1.1 below. The investigation would ideally be suited to a longitudinal repeated measures design. However, owing to time constraints a cross-sectional design was utilised. The participants were grouped according to the main Independent Variable (IV), stage of illness (diagnosis, treatment or follow-up). The nature of testicular cancer ensured that the groups were matched on important sociodemographic variables. Several Dependent Variables (DV's) were assessed in relation to stage of illness. These were defined as cancer-related quality of life (QoL), Coping strategies used and subjective well-being. Other factors that may act as IV's were hypothesised. These included previous cancer experience and concurrent stressors.

Therefore, the design was cross-sectional, allowing both entire sample analyses and between groups differences in the DV's to be examined.

**Figure 2.1.1: Study Design**



## 2.2 Participants

Participants were recruited from the population of men with testicular cancer from the geographical regions of Leicestershire, Nottinghamshire and Derbyshire. All participants were under the care of the Clinical Oncologists at local hospitals.

Permission to carry out the research was granted by each hospital's Ethics Committee. All newly diagnosed patients and those undergoing treatment were eligible for inclusion in the study along with a representative sample of those patients receiving follow-up care.

A letter signed by the consultant and which asked for consent to pass on personal details was sent to each patient (see Appendix 1). Eighty-six patients were approached by their consultants between September 1998 and April 1999. Out of those patients, 73 gave their permission to be contacted by the present researcher.

The eligibility criteria that applied were:

- All men with a diagnosis of primary testicular cancer either, Seminoma or Nonseminoma at stage 1 or 2 of the disease. Those with more advanced cancers (stages 3 and 4) were excluded.
- No previous cancer diagnosis.
- No known history of severe and debilitating physical or mental health problems.
- All men over the age of 18.
- For the follow-up group, not less than one year or more than five years post-recovery.

The patients receiving follow-up care were sent Patient Information Leaflets and Consent forms (See Appendix 2) to bring to their next outpatients appointments. Patients had between one and three months to decide whether they wanted to take part. The researcher was present at four of the monthly outpatient clinics between

September 1998 and May 1999 to approach those that had agreed to take part. Newly diagnosed patients and those undergoing treatment were approached in the same manner. If they agreed to take part, an appointment was arranged to see them either at home before their treatment-planning meeting or at the hospital before the planning meeting. At this stage the participants were unaware of the treatment that they would receive. For those patients undergoing treatment, appointments were arranged when the patients were at the hospital receiving their chemotherapy or radiotherapy.

Due to the relatively small number of patients diagnosed with testicular cancer each year, all of the newly diagnosed patients (n=20) and those undergoing treatment (n=22) who fulfilled the eligibility criteria and had given their permission to be contacted were approached at each site. Two outpatients clinics were attended by the researcher at each site and 31 follow up patients were approached.

Of the 73 patients approached by the researcher, 56 agreed to take part in the study. Sixteen of the 20 patients identified at diagnosis, 20 of the 22 patients undergoing treatment and 20 of the 31 follow-up patients. Two of the patients undergoing treatment were excluded as they were receiving surveillance only. Therefore, there were a total of 16 patients in the diagnosis group, 18 patients in the treatment group and 20 patients in the follow-up group.

Slightly more participants were recruited from the Nottinghamshire and Derbyshire regions as these have greater populations of young, white men who are most at risk for developing testicular cancer. Some of the patients at follow-up were taking part

in an MRC clinical trial and declined to participate. Otherwise, the available information showed that the individuals who did not want to take part in the study did not differ significantly in terms of age, diagnosis, stage at which the cancer was diagnosed, treatment, marital status, employment status or fatherhood status.

Of the patients who agreed to take part, 29 had a diagnosis of seminoma and 24 had a diagnosis of nonseminoma (14 stage 2 and 10 stage 1). All patients had undergone surgery to remove the affected testicle. In the treatment group, participants were receiving either radiotherapy (n=10) or chemotherapy (n=8).

### **2.3 Procedure**

**Follow-up group** – The researcher attended four outpatient clinics, two at each site. Those that had agreed to take part were approached to fill out a battery of questionnaires. It was not necessary to make separate appointments as the patients had to wait for approximately forty-five minutes to see the consultant and then again to have blood tests. The nature of the research was described in more detail. The participants were asked to complete the questionnaires in the order that they were presented. Written instructions for completing the measures were included in the questionnaires and the participants were left to complete them on their own. After approximately thirty minutes the researcher returned, answered any questions and debriefed the participants. They were given a telephone number to contact the researcher if they had any further questions.

**Treatment Group** – The patients were approached in the same manner as the follow-up group. Once permission had been obtained to make contact, each patient was contacted by telephone. An appointment was made to discuss the research during their next radiotherapy or chemotherapy session. Patients were given the opportunity to consider taking part and then approached the next day. Although the majority of patients were experiencing side effects from their treatment, all felt well enough to take part. The questionnaire administration and debrief then took place as with the follow up group.

**Diagnosis Group** – The patients were approached in the same manner as the other groups. It was crucial to interview patients before their treatment plan was decided. Therefore, those who agreed to being contacted were telephoned by the researcher and asked if they would be prepared to discuss the research before their planning meeting. Those that lived some distance from the hospital requested home visits, others were prepared to visit the researcher at the hospital. Despite being given the opportunity to think about taking part, all of the participants requested that they complete the questionnaires immediately. The questionnaire administration was carried out, as with the other groups, however, at the home visits, the researcher was present throughout questionnaire completion.

## 2.4 Measures

The measures were selected because of their suitability for use with this population, their psychometric properties and their relevance to the main research questions.

All measures were completed by each participant and presented in the same order.

Table 2.4.1 below summarises the standardised measures used in the study and gives details of the constructs measured and the authors. Table 2.4.2 below gives the operational definitions for the dependent measures.

**Table 2.4.1:** Standardised measures administered to participants

Measure	Construct(s) measured	Author(s)
EORTC QOLQ-C30 - Core Questionnaire (version 3)	Health related Quality of Life (QoL) of Cancer Patients.	Fayers, Aaronson, Bjordal and Sullivan (1997)
EORTC – Testicular Cancer Module.	QoL issues specific to testicular cancer patients.	Fossa, Moynihan and Serbouti (1996)
COPE (illness specific short form)	Coping with illness	Carver, Sheier and Weintraub (1989)
Satisfaction With Life Scale	Subjective Well-being	Diener, Emmons, Larson and Griffin (1985)
Positive and Negative Affect Scale	Mood <ul style="list-style-type: none"><li>• Positive affect</li><li>• Negative affect</li></ul>	Watson, Clark and Tellegen (1988)

**Table 2.4.2:** Operational definitions of the dependent measures

<b>Dependent Measure</b>	<b>Operational Definition</b>
<b>COPE</b>	‘Adaptive’ and ‘maladaptive’ coping strategies
<b>EORTC QLQ C30</b>	Global Health status/QoL
<b>EORTC Testicular Cancer Module</b>	Physical, Psychosocial and Psychosexual symptoms affecting QoL
<b>PANAS PA</b>	High well-being/good adjustment
<b>NA</b>	Low well-being/poor adjustment
<b>SWLS</b>	High well-being/good adjustment

A copy of the demographic and general information schedule is contained within Appendix 3. These additional questions were included to control for extraneous variables and concurrent stressors that may have been important for each participant. Demographic variables are important in predicting health and health outcomes. Other information such as previous cancer experience was included because the literature on coping with cancer (e.g. Rowland, 1989) indicates that these may be important independent variables.

The order in which the measures were presented for each participant is given below.

- Demographic/General Information Schedule
- EORTC-QOLQ C30 – Core Questionnaire
- EORTC – Testicular Cancer Module
- COPE
- Positive and Negative Affect Schedule (PANAS)
- Satisfaction With Life Schedule (SWLS)

#### 2.4.1 Constructs and the standardised measures used to assess them

##### Health related Quality of Life (QoL)

The European Organisation for Research and Treatment of Cancer (EORTC) have developed an integrated system for assessing the health-related QoL of cancer patients participating in international clinical trials as well as non trial studies. The current version of the questionnaire, QOLQ – C30 version 3 (see Appendix 4) is a 30 item self-administered questionnaire to be used with other cancer specific modules. The questionnaire was designed to be 1) cancer specific, 2) multidimensional in structure, 3) brief and easy to complete, and 4) applicable across a range of cultural settings (Fayers *et al.* 1997). The core questionnaire contains the following scales.

**1) Functional scales** – Physical functioning, Role functioning, Emotional functioning, Cognitive functioning and Social functioning.

**2) Global Health status/QoL**– An overall assessment of health and QoL

**3) Symptom scales/items** – Fatigue, Nausea and vomiting, Pain, Dyspnoea, Insomnia, Appetite loss, Constipation, Diarrhoea and Financial difficulties.

The questionnaire has detailed instructions and the time frame is ‘in relation to the past week’.

The items are rated on a four-point scale from 1 (not at all) to 4 (very much).

Thus a **high score for a functional scale** represents a *high / healthy level of functioning*, a **high score for the global health status / QOL** represents a *high QOL*, but a **high score for a symptom scale / item** represents a *high level of symptomatology / problems* (Fayers *et al.* 1997).

The principle for scoring these scales is the same in all cases:

1. Estimate the average of items that contribute to the scale; this is the raw score.
2. Use a linear transformation to standardise the raw score, so that the score ranges from 0 to 100; a higher score represents a higher level of functioning or a higher level of symptoms.

Aaronson, Bullinger and Ahmedzai, (1993), administered the questionnaire to 305 patients with nonresectable lung cancer from centres in 13 countries, before and once during treatment. They report that the average time to complete the questionnaires was 11 minutes and most patients required no assistance. The data supported the hypothesised scale structure of the questionnaire, i.e. the Cronbach's alpha coefficients that were obtained exceeded the minimum standards for reliability ( $>0.70$ ).

Validity was shown by three findings.

- 1) Interscale correlations were statistically significant, the correlation was moderate, indicating that the scales were assessing distinct components of the quality of life construct.
- 2) The functional and symptom measures discriminated clearly between patients differing in clinical status.
- 3) There were statistically significant changes in the expected direction, in physical and role functioning, global quality of life, fatigue and nausea and vomiting, for patients whose performance status had improved or worsened during treatment.

The reliability and validity have been found to be highly consistent across the language and cultural groups studied (Ringdal and Ringdal, 1993).

Hjermstad, Fossa, Bjordal and Kaasa (1995) examined the test-retest reliability of the questionnaire. Cancer patients were eligible for the study if they had been 'off' treatment for more than three months. The questionnaire was presented to patients at their outpatient appointment. The second questionnaire was received by the patients 4 days later. One hundred and ninety agreed to participate. The test-retest reliability was measured using Pearson's correlation coefficient, which ranged from 0.63 to 0.91 for all of the scales. They concluded that the reliability in patients with various cancer diagnoses whose condition is not expected to change during the time of measurement is adequate.

### **Testicular Cancer Module**

As the approach taken by the EORTC group is strictly a 'core plus modular' one, the testicular cancer module (Fossa, Moynihan and Serbouti, 1996) was administered to gain a more detailed impression of the specific quality of life issues faced by testicular cancer patients. The module consists of 16 items (see Appendix 5), each different to those contained within the core questionnaire. The three scales that related to different domains of quality of life are as follows.

- 1) **Physical symptoms** – Alopecia, Dry ejaculation, Raynaud-like phenomena, Neurotoxicity, Ototoxicity.
- 2) **Psychosocial symptoms** – Self-esteem, Satisfaction with care and Fear of recurrence of the cancer.
- 3) **Psychosexual symptoms** – Fertility concerns, Sexual desire, Impotence, Enjoyment of sex and Satisfaction with sexual relationship.

The instructions, scoring and methods of transformation are the same as for the core questionnaire. With high scores on each scale indicating a high degree of

symptomatology or impairment. Although the module has not been tested to the extent of the core questionnaire, its development followed the strict guidelines put forward by the EORTC. The QoL items were selected following extensive literature reviews, interviews with patients and clinicians. Fossa, Moynihan and Serbouti (1996), administered the questionnaire to 206 testicular cancer patients with different diagnoses (seminoma Vs nonseminoma) and at different stages of the illness and found that the QOL of life issues varied according to stage and type of treatment. The questionnaire is currently being used in International clinical trials. The MRC report adequate levels of validity and reliability.

The EORTC 'core plus module' approach was used to assess QoL as it is such a widely used measure and it taps illness-specific issues. It allows consideration of the relationship between coping and psychological outcomes, i.e. how particular coping strategies may be related to QoL of life outcomes at different stages of the illness. It also helps to highlight the different demands (health and psychological) individuals subjectively report at the differing stages of the illness (Niezgoda and Pater, 1993).

### **Coping with illness**

The COPE is a multidimensional coping inventory developed by Carver, Sheier and Weintraub (1989). After modification they developed the illness specific version (see Appendix 6) which has more stable factor structures than the original version (Carver *et al.*, 1993). This shortened version incorporates nine conceptually distinct subscales that were developed on sound theoretical grounds. The illness specific version of the COPE measures situational coping.

It is divided into the following scales:

1. Problem-Focused Coping (Active Coping): Taking action to remove or circumvent the illness and planning or thinking about one's active coping efforts.
2. Emotion-Focused Coping: Seeking emotional social support and focussing on and venting emotions.
3. Positive Reinterpretation and Growth: Making the best of the situation and viewing the illness in a more favourable light.
4. Acceptance: Accepting the fact that the illness has occurred and is real.
5. Denial: An attempt to reject the reality of the illness.
6. Alcohol and Drug use: Increased usage to help deal with the illness.

The inventory is self-administered and takes approximately 10 minutes to complete.

Separate scores for each of the sub-scales are computed by adding the scores on the items that make up each scale. Since the scores for each item range from 1 ('don't do this at all') to 4 ('do this a lot') the scores for each scale range from 4 to 16. The scores for each scale indicate to what extent each type of coping was used. The scores can be related to independent or dependent variables.

The internal consistency (Cronbach's alpha) of the COPE scales all exceed 0.6 and are therefore acceptably high. Test-retest reliabilities for the modified version range from 0.49 to 0.89 for different scales. The construct validity has also been shown to be acceptable (Weinman, Wright and Johnston, 1995). Interesting sex differences in coping strategies have been reported using the COPE.

Several investigations (Carver et al. 1993 and Sheier and Carver, 1992) have shown that some of the strategies can be reliably classified as 'Adaptive' and 'Maladaptive' in the case of coping with breast cancer. Carver et al. (1993) hypothesise that these are generalizable to other types of cancer. Acceptance, Positive Reinterpretation and Growth and Emotion Focussed Coping are all 'Adaptive Strategies'. Denial, Alcohol/Drug Use and Behavioural Disengagement are 'Maladaptive' strategies. The role of Problem-Focussed coping in cancer is unclear.

The reasons for choosing the COPE are:

- It has stronger psychometric properties than cancer-specific coping inventories (Carver and Scheier, 1994).
- It incorporates a wider range of coping behaviours than other questionnaires (cf. WOC, Folkman and Lazarus, 1988).
- This version relates to illness.
- It is less cumbersome than other measures.
- It has been widely used with cancer patients (Carver et al., 1993).

