

**Psychosocial Concerns and Individual Anxieties for Fathers with  
Testicular Cancer**

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**A thesis submitted in partial fulfillment of the requirements of the University of East  
London for the degree of the Professional Doctorate in Social Work**

**May 2015**

## **Abstract**

The purpose of this qualitative study was to explore the major areas of psychosocial concerns, individual anxieties and coping responses for fathers with testicular cancer. While numerous studies have been carried out with mothers with cancer, research from the perspective of fathers with cancer is sparse. This study attempts to identify and explore their specific concerns and priorities.

The study was approved by the Royal Marsden Hospital (RMH) Committee for Clinical Research (CCR) and the Local Research Ethics Committee (LREC). Men were recruited from the RMH Testicular Clinic. All of the men had two or three school age children and were from a range of ethnic backgrounds, professions and education levels.

The Biographical Narrative Interpretive Method (BNIM) of interviewing was used and the Interpretative Phenomenological Analysis (IPA) method was employed to analyze the data. Psychodynamic concepts were utilized as the theoretical framework to develop interpretations for each participant. Theories of masculinity were also incorporated.

A set of themes emerged which was supported by the current literature. The psychosocial concerns included: lack of adequate medical information, concerns for children and wife and work concerns. The individual anxieties included: concerns around self concepts and masculinity, physical changes and self-image, challenges to faith and finding meaning, fear of recurrence, fear of death and annihilation. The participants employed specific coping responses including: intellectualization, minimizing, maintaining stoic façade and idealization which helped them to cope with the impact of their disease AND allowed them to maintain their sense of masculinity. This phenomenon was labeled “The Masculine Way of Handling Illness”. Additionally, the men split their cancer into the “good one to get”.

The findings suggest that men need more reliable information, preferably on a reputable UK site, about talking to their children, the physical effects of treatment and the options of having a prosthesis.

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## **Acknowledgements**

I am deeply grateful to my primary supervisor, Andrew Cooper, for his guidance and support throughout the entire process. I would also like to thank my secondary supervisor, Clare Moynihan, whose knowledge and expertise was and continues to be an inspiration to me.

Additionally, I am grateful to Dr. Robert Huddart, Bernadette Johnson and the rest of the staff at the Royal Marsden Hospital for their ongoing support and practical assistance.

I am also indebted to the ten participants in the study whose honest and heartfelt discussions of their experience made this dissertation possible.

And finally, I am particularly grateful to my family. Specifically, I would like to thank my mother and brother who believed in me before I believed in myself. Most importantly, I would like to thank my children, Cameron, Alasdair and Lindsay, who were patient, supportive and encouraging during most of their childhood. I could not have done it without them.



## **Chapter 1: Introduction**

### **1.1 Statement of Research Topic and its Importance**

The purpose of this qualitative study is to explore the major areas of psychosocial concerns and individual anxieties for fathers with testicular cancer as well as their coping responses. While numerous research studies have been conducted exploring the concerns, anxieties and coping strategies of mothers with cancer and their partners, there is limited research from the perspective of fathers. Therefore, I hope that through in-depth interviews with ten men to provide information about their main areas of concern, anxieties and coping responses as patients and fathers. While the sample size is small, by using the Biographic Narrative Interpretive Method (BNIM) of interviewing and the Interpretative Phenomenological Analysis (IPA) methodology of analyzing the data and psychodynamic theory to inform the interpreting, I developed a very detailed account of the men's individual experiences within the context of their social environment. Hopefully, this unique perspective will be useful and informative