## **Affect**

Affect or mood was measured using the Positive and Negative Affect Schedule (PANAS) (Watson, Clark and Tellegen, 1988). This measure considers positive and negative affect as separate dimensions. Positive affect (PA) reflects the extent to which a person feels enthusiastic, active and alert and negative affect (NA) reflects the degree to which a person experiences subjective distress and unpleasurable engagement that subsumes a variety of aversive mood states (see Appendix 7).

The schedule consists of 20 adjectives used to describe different feelings and emotions. Ten of the adjectives describe negative moods while the other 10 describe positive moods. Subjects rate their feelings and indicate the extent to which the word describes their feelings on a five-point scale from 'very slightly or not at all' to extremely. The scale is self-administered and takes about five minutes to complete. The time instructions can vary between 'this moment' to 'in general'. For this study the past few days was chosen (see Appendix 7).

Watson, Clark and Tellegen, (1988) report the results from a study of 1002 undergraduates based on completion of the PANAS under the instruction 'the past few days'. They report a mean of 32.0 and a standard deviation of 7.0 for the PA scale and a mean of 19.50 and a standard deviation of 7.0 for the NA scale. No significant sex differences were found.

For the time frame 'the past few days', Watson, Clark and Tellegen (1988), report internal consistency figures (Cronbach's alpha) of 0.88 for PA and 0.85 for NA. The test-retest reliability over an eight week period was 0.48 for PA and 0.42 for NA. Correlation co-efficients between the PA and NA scales was  $-0.22$  which indicates that the scales measure independent dimensions, i.e. that a NA does not predict a PA score. The external validity of the PANAS has been investigated by exploring its relationship to other measures of distress and psychopathology. A correlation of .74 was found between the PANAS and the Hopkins Symptom Checklist (Derogatis et al. 1974) which is a measure of general distress and dysfunction. Watson and Pennebaker (1989, cited in Weinman, Wright and Johnston, 1995) used it in six

studies to establish a relationship between NA and health complaints this further demonstrated the validity of the PANAS.

The PANAS was chosen as a measure of mood for the following reasons:

- It is easy to administer and quick to complete.
- As most of the evidence suggests that cancer patients adapt well in general and that positive outcomes were being analysed in this study, a measure of positive affect was felt to be crucial.
- High levels of NA are related to poor coping and health complaints and high PA is associated with physical and social activity which can be construed as positive coping strategies.

The PANAS was scored to give separate PA and NA scores. Item scores range from 1 to 5 and were summed for each scale giving a possible range of scores from 10-50.

### **Subjective well-being**

The Satisfaction with Life Scale (SWLS) (Diener et al., 1985) measures the cognitive-judgmental component of subjective well-being i.e., general satisfaction with life (see Appendix 8). Along with the PANAS, this gives a good indication of well-being. It is a five item self-report scale on which participants rate their level of agreement on a seven-point scale for each item. It is self-administered and takes approximately two minutes to complete. An individual's score is obtained by adding the ratings for each item. Scores range from 5 (minimal life satisfaction) to 35 (best possible life satisfaction). Although there are no clinical normative data, each of two

student samples yielded mean satisfaction scores of 23.5 (standard deviation = 6.43, N=176) and 23.37 (standard deviation = 6.53, N=156).

The SWLS has good reliability and internal consistency (Weinman, Wright and Johnston, 1995). The authors two-month test-retest reliability was 0.82. The inter-item correlation's are all consistently positive and range from .044 and 0.71 (with a mean of 0.57). The scale was administered for the following reasons:

- It has strong psychometric properties.
- Along with the PANAS it gives a full picture of each individual's subjective well-being without implying psychopathology.
- It is quick and easy to administer.

### **3 Results**

#### **3.1 Description of analysis**

##### **Whole sample comparisons**

In order to assess relationships between well-being measures and coping strategies, one-tailed Pearson's Product Moment Correlation coefficients were calculated at the  $p \leq 0.05$  significance level. T-tests were calculated in order to examine differences between well-being scores for normative groups and between adaptive and maladaptive coping strategies. A series of multiple regression equations were calculated to examine the relative contribution of coping efforts and cancer-related Quality of Life variables to psychological outcomes. Finally, discriminant analyses were performed to examine predictors of adaptive and maladaptive coping strategies.

##### **Between-group comparisons**

Between-group analysis consisted of calculating Analyses of Variances (ANOVAs) with one-tailed linear contrasts, to examine any differences in the dependent variables.

The results are divided into four sections. The first section describes sample characteristics and the relevant illness related Quality of Life issues for all groups. The second section presents entire sample analyses. The third section presents between-group analyses. The final section discusses the predictive power of the various cancer-related and non-cancer-related stressors in relation to coping and

well-being. Analyses are discussed with reference to the hypotheses stated in the introduction.

### **3.2 Justification of analysis**

Before in-depth analysis could proceed, the variables were examined to see if the three major parametric assumptions were met.

#### **a) The dependent measures are at the interval/ratio level of scaling.**

Much debate exists regarding the suitability of Likert measures for parametric analysis (Howell, 1991). However, the measures used, were developed for parametric analysis (Carver, Sheier and Weintraub, 1989 and Aaronson et al, 1993). They possess interval properties as each item is graded on a linear equal interval scale.

#### **b) The distribution of population scores is normal**

The data was visually inspected using histograms with the distribution curve for each variable plotted. The scores of the dependent variables appeared to be normally distributed across the three groups with no significant skewness or kurtosis. The Kolmogorov-Smirnov test was used to statistically test for normal distribution. None of the scores were significantly different at the  $p=0.05$  level.

#### **c) The variances of the variables are homogenous**

Tests of homogeneity of variance were carried out using Levene's Statistic for each of the dependent measures (Coping, Quality of Life, well-being). None of the results were statistically significant, suggesting that there was equality of variances between the groups.

The small difference in sample sizes between the groups was judged insufficient to warrant the use of non-parametric statistics. Bryman and Cramer (1997) suggest making comparisons of results obtained from parametric and non-parametric analysis of between group differences. This revealed no difference between whether scores were significant or not. Finally, Howell (1991) argues that parametric tests are extremely robust and even violations of the assumptions have minimal effects on the power.

### **3.3 Sample Characteristics**

Demographic and Individual information for all participants was obtained from the patient information questionnaire (see Appendix 3). The groups were comparable in terms of demographic variables. An ANOVA revealed no significant age differences between the groups. Chi squared tests indicated that there were no significant differences in terms of education, marital status, employment and parental status.

The sample consisted of young, white males and this is representative of the population of men with testicular cancer (Horwich, 1996). Concerning type of testicular cancer, 53.7% of the sample had a diagnosis of seminoma and 46.3% of nonseminoma. The average age of the whole sample was 33.78 years with a standard deviation of 7.70 years. This accurately reflects the national statistics of peak incidence between 20 and 34 years (Horwich, 1996). For those men that had been diagnosed within the last year, there was a small difference in average age. The mean age for seminoma patients was 34.1 years and for nonseminoma, 29.6 years. The

literature suggests an age difference in incidence with seminoma reaching it's peak incidence at 37 years and nonseminoma at 27 years (Fossa, 1994).

The sample was evenly distributed in terms of treatment received. Radiotherapy had been received or was ongoing for 38.9% of the men and 31.5% had received or were undergoing chemotherapy. The quality of life issues related to treatment received will be discussed in the next section.

Table 3.3a below indicates that more than half of the sample were married or cohabiting and only 14.8% were divorced or separated. This could indicate that divorce rates for men with testicular cancer are lower than national statistics suggest (Moynihan, 1996) or that the sample is younger and has not reached the age at which divorce reaches its peak. There was no significant difference in relationship status between the groups.

**Table 3.3a:** Relationship status of the entire sample (N=54)

<b>Relationship status</b>	<b>N</b>	<b>Percentage (%)</b>
Married/cohabiting	31	57.4
Steady partner	2	3.7
Divorced/separated	8	14.8
Single	13	24.1

A large proportion of the sample (61.1%) felt that their family was not yet complete. Of those men, 48.1% did not have any children and felt that their family was not complete and 13% had children but wanted more in the future. The rest of the

participants reported either that they had children and their family was complete or that their family was complete without children. This reflects the fact that testicular cancer reaches its peak incidence when men are considering starting a family (Rowland, 1989). Table 3.3b below illustrates the differences between the groups. A Chi square test revealed that this difference was not significant at the  $p \leq 0.05$  level.

**Table 3.3 b:** Parental status between groups.

<b>Group</b>	<b>Family complete</b>		<b>Family not complete</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Diagnosis</b>	<b>6</b>	<b>37.5</b>	<b>10</b>	<b>63.5</b>
<b>Treatment</b>	<b>5</b>	<b>27.8</b>	<b>13</b>	<b>72.2</b>
<b>Follow-up</b>	<b>10</b>	<b>50</b>	<b>10</b>	<b>50</b>

Concerning education, the majority of men (57.4%) left school at 16 years. However, 22.2 % left school at 18, and 20.4% went on to further education. If educational achievement is considered as indicative of socio-economic status, the sample seems evenly distributed. This is reflected in the employment status of men in the sample, 83.3% were employed, of these, 25.9% were self-employed. Only 16.7% were unemployed. Again, Chi squared tests revealed no significant difference between the groups for employment status.

The patient information questionnaire (see Appendix 3) included a question about the participants' previous experience of cancer. They were asked if they had known any friends or family members who had suffered from cancer and if so whether they felt the outcome to be positive or negative. Despite the national statistics that cancer

affects 1 in 3 British people (Horwich, 1996), 55.6% reported that they had had no previous experience of cancer. However, 25.9% reported negative experiences with memories of suffering or that the cancer was terminal. Interestingly, no one reported knowing anyone who had had testicular cancer.

Participants were also asked whether they had any other physical health problems, relationship difficulties, and work-related stresses (see Appendix 3). This information is presented in Table 3.3c below. As can be seen, the majority of participants (n=32) reported work related stresses and relatively few (n=14) reported that they had relationship stresses. Very few (n=5) reported any significant physical health problems or illnesses unrelated to testicular cancer. Again, this reflects another characteristic of the impact of testicular cancer on men: it affects men at the peak of their lives in terms of physical well-being (Moynihan, 1996).

**Table 3.3c:** Self-perceived concurrent stresses reported by the sample (N=54)

<b>GROUP</b>	<b>Work Stress</b>		<b>Relationship Stress</b>		<b>Physical Health problems</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
<b>Diagnosis</b>	11	68.8	3	18.8	1	6.3
<b>Treatment</b>	11	61.1	5	27.8	3	16.7
<b>Follow-up</b>	10	50	6	30	1	5

In summary therefore, this sample seems to be representative of the population of men with testicular cancer. The characteristics are comparable with those discussed in the introduction (Rieker et al., 1989, Brodsky, 1995 and Moynihan, 1996).

### 3.4 Illness-related Quality of Life (QoL) issues.

Due to the fact that the EORTC QoL Questionnaire incorporates a large number of variables and that many of the symptom and functional scales applied only to the participants undergoing treatment, a brief descriptive analysis is given. Tables 3.3a, 3.3b and 3.3c below gives scores obtained on the functional scales of the EORTC core questionnaire and the testicular tumour module. All scores are out of 100.

**Table 3.4a:** Description of EORTC QoL functional scores for the entire sample  
(N=54)

	<b>Mean</b>	<b>Standard Deviation</b>
<b>Physical Functioning</b>	86.88	20.88
<b>Role Functioning</b>	77.28	29.40
<b>Emotional Functioning</b>	71.76	19.05
<b>Cognitive Functioning</b>	93.21	14.30
<b>Social Functioning</b>	79.32	26.09

The data suggests that, as a whole, this sample of men with testicular cancer function well in most domains.

**Table 3.4b:** Percentages of men reporting moderate to severe symptoms

associated with general cancer treatment for each group (N=54)

	<b>Diagnosis (n=16)</b>	<b>Treatment (n=18)</b>	<b>Follow-up (n=20)</b>
<b>Fatigue</b>	37.5	100	10
<b>Nausea and/or vomiting</b>	6.3	72.2	0
<b>Pain</b>	62.5	0	5
<b>Breathlessness</b>	0	11.1	20
<b>Insomnia</b>	18.8	38.9	20
<b>Appetite Loss</b>	0	83.3	10
<b>Constipation</b>	0	5.6	0
<b>Diarrhoea</b>	0	50	0
<b>Financial difficulties</b>	37.5	12.5	30

**Table 3.4c:** Percentages of men reporting moderate-severe symptoms associated

with specific testicular cancer treatment for each group (N=54)

	<b>Diagnosis (n=16)</b>	<b>Treatment (n=18)</b>	<b>Follow-up (n=20)</b>
<b>Physical symptoms</b>	0	69.3	20
<b>Psychosocial symptoms</b>	87.4	88.2	55
<b>Psychosexual symptoms</b>	31.3	66.7	60

The tables illustrate that in most instances, those men in the treatment group report more symptoms associated with the medical treatment of testicular cancer. The diagnosis group clearly reports significantly more pain than the other groups, and this is likely to be due to surgery (Horwich, 1996). This is an expected finding (Fossa, 1994). It is interesting to note that the psychosocial symptoms seem very high for all groups. This may in part be because the scale includes the item 'fear of recurrence' and most men no matter what stage of illness responded positively to this (92%). Although the psychosexual symptoms are slightly higher in the treatment group, they remain elevated at follow-up. The large percentage is a somewhat unexpected

finding, although it does reflect the literature concerning the possible long-term effects of testicular cancer (Moynihan, 1996).

Analyses of Variance (ANOVAs) were carried out with 2 and 51 degrees of freedom at the  $p < 0.05$  significance level, to examine whether differences between groups in QoL scores were statistically significant. There are too many comparisons to report here. However, all between-groups means were statistically different apart from psychosexual functioning where  $p = 0.771$ . Those that were significant at the  $p < 0.05$  level were further investigated with linear contrasts with 51 degrees of freedom. The analysis indicates that on all cancer-related quality of life measures, participants in the treatment group reported lower functioning and greater symptomatology compared to the follow-up and diagnosis groups. However, in terms of emotional functioning, participants in the diagnosis ( $t(51) = -3.25, p < 0.01$ ) and treatment groups ( $t(51) = -2.72, p < 0.01$ ) scored significantly lower than the follow-up group although there was no significant difference between their scores ( $t(51) = 0.66, p > 0.05$ ). And on the testicular tumour QoL questionnaire, the diagnosis ( $t(51) = 2.046, p > 0.05$ ) and treatment ( $t(51) = 3.58, p < 0.01$ ) groups reported more psychosocial symptoms than the follow-up group although there was no significant difference between their scores ( $t(51) = 1.34, p > 0.05$ ).

It was also deemed important to examine differences between QoL issues within the treatment group. Two-tailed independent sample t-tests were calculated at the  $p < 0.05$  significance level to examine differences in scores for participants receiving chemotherapy or radiotherapy. No significant differences were found apart from radiotherapy groups reporting significantly more diarrhoea ( $t(9) = 6.332, p < 0.01$ ).

### 3.5 General analyses

#### Key to abbreviations used

**PANAS** – Positive And Negative Affect Schedule

**PA** – Positive Affect

**NA** – Negative Affect

**SWLS** – Satisfaction With Life Scale

**GHS/QoL** – Global Health Status/QoL

**PRG** – Positive Reinterpretation and Growth

**EFC** – Emotion-focussed coping

**PFC** – Problem-focussed coping

**A/DU** – Alcohol/Drug Use

#### 3.5.1 Hypothesis 1 – There will be no significant difference between the self perceived psychological well-being of men with a diagnosis of testicular cancer receiving follow-up care and normative groups.

The psychological well-being scores obtained for the follow-up group were compared with published norms from large samples of college students (age range 18-30) for the PANAS (Watson, Clark & Tellegen, 1988) and the SWLS (Diener, Emmons, Larson, & Griffin, 1985). Their samples consisted of equal numbers of males and females and they found no differences in scores between the sexes or age ranges. The means and standard deviations are given in Table 3.5.1a below.

**Table 3.5.1a:** Means and standard deviations of scores on the psychological well-being measures

	<u><b>SWLS</b></u>		<u><b>PANAS-PA</b></u>		<u><b>PANAS-NA</b></u>	
	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>
<b>Follow-up group</b>	24.75	6.70	28.10	7.19	20.45	7.99
<b>Normative sample</b>	23.50	6.43	32	7.00	19.50	7.00

Table 3.5.1a shows that whilst all standard deviations seemed equal the mean scores for the follow-up group of the present sample are lower for PA and slightly higher for NA and SWLS scores. A series of two-tailed paired t-tests were calculated at the  $p < 0.05$  significance level. The results are presented in Table 3.5.1b below.

**Table 3.5.1b:** Results of paired t tests comparing present data from the follow-up group (n=20) with that obtained from normative samples (N=>150)

	t	df
<b>SWLS vs Normative scores</b>	0.83 (ns)	19
<b>PANAS PA vs Normative scores</b>	-2.42*	19
<b>PANAS NA vs Normative scores</b>	0.834 (ns)	19

\*significant at the  $p < 0.05$  level  
(ns) not significant

Although the PA scores were significantly lower, they were not deemed clinically significant and on the whole this indicates that survivors of testicular cancer adjust remarkably well to the demands of the illness over time (Moynihan, 1996). Specific between-group comparisons will be discussed in section 3.6.

### **3.5.2 Hypothesis 2 – There will be significant positive correlations between self-perceived global health status/QoL scores and psychological well-being scores.**

Pearson's Product Moment Correlation Coefficients (Pearson's  $r$ ) were calculated to establish the strength of the relationships between QoL scores and psychological well-being. Scattergrams were plotted and visual inspection indicated that they were

homoscedastic and that bivariate correlations were suitable. The results are presented in Table 3.5.2a below. The table shows that the well-being measures and illness-related QoL measures are related. As expected, SWLS and PA scores are positively correlated with QoL and NA scores are negatively correlated with QoL. This confirms that there is a relationship between QoL and Psychological Well-being.

**Table 3.5.2a:** Correlation Coefficients for the well-being measures and GHS/QoL  
(N=54)

	<b>GHS/QoL</b>	<b>SWLS</b>	<b>PANAS -PA</b>	<b>PANAS –NA</b>
<b>GHS/QoL</b>	.	0.52**	0.49**	-0.51**
<b>SWLS</b>	0.52**	.	0.56**	-0.47**
<b>PANAS - PA</b>	0.49**	0.56**	.	-0.51**
<b>PANAS – NA</b>	-0.42**	-0.47**	-0.51**	.

**\*\* significant at  $p < 0.01$  level (2-tailed)**

### **3.5.3 Relationship between coping strategies**

Means and standard deviations for the seven separate coping strategies are given in Table 3.5.3a below.

**Table 3.5.3a:** Descriptive statistics for coping strategies for the whole sample

(N=54)

Coping Strategy	Mean	Min.	Max.	SD
<b>PRG</b>	8.78	4	16	3.24
<b>EFC</b>	13.33	6	20	3.91
<b>PFC</b>	16.00	8	25	4.89
<b>Denial</b>	7.83	4	14	2.99
<b>Acceptance</b>	11.02	4	16	4.06
<b>A/DU</b>	6.37	4	13	3.18
<b>BD</b>	2.43	2	8	1.11

In order to establish the extent of the relationship between coping strategies, Correlation Coefficients (Pearson's  $r$ ) were calculated at the two-tailed,  $p < 0.05$  level for each of the seven coping strategies assessed by the illness-specific version of the COPE. Significant correlations are presented in Table 3.5.3b below.

**Table 3.5.3b:** Significant correlations between coping strategies

Variable pairs	Pearson's $r$
PRG & EFC	0.23*
PRG & Denial	-0.77**
PRG & Acceptance	0.76**
PRG & A/DU	-0.27*
EFC & PFC	0.33**
EFC & Denial	-0.29*
Denial & Acceptance	-0.67**
Denial & A/DU	0.29*

\*\* significant at  $p < 0.01$  level

\* significant at  $P < 0.05$  level

The above table clearly shows that there is a very strong positive relationship between participant's use of adaptive coping strategies. PRG, Acceptance and Emotion-focussed coping are all hypothesised to be adaptive in situations where the opportunity to exert control is minimal (Carver, Sheier and Weintraub, 1989). The

maladaptive coping strategies of Denial and A/DU are negatively correlated with the adaptive strategies. Interestingly the use of Behavioural Disengagement did not relate significantly to any strategies (cf. Carver *et al.*, 1993). This was due to the fact that virtually no participants reported using this strategy. Unexpectedly, PFC and EFC coping strategies were positively correlated indicating that participants used both of these groups of coping strategies to a certain degree. The fact that they are correlated indicates that they do not measure mutually exclusive coping strategies.

In order to test hypothesis 3, analysis had to be divided into a number of procedures. Firstly Pearson's Product Moment Correlation Coefficients (Pearson's  $r$ ) were calculated at the one tailed,  $p < 0.05$  significance level to test the following assumptions.

**Hypothesis 3a- There will be a significant negative correlation between maladaptive and adaptive coping strategies.**

As predicted this one tailed correlation was statistically significant with  $r = -0.60$  and  $p < 0.01$ , therefore individuals did not appear to use both types of strategy equally. As the use of adaptive strategies increases, the use of maladaptive strategies decreases and vice versa.

**Hypothesis 3b- There will be significant positive correlations between adaptive coping strategies and well-being and QoL scores.**

**Hypothesis 3c- There will be significant negative correlations between maladaptive coping strategies and well-being and QoL scores.**

The results are presented in Table 3.5.4a and b below.

**Table 3.5.4a:** Correlation coefficients (Pearson's  $r$ ) obtained for the relationships between well-being measures and adaptive coping strategies (N=54)

Well-being measure	Pearson's $r$
PA	0.56**
NA	-0.55**
SWLS	0.48**
GHS/QoL	0.74**

**\*\*significant at  $p < 0.01$  level (1-tailed)**

The above table shows that there are very strong relationships between well-being scores and adaptive coping strategies. The significant negative correlation between adaptive coping and negative affect is in the expected direction.

**Table 3.5.4b:** Correlation coefficients (Pearson's  $r$ ) obtained for the relationships between well-being scores and maladaptive coping strategies (N=54)

Well-being measure	Pearson's $r$
PA	-0.60**
NA	0.39**
SWLS	-0.46**
GHS/QoL	-0.47**

**\*\*significant at  $p < 0.01$  level (1-tailed)**

As expected, in contrast to adaptive coping, maladaptive coping was negatively associated with well-being and QoL. The positive correlation between NA and maladaptive coping indicates that as NA increases, so does the use of maladaptive coping strategies (or vice versa).

In order to test the main hypothesis that there will be a significant difference between the use of coping strategies for high and low well-being scores, median scores were

calculated for each well-being measure. The median well-being score was used as the grouping variable (i.e. above or below) and differences in mean scores for adaptive and maladaptive coping strategies as the test variable. One-tailed independent samples t-tests were then calculated at the  $p < 0.05$  significance level.

**Table 3.5.4c:** Results of t-tests for differences between the use of adaptive coping strategies and low vs. high well-being/QoL scores (N=54)

Dependent Measure	t	df
EORTC-GHS/QoL	-1.92(ns)	52
SWLS	-3.95**	52
PANAS-PA	-4.38**	52
PANAS-NA	5.28**	52

**\*\*significant at  $p < 0.01$  level (1-tailed)**  
**(ns)not significant**

**Table 3.5.4d:** Results of t-tests for differences between the use of maladaptive coping strategies and low vs high well-being/QoL scores (N=54).

Dependent Measure	t	Df
EORTC-GHS/QOL	-0.40(ns)	52
SWLS	3.23**	52
PANAS-PA	4.28**	52
PANAS-NA	-4.33**	52

**\*\*significant at  $p < 0.01$  level (1-tailed)**  
**(ns) not significant**

The analyses presented above confirm the hypothesis that there is a difference between coping strategies used by participants with lower vs. higher well-being

scores. Those participants with higher well-being scores used significantly more adaptive coping strategies than participants with lower well-being scores. Similarly, participants with higher well-being scores used significantly less maladaptive coping strategies than participants with lower well-being scores. The only non-significant finding was the difference between GHS/QoL. The findings indicate a strong association between the use of situation-specific coping strategies and psychological outcomes.

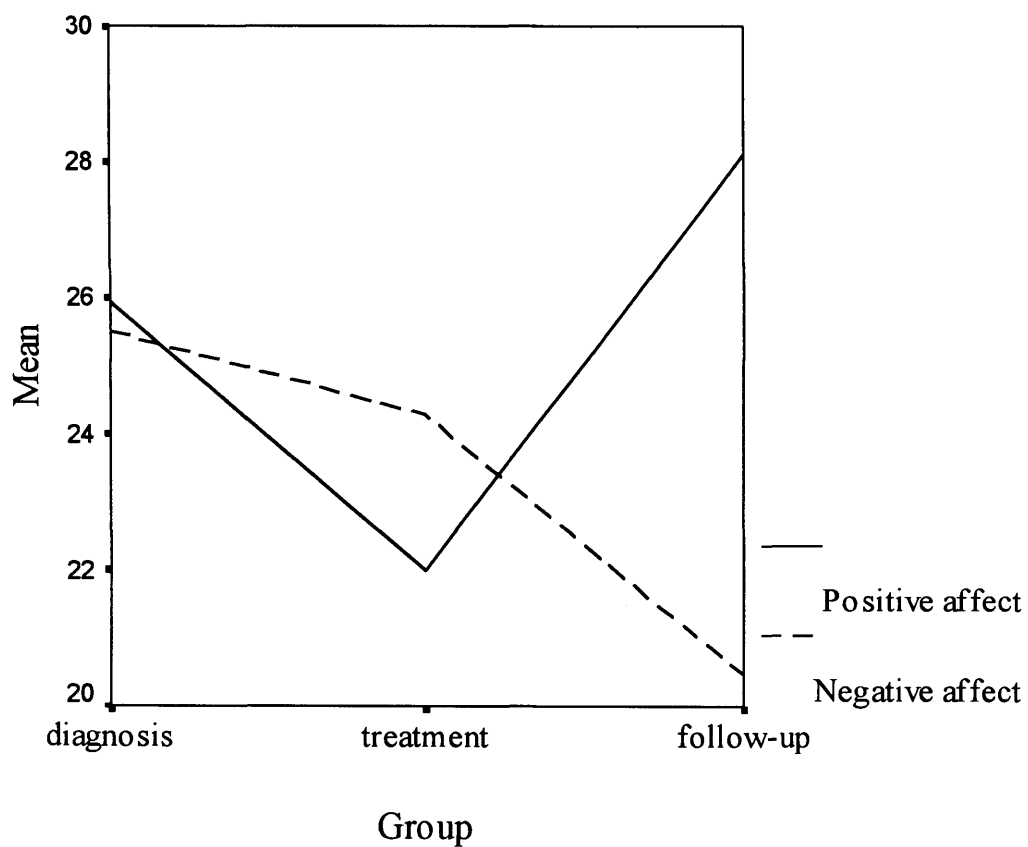
### **3.6 Between group comparisons**

#### **3.6.1 Differences in well-being scores between the three groups**

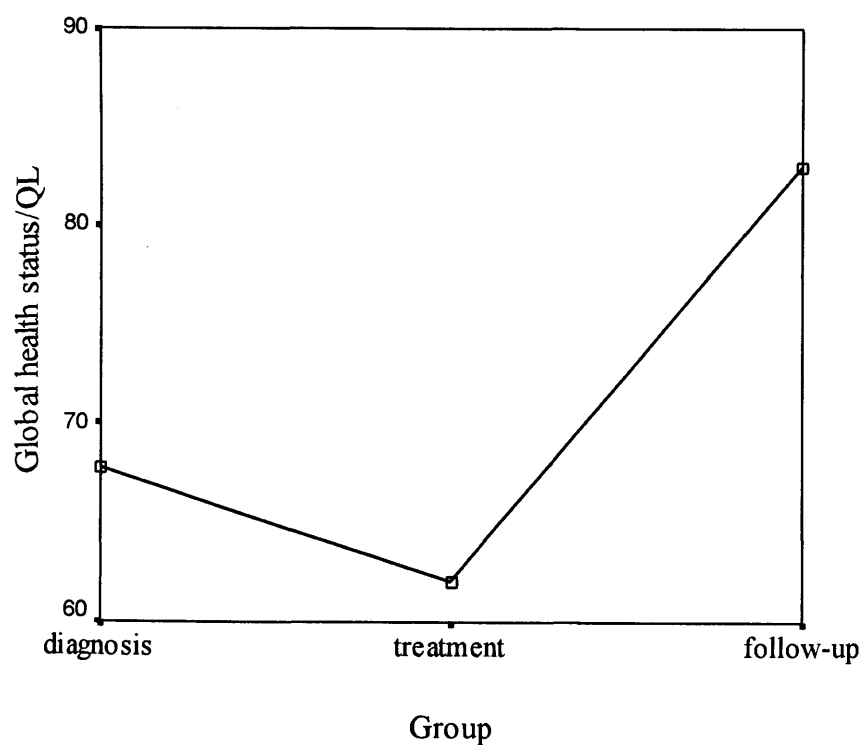
**Hypothesis 4 – There will be a significant temporal difference between the self-perceived well-being and GHS/QoL scores for the three stages of the illness, such that, treatment<diagnosis<follow-up.**

Visual inspection of Figures 3.6.1a to c below shows that the mean scores in the follow-up group are higher, with the exception of NA scores that are lower. The means for the treatment group are lowest with the exception of NA, which seems to be highest in the Diagnosis group.

**Figure 3.6.1a:** Mean well-being scores for the three groups.



**Figure 3.6.2b:** Mean GHS/QoL scores for the three groups.



**Figure 3.6.1c:** Mean SWLS scores for each of the three groups.

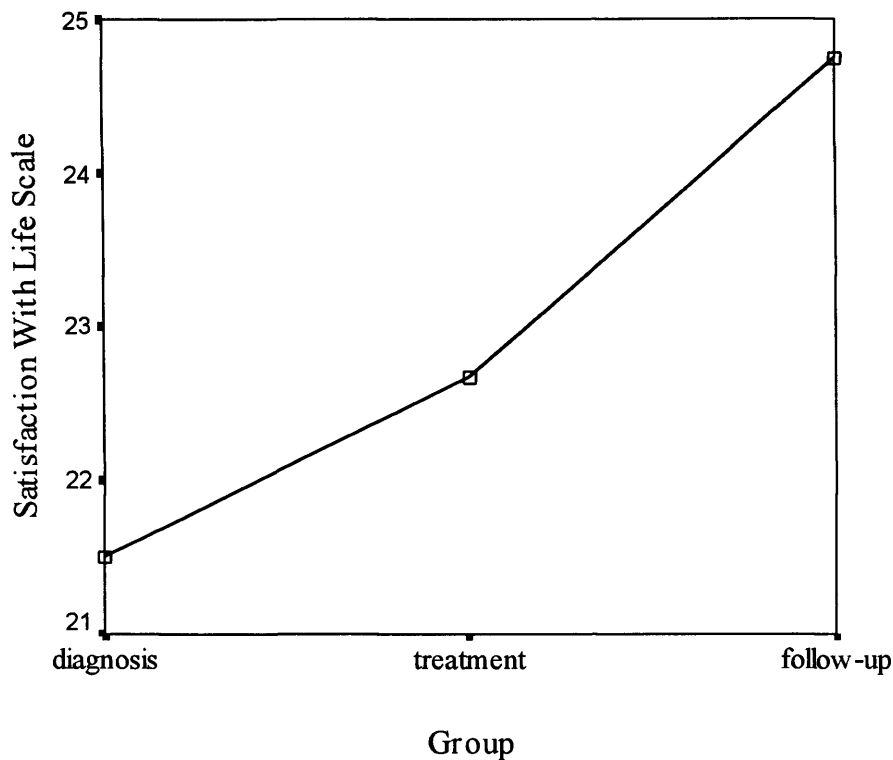


Table 3.6.1a below presents descriptive statistics and results of the ANOVAs for the three groups. A priori comparisons in the form of linear contrasts were calculated because differences were predicted before the major analyses were carried out. The results of the linear contrasts are presented in Tables 3.6.1 b and c.

**Table 3.6.1a:** Mean well-being scores, standard deviations (in brackets) and results of the ANOVAs for differences in well-being scores between the groups (N=54)

	Diagnosis	Treatment	Follow-up	F	Df
GHS/QoL	67.71 (13.57)	62.03 (15.45)	82.99 (10.37)	12.91**	2,53
SWLS	21.50 (4.29)	22.67 (4.55)	24.75 (6.70)	1.70(ns)	2,53
PA	25.94 (4.17)	22.00 (6.26)	28.10 (7.19)	4.78**	2,53
NA	25.50 (4.82)	24.28 (6.84)	20.45 (7.99)	2.78(ns)	2,53

\*\*significant at  $p < 0.01$  level  
(ns) not significant

Table 3.6.1a shows that there were significant differences between groups for GHS/QoL and PA. Differences in NA just failed to reach significance ( $F(2,53)=2.78, p=0.07$ ). Interestingly, the SWLS scores were not significantly different, indicating that the construct measured is less affected by stage of illness. This suggests that the cognitive judgmental aspect of well-being is more stable than affect.

**Table 3.6.1b:** Results of the linear contrasts calculated between the groups for GHS/QoL (N=54)

Contrasted groups	t
Treatment/Follow-up	-4.85**
Diagnosis/Follow-up	-3.72**
Treatment/diagnosis	-1.76**

**\*\*significant at  $p<0.01$  (1-tailed)**

The contrasts show that the follow-up group had significantly higher GHS/QoL scores than the treatment and diagnosis groups. However, there was no significant difference between the diagnosis and treatment groups. Therefore, hypothesis 4 has been partially confirmed for GHS/QoL.

**Table 3.6.1c:** Results of the linear contrasts calculated between the groups for PA (N=54)

Contrasted groups	t
Treatment/Follow-up	-3.07**
Diagnosis/Follow-up	-1.05(ns)
Treatment/diagnosis	-1.87(ns)

**\*\*significant at  $p<0.01$  level (1 tailed)**  
**(ns) not significant**

The results of the contrasts for PA presented in Table 3.6.1c above indicate that PA scores are significantly higher in the follow-up group than in the treatment group but surprisingly, there was no significant difference between the Follow-up and diagnosis groups. PA scores for the diagnosis group were higher, although just failed to reach statistical significance ( $p=0.06$ ), than the treatment group. Therefore, hypothesis 4 has been partially confirmed for PA.

### **3.6.2 Differences in coping strategies used between the groups**

A median split was performed to gain an impression of the number of subjects using each coping strategy. For each participant, a given coping strategy was defined as having been used to a relatively high degree if it was reported at a level above the group median (see Carver *et al.* 1993). Over 80% of the sample used between two and four coping strategies. Four participants used just one coping strategy and only six participants used 5-6 coping strategies in order to cope with their illness.

**Hypothesis 5a – Men in the diagnosis and treatment groups will report using more coping strategies than men in the follow-up group, such that treatment>diagnosis>follow-up.**

The number of separate coping strategies used by participants in each group was summed and the descriptive statistics and results of the ANOVA are presented in Table 3.6.2a below.

**Table 3.6.2a:** Means and Standard Deviations (in brackets) and the results of the ANOVA for differences in the number of coping strategies used by each group (N=54)

	<b>Diagnosis</b>	<b>Treatment</b>	<b>Follow-up</b>	<b>F</b>	<b>df</b>
<b>Number of coping strategies used</b>	2.50 (0.89)	3.11 (0.90)	3.80 (1.24)	7.04**	2,51

**\*\*significant at  $p < 0.01$  level (1-tailed)**

Although Table 3.6.2a shows that there is a small difference in the number of coping strategies used by each group. This difference is not in the expected direction.

Patients at follow-up report using more coping strategies than patients undergoing treatment. Patients at diagnosis report using less coping strategies than during treatment and follow-up. Patients at follow-up were expected to report using fewer strategies. The difference in the number of coping strategies used between the groups was significant. The linear contrasts revealed that the significant differences were between the follow-up and diagnosis groups,  $t(51) = 3.73$ ,  $p < 0.01$ , and the follow-up and treatment groups,  $t(51) = 2.04$ ,  $p < 0.05$ . The small difference between the treatment and diagnosis groups was not significant,  $t(51) = 1.71$ ,  $p > 0.05$ .

**Hypothesis 5b- There will be a significant difference in the types of coping strategies used between the groups.**

Figure 3.6.2a below shows that the mean scores for adaptive and maladaptive coping strategies were different between the groups

**Figure 3.6.2:** Mean scores for the use of adaptive and maladaptive coping strategies for the three groups.

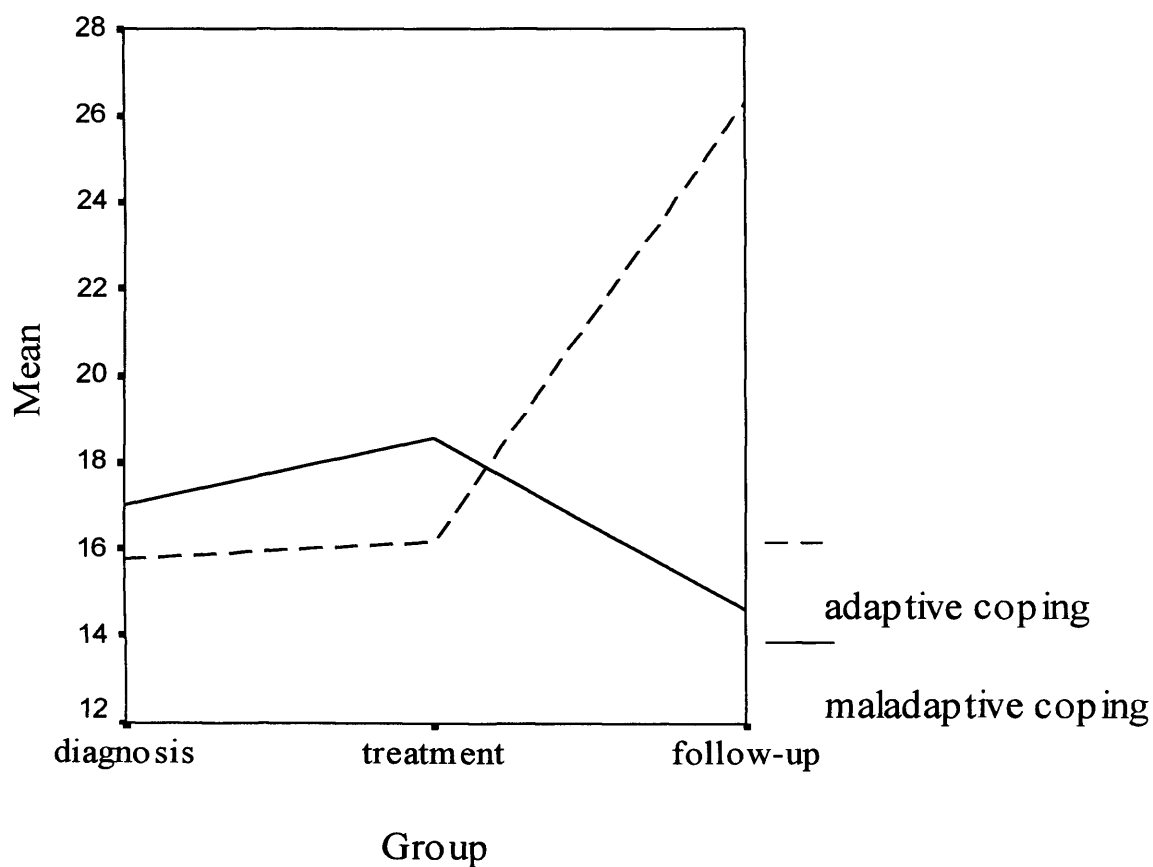


Table 3.6.2b below gives the means, standard deviations and the results of the ANOVAs for the scores on the different coping scales for each group.

**Table 3.6.2.b: Means, standard deviations (in brackets) and results of the ANOVAs**  
for coping strategy scores for each of the three groups (N=54)

	<b>Diagnosis</b>	<b>Treatment</b>	<b>Follow-up</b>	<b>F</b>	<b>df</b>
<b>PRG</b>	7.06 (2.20)	7.06 (2.75)	11.70 (2.10)	24.18**	2,51
<b>EFC</b>	12.81 (4.28)	13.5 (3.98)	13.60 (3.70)	0.19 (ns)	2,51
<b>PFC</b>	16.13 (5.75)	16.39 (5.21)	15.55 (3.99)	0.42 (ns)	2,51
<b>D</b>	9.38 (3.36)	8.56 (2.59)	5.95 (1.91)	8.55**	2,51
<b>A</b>	8.69 (3.14)	9.11 (3.59)	14.60 (2.28)	22.38**	2,51
<b>A/DU</b>	5.38 (2.50)	7.56 (3.67)	6.10 (2.99)	2.21 (ns)	2,51
<b>BD</b>	2.25 (0.77)	2.44 (0.86)	2.55 (1.50)	0.32 (ns)	2,51

**\*\*significant at  $p < 0.01$  level (1 tailed)**  
**(ns) not significant**

Linear contrasts were calculated to investigate these differences further. The results are detailed in tables 3.6.2b to e below.

As expected, there were significant between group differences in the use of the adaptive coping strategies of Positive reinterpretation and growth and Acceptance, and Denial as a maladaptive coping strategy. The broader strategies assessed by the EFC and PFC scales were not significantly different. Therefore hypothesis 5b is only partially confirmed.

**Table 3.6.2c:** Results of the linear contrasts calculated between the groups for  
Positive Reinterpretation and Growth

Contrasted groups	t
Follow-up/Treatment	6.04**
Follow-up/Diagnosis	5.83**
Treatment/Diagnosis	0.04 (ns)

**\*\*significant at  $p < 0.01$  level (1-tailed)**  
**(ns) not significant**

The contrasts show that the follow-up group had significantly higher PRG scores than the diagnosis and treatment groups. The difference in scores between the treatment and diagnosis groups was not significant.

**Table 3.6.2d:** Results of the linear contrasts calculated between the groups for  
Denial

Contrasted groups	t
Follow-up/Treatment	-3.05**
Follow-up/Diagnosis	-3.88**
Treatment/Diagnosis	0.91 (ns)

**\*\*significant at  $P < 0.01$  level (1-tailed)**  
**(ns) not significant**

Again, the results of the contrasts are in the expected direction. Participants in the diagnosis and treatment groups had significantly higher scores for Denial than did participants in the follow-up group. The difference in scores between the treatment and diagnosis group was not significant.

**Table 3.6.2e:** Results of the linear contrasts calculated between the groups for  
Acceptance

Contrasted groups	t
Follow-up/Treatment	5.59**
Follow-up/Diagnosis	5.83**
Treatment/Diagnosis	0.41 (ns)

**\*\*significant at  $p < 0.01$  level (1-tailed)**  
**(ns) not significant**

The final set of contrasts revealed significant differences in the expected direction. The follow-up group reported significantly higher acceptance scores than the treatment and diagnosis groups. The difference between acceptance scores for the diagnosis and treatment groups was not significant.

### **3.7 Relationships between coping strategies, psychological outcomes and variables assessed in the Patient Information Questionnaire (Hypothesis 6)**

Relationships between psychological well-being, coping strategies, QoL and other outcome variables were analysed further using multiple linear regression and discriminant analysis. The theoretical literature discussed in the introduction was drawn upon to determine which coping strategies and QoL issues (Independent Variables) were most likely to explain well-being scores (Dependent Variables). Conversely, the literature was also drawn upon to determine which psychological outcome measures (Independent Variables) were most likely to explain the use of coping strategy. Due to the small sample size, multiple regression equations were calculated for the entire sample.

Because most of the variables assessed in the patient information questionnaire were categorical, discriminant analysis was used to predict group membership for high and low scores for 'adaptive' and 'maladaptive' coping. Whilst this technique may ignore the richness of the data, it is flexible regarding the variables analysed.

### **3.7.1 Results of multiple regression equations to explain affect**

The independent variables were selected based on significant correlation coefficients. All of the independent variables were entered using the stepwise method in order to calculate the multiple coefficient of determination ( $R^2$ ). The stepwise method was chosen as it is regarded as exploratory. It eliminates all variables that fail to reach statistical significance. The standardised regression coefficient, beta, was used, as this allows comparison of the relative importance of each of the independent variables in relation to the dependent variable. The tolerance statistic was over 0.70 for all of the calculations and this suggests that multicollinearity is unlikely. The results are given in Tables 3.7.2a-f below.

Table 3.7.1a below indicates that 45% of the variance in scores on the dependent variable PA, was accounted for by the independent variables in the equation. High PA scores were significantly predicted by high SWLS scores, high adaptive coping scores and low physical symptom scores.

**Table 3.7.1a:** Multiple regression equation to explain PA scores in relation to coping with testicular cancer (N=54)

<b>Independent Variables</b>	<b>Multiple R<sup>2</sup> (Adjusted R<sup>2</sup>)</b>	<b>Beta</b>
<b>All Variables</b>	0.479 (0.447)	-
<b>SWLS</b>	-	0.371**
<b>GHS/QoL</b>	-	-0.068(ns)
<b>Adaptive coping</b>	-	0.319**
<b>Physical Symptoms</b>	-	-0.240*
<b>Psychosocial Symptoms</b>	-	-0.070(ns)
<b>Psychosexual symptoms</b>	-	-0.134(ns)

**\*\*significant at p<0.01 level**  
(ns) not significant

**\*significant at p<0.05 level**

**Table 3.7.1b:** Multiple regression equation to explain NA scores in relation to coping with testicular cancer (N=54)

<b>Independent Variables</b>	<b>Multiple R<sup>2</sup> (Adjusted R<sup>2</sup>)</b>	<b>Beta</b>
<b>All Variables</b>	0.298 (0.270)	-
<b>SWLS</b>	-	-0.405**
<b>GHS/QoL</b>	-	-0.093(ns)
<b>Maladaptive coping</b>	-	0.132(ns)
<b>Physical Symptoms</b>	-	0.094(ns)
<b>Psychosocial Symptoms</b>	-	0.285*
<b>Psychosexual symptoms</b>	-	0.189(ns)

**\*\* significant at p<0.01 level**  
(ns) not significant

**\*significant at p<0.05 level**

Table 3.7.1b, shows that low scores on the SWLS scale and psychosocial symptoms resulting from the illness, predicted high NA scores. Only 30% of the variance in NA was accounted for by the variables included in the regression equation. No other variables reliably predicted NA scores.

### 3.7.2 Results of multiple regression equations to explain coping strategies

Table 3.7.2a below shows that high GHS/QoL scores, high PA scores and low psychosocial symptom scores are significant predictors of the use of adaptive coping strategies. The model accounts for 58% of the variance in adaptive coping scores.

**Table 3.7.2a:** Multiple regression equation to explain the use of adaptive coping strategies in relation to psychological and physical outcomes in testicular cancer (N=54)

<b>Independent Variables</b>	<b>Multiple R<sup>2</sup> (Adjusted R<sup>2</sup>)</b>	<b>Beta</b>
<b>All Variables</b>	0.595 (0.579)	-
<b>SWLS</b>	-	0.029(ns)
<b>GHS/QoL</b>	-	0.607**
<b>PA</b>	-	0.263*
<b>Physical Symptoms</b>	-	0.076(ns)
<b>Psychosocial Symptoms</b>	-	-0.209*
<b>Psychosexual symptoms</b>	-	-0.059(ns)

**\*\*significant at p<0.01 level  
(ns) not significant**

**\*significant at p<0.05 level**

**Table 3.7.2b:** Multiple regression equation to explain the use of maladaptive coping strategies in relation to psychological outcomes in testicular cancer (N=54)

<b>Independent Variables</b>	<b>Multiple R<sup>2</sup> (Adjusted R<sup>2</sup>)</b>	<b>Beta</b>
<b>All Variables</b>	0.355 (0.342)	-
<b>SWLS</b>	-	-0.184(ns)
<b>GHS/QoL</b>	-	-0.171(ns)
<b>PA</b>	-	-0.595**
<b>Physical Symptoms</b>	-	0.034(ns)
<b>Psychosocial Symptoms</b>	-	0.149(ns)
<b>Psychosexual symptoms</b>	-	0.008(ns)

**\*\*significant at p<0.01 level                      (ns) not significant**

Table 3.7.2b above shows that 35% of the variance in maladaptive coping scores was accounted for by the independent variables in the equation. The only variable that reliably predicted the use of maladaptive coping strategies was low PA scores. Low GHS/QoL scores just failed to reach significance (p=0.061).

Table 3.7.2c below indicates that the IV's accounted for 47% of the variance in PRG scores. High GHS/QoL scores and high PA scores are significant predictors of the use of the coping strategy PRG. Low psychosocial symptom scores just failed to reach significance (p=0.07).

**Table 3.7.2c:** Multiple regression equation to explain the use of the coping strategy

‘PRG’ in relation to psychological outcomes in testicular cancer (N=54)

<b>Independent Variables</b>	<b>Multiple R<sup>2</sup> (Adjusted R<sup>2</sup>)</b>	<b>Beta</b>
<b>All Variables</b>	0.490 (0.470)	-
<b>SWLS</b>	-	0.074(ns)
<b>GHS/QoL</b>	-	0.508**
<b>PA</b>	-	0.292*
<b>Physical Symptoms</b>	-	0.110(ns)
<b>Psychosocial Symptoms</b>	-	-0.205(ns)
<b>Psychosexual symptoms</b>	-	-0.134(ns)

**\*\*significant at p<0.01 level**  
(ns) not significant

**\*significant at p<0.05 level**

**Table 3.7.2d:** Multiple regression equation to explain the use of the coping strategy

‘Denial’ in relation to psychological outcomes in testicular cancer (N=54)

<b>Independent Variables</b>	<b>Multiple R<sup>2</sup> (Adjusted R<sup>2</sup>)</b>	<b>Beta</b>
<b>All Variables</b>	0.342 (0.316)	-
<b>SWLS</b>	-	0.085(ns)
<b>GHS/QoL</b>	-	-0.267*
<b>PA</b>	-	-0.405**
<b>Physical Symptoms</b>	-	-0.184(ns)
<b>Psychosocial Symptoms</b>	-	0.060(ns)
<b>Psychosexual symptoms</b>	-	0.169(ns)

**\*\* significant at p<0.01 level**  
(ns) not significant

**\*significant at p<0.05 level**

The IV's accounted for 32% of the variance in scores for denial. The only significant predictors of denial were low PA and GHS/QoL scores.

The multiple regression equation in Table 3.7.2e below indicates that the IV's accounted for 54% of the variance in scores for acceptance. It shows that high GHS/QoL scores and low psychosocial symptomatology significantly predicted the use of the coping strategy 'acceptance'. GHS/QoL was by far the strongest predictor.

**Table 3.7.2e:** Multiple regression equation to explain the use of the coping strategy 'Acceptance' in relation to psychological outcomes in testicular cancer (N=54)

<b>Independent Variables</b>	<b>Multiple R<sup>2</sup> (Adjusted R<sup>2</sup>)</b>	<b>Beta</b>
<b>All Variables</b>	0.559 (0.542)	-
<b>SWLS</b>	-	0.097
<b>GHS/QoL</b>	-	0.600**
<b>PA</b>	-	0.171(ns)
<b>Physical Symptoms</b>	-	0.010(ns)
<b>Psychosocial Symptoms</b>	-	-0.227*
<b>Psychosexual symptoms</b>	-	0.006(ns)

**\*\*significant at p<0.01 level  
(ns) not significant**

**\*significant at p<0.05 level**

Table 3.7.2f below shows that none of the IV's were strong predictors of alcohol or drug use, and they only accounted for 11% of the variance in scores. This reflects the finding that most men reported using alcohol somewhat and that other unidentified IV's may be important here.

**Table 3.7.2f:** Multiple regression equation to explain the use of the coping strategy

‘Alcohol/Drug use’ in relation to psychological outcomes in testicular cancer (N=54)

<b>Independent Variables</b>	<b>Multiple R<sup>2</sup> (Adjusted R<sup>2</sup>)</b>	<b>Beta</b>
<b>All Variables</b>	0.114 (0.097)	-
<b>SWLS</b>	-	-0.338*
<b>GHS/QoL</b>	-	-0.152(ns)
<b>NA</b>	-	-0.277(ns)
<b>Physical Symptoms</b>	-	0.211(ns)
<b>Psychosocial Symptoms</b>	-	0.167(ns)
<b>Psychosexual symptoms</b>	-	-0.110(ns)

**\*significant at p<0.05 level**

**(ns) not significant**

Regression coefficients were also calculated for the broad categories of problem-focussed and emotion-focussed coping strategies using the same independent variables. However, as none of the coefficients were significant and R<sup>2</sup> was very small, the results are not reported here.

### **3.7.3 Results of discriminant analysis**

Tables 3.7.3 a to d below give the models and success of predicted group membership and standardised Canonical Discriminant Function Coefficients for high scores for ‘adaptive’ and ‘maladaptive’ coping strategies.

**Table 3.7.3a:** Significant predictors for the use of adaptive coping strategies

Step	Independent Variable	Wilks' Lambda Statistic
1	Number of coping strategies used	0.672**
2	PA	0.513**
3	Group	0.429**
4	Employment status	0.390**
5	Parental status	0.357**

**\*\*significant at  $p < 0.01$  level**

The variables rejected by the model were the presence/absence of work or relationship stresses, previous cancer experience, concerns about fertility, marital status and GHS/QoL. Eighty seven percent of the original grouped cases were classified correctly. The use of more coping strategies appears to be related to adaptive coping.

**Table 3.7.3b:** Standardised Canonical Discriminant Function Coefficients for adaptive coping

Independent Variable	Coefficient
Group	-0.479
Employment Status	-0.425
Parental status	-0.370
PA	0.737
Number of coping strategies used	0.548

The table above indicates that high scores for adaptive coping strategies are positively related to high PA scores and the use of more coping strategies. High scores for adaptive coping are negatively related to treatment and diagnosis groups, self-employed and unemployed participants and those participants whose families are not complete.

**Table 3.7.3c:** Significant predictors for the use of ‘maladaptive’ coping strategies

Step	Independent Variable	Wilks' Lambda Statistic
1	PA	0.688
2	Employment status	0.635

**\*\*significant at  $p < 0.01$**

The independent variables that were rejected by the model were the same as for adaptive coping strategies plus, parental status, group and number of coping strategies used. Seventy nine-percent of the original grouped cases were classified correctly.

**Table 3.7.3d:** Standardised Canonical Discriminant Function Coefficients for  
maladaptive coping

IV	Coefficient
Employment Status	0.466
PA	-0.959

Table 3.7.3d above indicates that higher scores for maladaptive coping strategies are positively related to self-employed and unemployed participants and that higher PA scores are negatively related to higher scores for maladaptive coping.

### **3.7.4 Summary of the multivariate analyses**

**Hypothesis 6– There will be a significant effect of the following variables upon coping and psychological adjustment: cancer-related QoL, stage of illness, employment, previous cancer experience, work-related stress, relationship-related stress, parental status and fertility concerns.**

Hypothesis 6 has only been partially confirmed. High PA scores, which imply good psychological adjustment were predicted by high SWLS scores, low physical symptom scores and the use of adaptive coping strategies. The use of adaptive coping strategies was further predicted by high GHS/QoL scores and low psychosocial symptom scores. High NA scores, which imply poor psychological adjustment were only predicted by low SWLS scores and more psychosocial symptoms. In general, the use of maladaptive coping strategies was not sufficiently explained. The results of discriminant analysis confirm further the relationship between adaptive coping strategies, PA, number of coping strategies used, group, parental status, and employment. Discriminant analysis did confirm the relationship between low PA scores, employment status, and the use of maladaptive coping strategies. However, no other relationships were established.

## **4 Discussion**

### **4.1 Introduction**

The results will be discussed in relation to health-related QoL and to the hypotheses presented in the introduction. The clinical implications, limitations, and strengths of the present study will be presented before going on to consider ideas for further research.

### **4.2 Health-related QoL**

Health-related QoL was highest at follow-up with men reporting fewer residual symptoms. Men at diagnosis reported higher psychosocial disturbance and men receiving treatment reported the greatest all round physical and psychological disturbances in QoL domains. This supports the notion that it is not the diagnosis of cancer that affects well-being per se, but the side effects of curative therapies (Somerfield, 1997). The major impact at diagnosis appears to be psychological however; treatment adds physical disturbances, which must place even greater demands upon coping resources. The fact that there were no significant differences in effects on QoL between men receiving chemotherapy and radiotherapy supports the notion that both have significant impacts. Although testicular cancer is perceived to be relatively acute and curable, the impact of treatment should not be underestimated. Interestingly, psychosexual disturbances were reported at high levels for all three groups. Whereas this was unrelated to coping and psychological adjustment, it lends weight to earlier research that the impact of testicular cancer is

greatest in this area (Moynihan, 1987 and Rieker et al. 1989). Psychosexual difficulties are treatable and their resolution often has profound impacts upon self-esteem and relationships.

#### **4.3 Psychological well-being at follow-up (Hypothesis 1)**

Although there was no significant difference between the present sample and normative groups for the SWLS scores and NA, the differences between the PA scores were significant. Positive affect scores were significantly lower in the present sample. Whilst this does not imply high levels of psychopathology, it does indicate that the challenge of testicular cancer may have a long-term negative impact on self-perceived psychological well-being. However, high levels of negative affect are related to poor coping and health complaints (Watson and Pennebaker, 1989) and these are not indicated in the follow-up group. The SWLS scores were slightly higher in the present sample than the normative sample. Whilst this is not statistically significant it could indicate a trend. The SWLS scale measures stable cognitive-judgmental aspects of well-being, whilst the PANAS assesses the emotional component of affect that can vary on a day to day basis (Weinman, Wright and Johnston, 1995). Coupled with the high EORTC global health status/QoL and low symptoms scores for this group, this indicates that the majority of men adjust well over time to the demands of their illness. This supports the findings of previous research (Moynihan, 1987) which reports that at follow-up psychological well-being is the norm. It also supports the notion that a more enhanced view of life is experienced by some men (Brodsky, 1995).

#### **4.4 The relationship between psychological well-being measures and Global Health Status/QoL (Hypothesis 2)**

Pearson's correlations revealed that as expected, the well-being and global health status/QoL scores were positively related. Negative affect, which may imply poor adjustment and high levels of health complaints, was negatively related to the other well-being measures. Although the correlation coefficients were statistically significant, the relationships were moderate rather than strong, with Pearson's  $r$  ranging from 0.42 to 0.56. This indicates that they do tap qualitatively different aspects of overall adjustment and well-being (Aaronson et al., 1989). These findings lend support to the validity of the EORTC QLQ C30 core questionnaire as a global assessment of physical and psychological adjustment to cancer.

#### **4.5 The relationship between psychological adjustment and coping strategies (Hypothesis 3)**

The process theory of coping (Lazarus and Folkman, 1984 and Lazarus, 1993) posits that in situations where the stressor is perceived to be controllable then problem-focussed coping strategies are adaptive. However, where the stressor is associated with an illness such as cancer, which is perceived by many to be uncontrollable, then emotion-focussed strategies are helpful. The statistically significant negative correlation between the strategies previously identified as adaptive and maladaptive indicates that individuals do not use both types of strategy concurrently. This is an interesting finding and lends support to earlier research (Dunkel-Schetter et al., 1992 and Carver et al., 1993). The specific strategies that are thought to be adaptive in relation to coping with cancer are positive reinterpretation and growth, emotion-

focussed coping and acceptance. Grouped together these help to foster the fighting spirit attitude that has been found to facilitate recovery (Moorey and Greer, 1989). In contrast the use of the maladaptive strategies behavioural disengagement, using alcohol or drugs and denial are associated with poor health and psychological outcomes in adjusting to cancer (Carver et al., 1993). The status of denial as a maladaptive coping response in cancer is controversial.

The correlations between well-being scores and adaptive coping strategies were all significant. Interestingly the strongest relationship was between global health status/QoL scores and adaptive coping strategies ( $r=0.74$ ). The smallest relationship was between SWLS and adaptive coping. It may be that the more stable construct of life satisfaction, does not vary so greatly as a function of coping or changes in general well-being. Although direction cannot be determined, previous research has indicated that the relationship between coping and adjustment is bi-directional (Blanchard and Harper, 1996). As the stress of cancer demands that different coping strategies are employed at different times, the effectiveness of these is appraised via changes in well-being and global health status. However, changes in well-being must also call for the use of different coping strategies. Although this argument is circular, it is clear that further research is needed in order to determine causality.

Whilst all of the correlations between maladaptive coping strategies and well-being were statistically significant, they were not strong. The relationship between the use of maladaptive coping strategies and positive affect scores was the strongest ( $r=-0.60$ ). Interestingly, the use of maladaptive coping strategies does not strongly imply high negative affect scores ( $r=0.39$ ). Again, the relationship between life satisfaction

and maladaptive coping strategies was moderate. The strength of the relationship between maladaptive coping strategies and global health status/QoL was also only moderate. This indicates that the relationship between high and low well-being and adaptive and maladaptive coping strategies is more complex. At this early stage, the results appear to shed more light on the relationship between, and the function of, adaptive coping strategies and good psychological adjustment.

T-tests revealed significant differences between the use of adaptive coping strategies and high vs. low well-being scores. Men with higher well-being scores, indicating good psychological adjustment, reported using more adaptive coping strategies in order to cope with their illness than participants with low well-being scores. In direct contrast, men with lower well-being scores reported using more maladaptive coping strategies in order to deal with their illness than men with higher well-being scores. This confirms hypothesis number three. It lends support to earlier findings regarding coping and psychological adjustment. For example, Carver et al., (1993) found that for women with early stage breast cancer, the use of adaptive coping strategies prospectively predicted lower distress, indicating good psychological adjustment. Conversely, the use of maladaptive coping strategies prospectively predicted higher distress indicating poor psychological adjustment. Similarly, in their investigation into patterns of coping with cancer, Dunkel-Schetter et al., (1992) found that the strategies labelled in the present study as adaptive were associated with less emotional distress and those labelled as maladaptive were associated with greater emotional distress. These results further clarify the utility of certain coping strategies in the process of adjustment to the demands of cancer. They also indicate that young men with testicular cancer use similar strategies to women with early stage breast

cancer (Carver et al., 1993). Controversially, the findings also indicate that denial is not a useful strategy in coping with cancer at any stage and it may hinder adjustment.

#### **4.6 Temporal differences in well-being (Hypothesis 4)**

The ANOVAs revealed statistically significant differences in some of the well-being scores between the groups. Positive affect was lowest in the treatment group and highest in the follow-up group. All three groups' scores were significantly different (treatment<diagnosis<follow-up). This indicates that there was a main effect for stage of illness. Global health status/QoL scores were also statistically different between the groups. Scores in the diagnosis and treatment groups were significantly lower than in the follow-up groups. The difference in scores between the diagnosis and treatment groups was not significant, although the treatment group's mean score was lower.

This is an expected finding in that cancer-related global health status gives an indication of the impact of treatment factors upon physical and psychological well-being. The high functional status and low symptomology reported by the follow-up group supports the notion that in the longer-term, health status, QoL and well-being return to satisfactory levels. The difference between groups in negative affect was nearly significant and this may indicate a trend. However, the scores were highest in the diagnosis group, not the treatment group. This indicates that high negative affect scores do not necessarily imply poor adjustment to cancer. A larger sample would have made these findings more reliable. The satisfaction with life scores were not

significantly different. As mentioned previously, it may be that the satisfaction with life construct is stable and not affected by changes in psychological well-being associated with the demands of testicular cancer. Future research with larger samples may further clarify these findings.

In summary, there are clear and important differences between the self-perceived well-being of men at different stages of testicular cancer. This indicates that the illness does place different demands on the individual at different stages. Cancer cannot be classified as a unitary stressor (Rowland, 1989 and Somerfield, 1997). So far, it would appear that the demands of treatment place the greatest strain on coping resources and well-being (Moynihan, 1987). The lack of differences between the diagnosis and treatment groups in some areas may reflect the small amount of time between a diagnosis being given and treatment commencing. Although this study does not support the notion that the diagnosis period has the greatest impact on well-being, clinical experience would suggest that its importance cannot be overestimated.

#### **4.7 Temporal differences in the use of coping strategies (hypothesis 5)**

Over 80% of the sample used between two and four coping strategies. Four participants used just one coping strategy and only six participants used 5-6 coping strategies. The difference in the number of coping strategies used by each group was significant, although not in the expected direction. Patients at follow-up reported using more coping strategies than patients undergoing treatment. Patients at diagnosis reported using less coping strategies than during follow-up and treatment. Carver et al. (1993) found, prospectively, that the number of coping strategies used

by women with early stage breast cancer decreased steadily throughout a 12-month period. They concluded that at follow-up women did not need to continue their coping efforts. Although the present study was not prospective, it does indicate that at follow-up men still have to engage in coping efforts in order to maintain adjustment to testicular cancer. It may be the case that the men at follow-up who reported using more coping strategies, would have reported using far more during the earlier stages. Distortions in self-reports cannot be ruled out. Men at follow-up could have retrospectively reported on the strategies that they had used during the earlier, more challenging stages of their illness.

A comment on coping flexibility is relevant here. Men in the follow-up group reported using more coping strategies and had higher well-being scores. Although this could be construed as anecdotal, it gives support to the notion that coping flexibility facilitates good psychological adjustment (Dunkel-Schetter et al., 1992), rather than the ineffectiveness of the coping strategies in use.

As expected, concerning differences in types of coping strategies used, there were significant group differences in the use of the adaptive coping strategies of positive reinterpretation and growth, and acceptance. There were also significant differences in the use of the maladaptive coping strategy, denial. There were no between-group differences in the use of the broader categories of emotion-focussed and problem-focussed strategies. Finally, there were no significant differences in the use the coping strategies of alcohol and drug use or behavioural disengagement. The null findings will be discussed first. Concerning alcohol and drug use, whilst the scores were not excessively high, they do indicate that a significant proportion of men in all

groups used alcohol and/or drugs as a coping strategy. This reflects earlier findings regarding sex-differences in coping (Carver, Sheier and Weintraub, 1989). However, it may be that the use of alcohol is a constant for some of these men and a way of dealing with life's stresses in general. Assessment of how participants usually dealt with stress would have clarified this and answered the question of whether successful adjustment to cancer requires the use of novel coping strategies (Rowland, 1989). In contrast, the scores for behavioural disengagement were extremely low. This is a positive finding and indicates that even when well-being and QoL are compromised, at no stage do men with testicular cancer report giving up on their life goals. The lack of temporal difference between the use of emotion-focussed and problem-focussed coping is interesting. Previous research suggests that emotion-focussed rather than problem-focussed strategies should predominate in coping with cancer, as it is often perceived to be uncontrollable (Lazarus, 1993). However, there was no difference in their use between the groups, and earlier analysis revealed that they were unrelated to well-being. Previous research also established that problem-focussed strategies are used more during the diagnosis and early stages of cancer and that emotion-focussed strategies are called upon during the demands of treatment (Weisman and Worden, 1976 and Carver et al. 1993). However, for this sample they were used roughly to the same degree for all groups. This suggests that crucial differences in adjustment may be attributable to more specific strategies such as acceptance and denial.

The significant findings show that men in the follow-up group reported using the coping strategy of acceptance more than men in the treatment group and diagnosis group. Again, this is a positive finding and supports earlier research. Carver et al. (1993) demonstrated that at follow-up women with breast cancer reported more

acceptance of their illness. This may reflect temporal differences; it is far easier to accept cancer at follow-up when its impact upon life is not such a challenge. The results for positive reinterpretation and growth were also significant. The follow-up group reported using this strategy significantly more than the diagnosis and treatment groups. Again, this reflects earlier findings (Weisman and Worden, 1976). Positive reinterpretation may develop only after cure has been achieved. In contrast, the follow-up group reported using significantly less denial than the diagnosis and treatment groups. This supports the findings of Carver et al. (1993) who found that at follow-up, the use of denial as a coping strategy was reported less than any other stage of breast cancer.

The present findings suggest that the use of adaptive coping strategies increase temporally as a function of stage of illness. Whilst most cancer patients come to accept and adjust to their illness over time (Rowland, 1989), it may prevent some distress to encourage the use of these strategies early on.

#### **4.8 The relationship between coping, well-being, QoL and concurrent stressors (hypothesis 6)**

The results of the multiple regression equations were far from conclusive. The lack of consistent significant predictive variables indicates that there are other important variables that influence coping and well-being which were not included in the analysis. A larger sample size may have confirmed this.

Interestingly, there were more predictors of positive outcomes than negative outcomes. Positive affect was predicted by high satisfaction with life scores, the use of adaptive coping strategies, and fewer reported physical symptoms associated with the treatment of testicular cancer. Therefore, good psychological adjustment is associated with life satisfaction, the use of adaptive coping strategies, and low physical symptoms. Similarly, adaptive coping strategies were predicted by high general health status, less psychosocial symptoms and high positive affect. As men undergoing treatment report lower general health status and more physical symptoms, then adjustment may be facilitated by encouraging the use of more adaptive coping strategies. However, physical symptoms seem to be an inevitable side effect of cancer treatment.

Negative affect scores were only significantly predicted by low satisfaction with life scores and high psychosocial symptomatology. Low positive affect scores further predicted the use of maladaptive coping strategies. This seems logical and indicates that the relationship between coping and psychological adjustment is bi-directional. These results seem to offer more information about good adjustment than poor adjustment to testicular cancer.

With a larger sample size, separate regression equations could be calculated for each group. This may shed more light on the predictors of coping and well-being at the different stages of the illness.

The categorical data obtained from the patient information questionnaire was analysed using discriminant analysis in order to examine Blanchard and Harper's

(1996) contextual model of coping with cancer. Process theories of coping postulate, that the accumulative effects of multiple concurrent stressors place vast strains on coping ability and well-being (Lazarus and Folkman, 1984). Previous research in the area of cancer indicates that the presence of concurrent life stresses and previous cancer experience contribute significantly to the processes of coping and adjustment (Rowland, 1989).

The results of discriminant analysis are difficult to interpret. Attempts were made to predict high and low adaptive and maladaptive coping scores using well-being and variables not specifically associated with testicular cancer. As with the multiple regression analyses, more light was shed on adaptive, rather than maladaptive coping strategies. The use of adaptive coping strategies was significantly associated with high positive affect, family being complete (i.e. having children) and being in the follow-up group. It was further associated with being employed rather than unemployed or self-employed. Similarly, the use of maladaptive coping strategies was associated with being unemployed or self-employed and low positive affect scores. Interestingly, previous cancer experience, concurrent work and relationship stresses were unrelated to adaptive or maladaptive coping. Therefore, the presence or absence of these concurrent stressors bore no relation to adaptive coping and adjustment. Although the findings are not as strong as predicted, they go some way towards confirming earlier research. Parental status has been identified as an important factor in adjustment to testicular cancer. One of the developmental tasks of early adulthood is to begin a family. Testicular cancer strikes men at this stage and fertility can often be compromised (Tross, 1989). For those men who already have children this is not such a threat. Concerning employment status, stress associated

with unemployment may affect coping resources and adjustment (Edbril and Rieker, 1985). Unemployment is associated in general with low affect and self-esteem. The demands of the treatment of testicular cancer are costly in terms of time. Outpatients' appointments last for several hours. Clinical experience suggests that self-employed men become stressed when attending appointments in work hours, they are not paid if they do not work. This must place extra strain on their coping resources. Perhaps it would be possible for hospital staff to be aware of these factors and tailor appointments more sensitively. The results indicate that adjustment and coping are not just a function of individual characteristics, but must be viewed within the context of an individual's wider system. Further research is needed to examine why coping with testicular cancer is so closely related to employment status.

Although the presence or absence of concurrent stressors did not predict adaptive coping and adjustment, their importance cannot be ignored. A prospective design with a larger number of participants may have confirmed their importance. However, clinical experience suggests that individuals do not have coping and adjustment difficulties purely because of the demands of cancer. With an illness such as testicular cancer, where prognosis is good and treatment is often brief, life does not stand still. Work and family still place demands on the patients. Sometimes consultants and psychologists alike are guilty of seeing the person as 'cancer' and all psychological problems as a consequence of the cancer. It seems important to view each patient as an individual within a complex system of which cancer is a significant part.

#### **4.9 Summary of Findings**

Significant differences were found between groups in the areas of well-being, QoL and the use of coping strategies. Most notably the follow-up group scored highest on all well-being measures and QoL of life scales. This indicates that over time, psychological adjustment is good in testicular cancer patients. Overall, well-being was associated with the use of adaptive coping strategies. The diagnosis and treatment groups reported lower psychological well-being and used more maladaptive coping strategies. Concerning health related QoL, the treatment group reported the highest disruption of functional status and more symptoms associated with the side effects of treatment. All groups reported high levels of psychosexual symptoms which supports earlier research (Rieker et al., 1989). However, high psychosexual symptoms were not predictive of poor psychological adjustment. The follow-up group reported using more coping strategies than the other two groups and this was associated with higher well-being scores.

Overall, more variables appear to predict good psychological adjustment and adaptive coping than poor adjustment and maladaptive coping. This suggests that important predictors of poor adjustment were not assessed in the present study. High well-being, QoL, the use of more coping strategies, being employed and already having a complete family appear to act as buffers against distress and are associated with the use of adaptive coping strategies. Maladaptive coping was associated with poor adjustment and being self-employed or unemployed.

#### **4.10 Clinical Implications**

As discussed earlier, the value of applied research into a specific type of cancer is that it improves our understanding of the issues that are important for the specific population. It guides clinical practice regarding when and how to intervene.

However, more general comparisons can be made with other sites of cancer and of particular importance, with how women adjust to the demands of cancer.

Historically, men with cancer have been neglected within the health care system both in terms of provision of specialist screening and education and psychological research. However, recent publicity about testicular cancer in particular is changing this.

##### **4.10.1 Positive Implications**

It is clear from the present research, that whilst well-being scores were lower than in the general population, most men appeared to be coping well with their illness.

Indeed, at follow-up men did report total acceptance and positive re-appraisal of the illness and their lives. Residual effects, as assessed by the EORTC QoL questionnaires, were small. Physical and psychological health return to normal levels after treatment. Marital and work status, if affected at all, are comparable with normative populations. Concerns about fertility were apparent at all stages however, infertility did not seem to be an inevitable consequence although all groups reported high levels of psychosexual difficulties. These psychosexual disturbances should be addressed more readily by clinicians, early in the treatment process.

Therefore, despite evidence that men at diagnosis and undergoing treatment have lower psychological well-being and use more 'maladaptive' coping strategies, this and previous research implies that over time they will adjust well. Whilst acknowledging the presence of disturbance, Oncologists should reinforce this at all stages. Men are not just concerned about their physical health, but would also benefit from reassurances about their psychological and sexual health.

#### **4.10.2 When to intervene and with whom**

Previous research (Moynihan, 1998) has established that not all men with testicular cancer need specialist psychological intervention. However, a significant minority do. As the prevalence of testicular cancer has doubled over the last twenty years, we can only assume that it will continue to increase. Therefore, the number of men who will require psychological intervention is quite high.

Diagnosis and treatment are the critical times and therefore early intervention is crucial. Evidence that psychological adjustment interacts with a stressful encounter to produce 'maladaptive' coping responses has important clinical implications. This research highlights the vulnerability of men at diagnosis and undergoing treatment and some of the factors that affect their psychological adjustment to the illness. Due to the probable bi-directional relationship between coping and adjustment, it would seem that the clinical psychologist has the option of intervening at both the levels of enhancing adjustment and improving the individual's coping skills. Adjuvant Psychological Therapy for cancer patients is a suitable vehicle for achieving either or both of these outcomes (Moorey and Greer, 1989). Whilst this research did not

demonstrate the significance of non-cancer-related sources of stress, it seems vitally important to assess these at diagnosis as it is likely that the accumulation of stress has implications for psychological distress. This research highlighted the importance of employment status. Self-employed and unemployed men reported more work stress and had lower well-being and adaptive coping scores. This suggests that these men are more in need of psychological support. For example, one participant, who scored quite low on psychological adjustment reported that he was self-employed, and was coping well with his illness, but felt under a great deal of pressure. This was because he had to take time off work because of the treatment and had no income to cover this. Therefore, it remains crucial to assess what else is going on in people's lives and to try and ease the pressure. The same can be said of parental status, those men who reported that their family was complete reported better adjustment. In view of the fact that many testicular cancer patients have not yet started a family, the psychological impact of the illness and concerns about fertility should be addressed early on. It is all too common for clinicians and others to view the cancer as central and lose sight of the whole person.

#### **4.10.3 Implications from coping theory**

The research highlights that coping with the stress of cancer is different to coping with other stressors. It lends support to previous research into adjustment to cancer (Carver et al., 1993 and Dunkel-Schetter et al., 1992). Indeed, cancer must be viewed as a dynamic stressor placing very different demands on coping resources at different stages. There is evidence of a core number of adaptive strategies, acceptance and positive reinterpretation and growth, which are associated with good psychological

adjustment. Acceptance means accepting the reality of the illness. Positive reinterpretation calls for finding something good in having to adjust to the illness. It does seem inappropriate to encourage these at the early stages of the illness where naturally, 'maladaptive' coping strategies such as denial, are more prevalent. Whilst denial and the use of alcohol and drugs was associated with higher negative affect, it remains a possibility that they are important coping strategies early in the illness and, without them, adjustment scores may have been even lower.

Finally, this research failed to establish the importance of problem-focussed and emotion-focussed coping strategies in adjusting to testicular cancer. Previous research has demonstrated that although active coping strategies are unhelpful in dealing with cancer in the long term, they may be more important in the early stages. Emotion-focussed strategies have been found to be beneficial in dealing with cancer. Whilst neither were related to good or poor adjustment and remained constant for all groups, it may be that they are crucial in dealing with cancer at all stages and that a baseline in these two forms of coping remains stable throughout the stressor.

The process theory emphasises the importance of the response of the individual as well as the features of the situation and this is clinically important. An examination of the resources of the individual and their environment may be helpful in predicting psychological adjustment.

#### **4.10.4 Improving psychological well-being and adjustment**

The research has already pointed to ways in which well-being can be enhanced for individuals at the earlier stages of the illness. Clinicians must take into account the whole life of any patient and this may sometimes need to be the focus of therapy rather than coping with the cancer.

Information must be sensitively provided at diagnosis regarding both physical and psychological issues. It should not have to be requested by the individual. The subject of infertility and sexual disturbance are constant themes for men with testicular cancer. These issues should be addressed thoroughly and sensitively by the clinician.

Testicular cancer strikes young men at a stage in life when fertility, work and relationships are crucial. All these are potentially compromised by the experience of testicular cancer. In order for adjustment to be successful, integrity in these areas must be preserved. Clinicians should bear these issues in mind. A good prognosis is not always the only reassurance a patient needs. Whilst emphasising the high cure rate, the side effects of treatment must not be overlooked, and some attempt to prepare and reassure the patient is necessary.

Brief assessments of coping, well-being, psychosexual functioning, and concurrent stressors should be routinely carried out to identify those most at risk at the various stages. Full psychological intervention will not be required for many, but more

sensitive awareness on the part of the responsible clinician with early referrals to clinical psychology, would prevent chronic adjustment difficulties occurring.

At this stage, tentative conclusions can be drawn regarding the different QoL issues that are relevant at each stage of the illness. Treatment poses the greatest threat to QoL in both physical and psychological domains. At diagnosis, emotional and psychosocial functioning are most affected. However, at follow-up cancer-related QoL is no longer an issue apart from in the domain of psychosexual functioning. The critical time for adjustment is during treatment when the demands on coping resources are at their peak. The sub-groups of self-employed and unemployed men clearly need more psychological support. Reassurance about regaining a high sense of QoL and well-being at follow-up may be useful to some people.

#### **4.11 Limitations and strengths of the present study**

The limitations of the present study include some of those that are all too common in coping research. They will be discussed in relation to the design, samples, measures used, and analysis. The generalisability of the findings is also considered. The strengths of the study are acknowledged at the end of this section.

##### **4.11.1 Design**

A frequent criticism of investigations into adjustment to cancer and coping in general is their cross-sectional nature (Somerfield, 1997). The cross-sectional design used in this research was chosen because of time constraints. Although it allowed

comparisons between men at different stages of testicular cancer, generalisations are only hypotheses. A longitudinal design, which followed a group of men through their illness, would have enabled more predictions regarding causality for coping and adjustment to have been made.

The decision not to use a control group of healthy men was made because testicular cancer was the focus of the study. However, a control group would have provided further validity for the measures used and help clarify that the processes being measured were a function of testicular cancer, rather than of simply being a healthy young man.

A further limitation of the present design was the inclusion of three groups of men at different stages of the illness. More research is needed to identify the critical phases for testicular cancer patients. The lack of differences between the diagnosis and treatment groups could reflect the lack of temporal differences. Perhaps it would have been more reliable to assess the participants in the diagnosis group before they had had their orchidectomy. However, at that stage they would not have received a diagnosis of testicular cancer. Testicular cancer diagnosis and treatment are separated by a mere two to four weeks. Therefore, differences in adjustment and coping may be difficult to gauge. The follow-up group may have benefited from a more rigorous definition of time since treatment. A maximum of six months would have meant that the illness was still fresh in people's minds. Finally, the inclusion of a group four weeks following the completion of treatment would have further enriched the results.

#### **4.11.2 Study sample**

Although the sample was representative of the population of men with testicular cancer, it was very small and as such, the power of the findings is limited. The size of the diagnosis and treatment groups was limited by the fact that testicular cancer is relatively rare. If the recruitment of participants had started earlier or used a larger geographical region, the sample size and therefore the power would have increased considerably.

Due to the small numbers of patients diagnosed with testicular cancer, it was not possible to randomly select the sample. This may have biased the findings in some way. Although the response rate was very high, a small number of participants at follow-up could not be assessed. This was because they did not attend their outpatient appointments. It may be that these men were not coping with their illness and these responses may have altered the results.

#### **4.11.3 Measures used**

Despite careful selection of the measures, some limitations are inevitable. A general criticism of the well-being measures is that they were not standardised on a population of men with testicular cancer. Despite their obvious utility, the three well-being questionnaires gave three separate scores rather than an overall psychological well-being score. This made analyses more complicated. A significant minority of men (n=12) found the PANAS questionnaire confusing and difficult to complete. This may have affected the responses they gave. The lack of differences between

group scores on the SWLS measure was interesting. It could be tapping an aspect of well-being that is unaffected by testicular cancer. With hindsight, it did not need to be included in this study.

The illness-specific version of the COPE (Carver *et al.*, 1993) had obvious limitations. It was shorter than the standard version and failed to include the coping strategies of using humour and turning to religion. These have been previously found to have a positive impact on psychological well-being (Dunkel-Schetter *et al.*, 1992). A further criticism is that it was not specific enough (Somerfield, 1996). The phrase ‘coping with your illness’ does not capture the dynamic nature of cancer-related stress. It would have been more useful to ask ‘which aspects of your illness do you find most stressful’ and then examine coping responses in relation to those. Self-reports of coping may not reflect what an individual actually does. Informant reports are needed to validate coping assessments. Although a conscious decision was made not to include coping styles, it may have shed more light on ‘adaptive’ coping and well-being.

The EORTC QoL questionnaires are crucially important in European cancer clinical trials. However, their utility in this study was affected by their primary focus on physical symptoms and the side effects of treatment. It meant that many participants in the diagnosis and follow-up groups felt that the questions were irrelevant. It is quite a long questionnaire and a shorter version would have been more useful in this study. The authors (Aaronson *et al.*, 1993) suggest that the GHS/QoL items are good indicators of overall well-being and future research may just include these items and those specifically pertaining to testicular cancer.

Finally the personal information questionnaire was not standardised and included items that were hypothesised to relate to coping and well-being. The categorical nature of most of the questions meant that the data could not be included in the multiple regression analysis. The questionnaire should have included continuous visual analogue scales to tap these issues more appropriately. The forced choice format meant that participants did not have the option to give responses that are more detailed. Whilst this made analysis easier, it ignored the richness of information that could have been obtained. A structured interview format would have given participants the opportunity to discuss stressful aspects of their lives and their illness.

Certain factors that could potentially have influenced both coping and psychological adjustment were not measured. Social support and socio-cultural variables have been hypothesised to influence both coping and adjustment (Blanchard and Harper, 1996). These variables may have important predictive value.

Multiple assessment measures were chosen to ensure breadth of coverage of the dependent variables under study. However, this made both data collection and analysis time consuming and complicated. There is a continuing need for better measurement in coping research. More attention should be paid to developing assessments specifically for testicular patients in the areas of coping and well-being. This will ensure that variables measured are relevant.

#### **4.11.4 Analysis of the data**

Due to the small number of participants, the power of the study was limited. Had there been a larger sample and all variables were continuous, then multiple regression equations may have provided more support for the Blanchard and Harper (1996) model as it does make intuitive sense.

The use of multiple statistical techniques increases the probability of Type 1 errors. However, those relationships and differences that were significant were usually exceptionally so and it is likely that the power was not significantly affected.

The fact that this study failed to provide support for the impact of various stressors may indicate weaknesses in the study design and analysis. Although predictors of 'adaptive' coping strategies and high positive affect were found, there were fewer significant findings for 'maladaptive' coping strategies and high negative affect. This indicates that, conceptually, 'adaptive' and 'maladaptive' coping strategies are not polar opposites.

The use of more exploratory statistical techniques and a continuous data-set may have provided more of an explanation of 'maladaptive' coping and negative affect. Furthermore, if the relationship between negative affect and 'maladaptive' coping and other variables were curvilinear, it would have been ignored by the analysis which used a linear regression model.

#### **4.11.5 Can the results of the study be generalised?**

Whether the results of the present study can be generalised to other populations in other contexts is debatable. However, in the opinion of the present researcher, the utility of generalisability is also debatable in this context. The purpose of the present study was to examine how men cope with and adjust to the demands of testicular cancer, in order to generate ideas for future longitudinal research that will be of benefit to clinical psychologists and oncologists working with these men. Due to the fact that the sample characteristics and findings were comparable with other research (Moynihan, 1987), it would indicate that the findings are generalisable to the population of men with testicular cancer.

However, comparisons made between how men cope with testicular cancer and how women cope with early stage breast or cervical cancer seem appropriate. The findings of this study were very similar to those found by Carver *et al.* (1993). Although in the general coping literature there are established sex differences in coping, men do not appear to cope with cancer very differently and this is important. A stereotyped view of men and health is that they do not cope well with illness and commonly avoid their concerns. However, this study debunks that myth. In terms of coping and adjustment to cancer, young men are just as resourceful and flexible as women are. Psychological outcomes are positive. Repeating the present study with other sites of cancer at early stages is necessary to answer fully the question of generalisability.

#### **4.11.6 Strengths of the present study**

Despite the limitations, the study has a number of obvious strengths. Given the time and resource constraints the design was appropriate and analysis yielded some interesting results. It permitted the testing of the process theory of coping across specific situations and offers support for the view that coping is dynamic. It allowed a partial examination of a holistic model of coping with cancer. More specifically it supported the notion that cancer is a dynamic stressor and places different demands on the individual at different stages. It clarifies the need to promote active acceptance of illness in cancer patients.

The sample was homogenous and this meant that potentially confounding variables were controlled for naturally. Participants were recruited from a large geographical area and this added further reliability. All the questionnaires had previously been used with populations of cancer patients and therefore it is applicable within the field of psycho-oncology. By assessing men at different stages of the illness it did not rely solely on retrospective reports and therefore adds a further dimension to the literature on coping and adjustment in testicular cancer (cf. Brodsky, 1995 and Rieker et al., 1989).

#### **4.12 Further research**

Ideas for future research have been presented throughout the discussion and will be summarised here. Firstly, a prospective longitudinal design with a larger sample size is required to fully examine how individual's coping strategies and psychological

adjustment changes throughout the course of the illness. This research failed to examine environmental factors such as social support. Whereas social support has been found to be important for women adjusting to cancer, no information is available regarding its importance for men with cancer. Assessment of religious beliefs and humour as coping strategies would also be interesting. Finally an assessment of personality and how men usually cope with stress would clarify whether adjustment to cancer does require different strategies for each individual.

Within the context of the present findings, clarification is needed as to differences between the stages of diagnosis and treatment. The finding that men at follow-up report using more coping strategies when the demands of the illness are less needs clarification. This research also calls for further investigation into the role of employment status in adjusting to testicular cancer, as this is clearly a relevant factor. Psychosexual issues are important and the type of problems and their meaning for the individuals should be investigated in an attempt to reduce the high incidence.

The conceptual status of the well-being measures needs further investigation. It is not clear what aspects of well-being were being tapped by the different measures. Finally, there is a continuing need for applied research into the development of better and more clinically relevant measurements of coping and adjustment.

On a more general level, more research is needed into men's health. In particular, age differences in coping with illness. Comparisons of how young men cope with testicular cancer and how older men cope with prostatic cancer would illustrate differences in coping resources, attitudes and beliefs about cancer and health in

general. The stereotyped view of men's avoidance and neglect of their health care could then be more fully addressed. Psychosocial research such as this may illustrate ways in which early detection and even prevention of cancer may be facilitated at the primary level.

## 5 Conclusion

This piece of research gives rise to the conclusion that, at follow-up, the experience of testicular cancer has no major detrimental affect upon psychological adjustment or health related QoL for most individuals. Residual effects remain in the area of psychosexual functioning, although this appears unrelated to adjustment. However, at the stages of diagnosis and treatment, well-being is threatened and adjustment is poor. Furthermore, during treatment, physical well-being is also severely compromised. At these points in time, psychological adjustment interacts with the demands of testicular cancer resulting in a negative effect upon individuals' coping behaviour. Other concurrent stressors are also likely to have important effects on coping ability. It is likely that these relationships are bi-directional and that coping is a critical factor in the adjustment to cancer. The research lends support to the process theories of coping. Cancer is a complicated and chronic stressor, and calls for flexibility in the use of coping strategies.

The strategies that were shown to be useful in adjusting to the demands of cancer were acceptance and positive reinterpretation and growth. It may be that these strategies evolve naturally as a function of time. Prospective and longitudinal research is needed to untangle this. The strategies that were related to poor adjustment were denial, behavioural disengagement and alcohol and drug use. In particular denial does not seem to facilitate adjustment and would not appear to be a useful strategy at any stage of the illness. These findings support earlier research into coping with early stage breast cancer. The findings are positive in that these young men appear to have good coping resources and adjust well over time.

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## **Appendix 1 – Initial contact letter to participants**



THE  
LEICESTER ROYAL INFIRMARY  
NHS TRUST

FJFM/MJG

26th January, 1999

Dear

I am requesting your permission to pass your name to a research team based at the Leicester Royal Infirmary who are investigating the quality of life in patients with testicular teratoma. A patient information leaflet is enclosed.

The clinical trial will not affect your routine management and follow up in the department with myself.

If you agree to your name being passed on to the research team and you would like to participate in the research, please complete the form below.

If you do not wish to participate, then this will not affect your care in the Oncology Department.

Yours sincerely

Dr F Madden  
Clinical Oncologist

*I, Mr ..... would like/ would not like to  
participate in the research study into the quality of life of patients with  
testicular teratoma.*

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## **Appendix 2 – Patient Information Leaflet and Consent Form**

## **PATIENT INFORMATION LEAFLET**

**An investigation into coping strategies, quality of life and psychological outcomes for four groups of men at different critical phases of testicular cancer.**

**We are carrying out a research project within the Department of Oncology and would like to invite you to participate. Details are given below.**

**Principal investigator:** Holly Capey

**You may contact:**

Holly Capey  
Trainee Clinical Psychologist  
University of Leicester  
Centre for Applied Psychology  
The New Building  
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Leicester-LE1 7RH  
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or via,  
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### **1. What is the purpose of the study?**

Testicular cancer is the most common form of cancer in 18-35 year old men in Britain. However, there is very little research into the psychological impact of the illness. Therefore, this study will assess the psychological impact of testicular cancer at its different phases. We intend to examine the different coping strategies that men use to adjust to the illness and the quality of life issues that are relevant at different phases of diagnosis, treatment and recovery.

The study will shed light on the different psychological processes that help men to adjust to the different stages of the illness and will help to predict those who may be at risk of psychological disturbance such as depression, anxiety and relationship problems. This will help to ensure that psychological aspects of the impact of cancer are addressed for all individuals throughout diagnosis and treatment.

### **2. What will be involved if I take part in the study?**

If you are interested in taking part in the study, a 45 minute appointment will be made for you at the hospital. The principle investigator will explain the process of the research and answer any questions you may have. If you then give your consent to participate in the study, you will be given four brief questionnaires to fill out. You may find some of the questions difficult to answer so even after you agree to take part, you will not have to answer every single question. The questionnaires should not take more

than 30 minutes to complete. They will measure your well-being, the coping strategies that you use and quality of life issues that are important to you.

If you feel a need to discuss any of the issues further, a referral can be made to the Department of Medical Psychology.

**3. Will information obtained in the study be confidential?**

Your responses will remain confidential to the principle researcher unless requested otherwise by yourself. The results of the study will be made anonymous and held on a password protected computer. No individuals will be identified in the data or in any documents relating to the research.

**4. What if I am harmed by the study?**

Medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

**5. What happens if I do not wish to participate in the study or wish to withdraw from the study?**

If you do not wish to take part in this study or if you wish to withdraw from the study you may do so without justifying your decision and your future treatment will not be affected.

**If you have any further questions please do not hesitate to contact me.**

## **PATIENT CONSENT FORM**

**“An investigation into coping strategies, quality of life and psychological outcomes for four groups of men at different critical phases of testicular cancer”.**

Principle Investigator: Holly Capey, Trainee Clinical Psychologist.

**This form should be read in conjunction with the Patient Information Leaflet**

I agree to take part in the above study as detailed in the Patient Information sheet.

I understand that I may withdraw from the study at any time without justifying my decision and without affecting my normal care and medical management.

I understand that members of the research team may wish to view relevant sections of my medical records, but that all of the information will be treated as confidential.

I understand that medical research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

I have read the patient information leaflet on the above study and have had the opportunity to discuss the details with Holly Capey and ask any questions. The nature of the questionnaires have been explained to me and I understand what will be required if I take part in the study.

Signature of patient..... Date.....

Name (in BLOCK LETTERS).....

I confirm that I have explained the nature of the Research, as detailed in the Patient Information Sheet, in terms which in my judgement are suited to the understanding of the patient.

Signature of Investigator..... Date.....

Name (in BLOCK LETTERS).....

## **Appendix 3 – General Information Questionnaire**

## **PATIENT INFORMATION QUESTIONNAIRE**

**PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOURSELF**

- 1. How old are you?**
- 2. What is your diagnosis?**
- 3. When were you diagnosed?**
- 4. What treatment are you receiving? (If receiving follow-up care what treatment did you receive?)**
- 5. What is your current marital/relationship status?**
  - 1= Married/Cohabiting**
  - 2=Steady Partner**
  - 3=Single**
  - 4=Divorced/Separated**
- 6. What is your current employment status? (please circle)**
  - 1 = Employed**
  - 2 = Self-employed**
  - 3 = Unemployed**
  - 4 = Student in full time education**
- 7. How old were you when you left school?**

**8. Do you have children?**

**9. Do you hope to have children in the future or is your family complete?**

**10. We are also interested in other areas of your life that you find stressful apart from having testicular cancer.**

**Do you have any health problems?**

**If yes please specify.....**

**Do you find your work stressful?**

**If yes what aspects.....**

**Have you any relationship difficulties?**

**If yes please specify.....**

**11. Have you had any previous cancer related experiences. Have any family members or friends suffered from cancer?**

**If yes did you find this to be positive or negative? Please specify.**

**Thank you for answering these questions.**

## **Appendix 4 – EORTC QLQ C-30 Core Questionnaire**



## EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

--	--	--	--	--

Your birthdate (Day, Month, Year):

--	--	--	--	--	--	--	--	--	--

Today's date (Day, Month, Year):

31

--	--	--	--	--	--	--	--	--	--

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

### During the past week:

	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4

Please go on to the next page

**During the past week:**

	Not at All	A Little	Quite a Bit	Very Much
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

**For the following questions please circle the number between 1 and 7 that best applies to you**

29. How would you rate your overall health during the past week?

1            2            3            4            5            6            7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1            2            3            4            5            6            7

Very poor

Excellent

## **Appendix 5 – EORTC Testicular Cancer Module**

## TESTICULAR TUMOUR QUESTIONNAIRE

We are interested in some things about you and your health (especially as it applies to your testicular tumour). Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you supply will remain strictly confidential.

PLEASE ANSWER THE QUESTIONS IN RELATION TO THE PAST WEEK.

	NOT AT ALL	A LITTLE	QUITE A BIT	VERY MUCH
During the past week				
1. Have you lost any hair?	1	2	3	4
2. Have you been upset by the loss of your hair?	1	2	3	4
3. Have you had pain, numbness or tingling in your hands and/or feet?	1	2	3	4
4. Have you had pale/cold feet/toes or hands/fingers?	1	2	3	4
5. Have you had ringing in the ears?	1	2	3	4
6. Have you had difficulty hearing?	1	2	3	4
7. Have you been feeling less masculine as a result of your disease or treatment?	1	2	3	4
8. Have you been worried about the possibility of being unable to father a child?	1	2	3	4
9. Have you been anxious about the possible recurrence of the disease?	1	2	3	4
10. Have you been happy with the medical management of your illness?	1	2	3	4

### THE NEXT QUESTIONS CONCERN POSSIBLE CHANGES IN YOUR SEXUAL LIFE

If you were sexually active before your testicular illness, please answer questions 11 and 12.

During the past month

11. Have you been less interested in sex than before your illness?	1	2	3	4
12. Have you been less sexually active than before your illness?	1	2	3	4

Cont.

**If you have been sexually active during the last month please continue with questions 13-16.**

<b>13. Have you had difficulty in getting or maintaining an erection?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
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<b>14. Has sex been less enjoyable for you than before your illness?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
--	----------	----------	----------	----------

<b>15. Have you had dry ejaculation (no fluid from your penis) during orgasm?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
---	----------	----------	----------	----------

**If you have a partner**

<b>16. Has the sexual relationship with your partner been satisfying?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
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**THANK YOU FOR ANSWERING THE QUESTIONS**

## **Appendix 6 – Illness specific version of the COPE**

There are lots of ways to try to deal with illness. This questionnaire asks you to indicate what you have done and how you feel about your illness.

Please respond to each of the following items by circling one number on your answer sheet, using the choices listed below. Please think about each item **separately from each other** item. Choose your answers thoughtfully, and make your answers as true for you as you can. Please answer every item. There are no 'right' or 'wrong' answers, so choose the most accurate answer for you - not what you think 'most people' would say or do. Indicate what **YOU** have done in response to your illness.

Answer each item from these choices:

1 = I haven't done this at all

2 = I have done this a little bit

3 = I have done this a moderate amount

4 = I have done this a lot

- |  |   |   |   |   |
|--|---|---|---|---|
| 1. I have tried to grow as a person as a result of the experience.               | 1 | 2 | 3 | 4 |
| 2. I have got upset and let my emotions out.                                     | 1 | 2 | 3 | 4 |
| 3. I have tried to get advice from someone about what to do.                     | 1 | 2 | 3 | 4 |
| 4. I have concentrated my efforts on doing something about it.                   | 1 | 2 | 3 | 4 |
| 5. I have said to myself "this isn't real".                                      | 1 | 2 | 3 | 4 |
| 6. I have discussed my feelings with someone.                                    | 1 | 2 | 3 | 4 |
| 7. I have used alcohol or drugs to make myself feel better.                      | 1 | 2 | 3 | 4 |
| 8. I have got used to the idea that it has happened.                             | 1 | 2 | 3 | 4 |
| 9. I have talked to someone to find out more about the situation.                | 1 | 2 | 3 | 4 |
| 10. I have got upset, and have been really aware of it.                          | 1 | 2 | 3 | 4 |
| 11. I have accepted that this has happened and that it can't be changed.         | 1 | 2 | 3 | 4 |
| 12. I have given up trying to reach my goals.                                    | 1 | 2 | 3 | 4 |
| 13. I have taken additional action to try to get rid of the problem.             | 1 | 2 | 3 | 4 |
| 14. I have tried to lose myself for a while by drinking alcohol or taking drugs. | 1 | 2 | 3 | 4 |

Date \_\_\_\_/\_\_\_\_/\_\_\_\_

---

Answer each item with these choices:

1 = I haven't done this at all

2 = I have done this a little bit

3 = I have done this a moderate amount

4 = I have done this a lot

15. I have refused to believe that it has happened.	1	2	3	4
16. I have let my feelings out.	1	2	3	4
17. I have tried to see it in a different light, to make it seem more positive.	1	2	3	4
18. I have talked to someone who could do something concrete about the problem.	1	2	3	4
19. I have tried to come up with a strategy about what to do.	1	2	3	4
20. I have drunk alcohol or taken drugs, in order to think less about it.	1	2	3	4
21. I have pretended that it hasn't really happened.	1	2	3	4
22. I have given up the attempt to get what I want.	1	2	3	4
23. I have looked for something good in what has happened.	1	2	3	4
24. I have accepted the reality of the fact that it has happened.	1	2	3	4
25. I have felt a lot of emotional distress and I have found myself expressing these feelings a lot.	1	2	3	4
26. I have taken direct action to get around the problem.	1	2	3	4
27. I have talked to someone about how I feel.	1	2	3	4
28. I have used alcohol or drugs to help me get through it.	1	2	3	4
29. I have learnt to live with it.	1	2	3	4
30. I have thought hard about what steps to take.	1	2	3	4
31. I have acted as though it hasn't even happened.	1	2	3	4
32. I have learnt something from the experience.	1	2	3	4

## **Appendix 7 – Positive and Negative Affect Schedule**

# POSITIVE AND NEGATIVE AFFECT SCHEDULE



Name: .....

Date: ..... Record Number: .....

This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate to what extent\* YOU HAVE FELT THIS WAY DURING THE PAST WEEK .....

Use the following scale to record your answers.

1	2	3	4	5
<i>very slightly</i>	<i>a little</i>	<i>moderately</i>	<i>quite a bit</i>	<i>extremely</i>
<i>or not at all</i>				
		.....interested		
		.....distressed		
		.....excited		
		.....upset		
		.....strong		
		.....guilty		
		.....scared		
		.....hostile		
		.....enthusiastic		
		.....proud		
		.....irritable		
		.....alert		
		.....ashamed		
		.....inspired		
		.....nervous		
		.....determined		
		.....attentive		
		.....jittery		
		.....active		
		.....afraid		

\*Insert appropriate time instructions above from page 27

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## **Appendix 8 – Satisfaction With Life Scale**

# SATISFACTION WITH LIFE SCALE



Name: .....

Date: ..... Record Number: .....

Below are five statements with which you may agree or disagree. Using a 1 to 7 scale, indicate your agreement with each item by placing the appropriate number in the box next to that item. Please be open and honest in your responses. The 7-point scale is:

- 1 = strongly disagree
- 2 = disagree
- 3 = slightly disagree
- 4 = neither agree nor disagree
- 5 = slightly agree
- 6 = agree
- 7 = strongly agree

☐

In most ways my life is close to ideal.

☐

The conditions of my life are excellent.

☐

I am satisfied with my life.

☐

So far I have got the important things I want in life.

☐

If I could live my life again, I would change almost nothing.

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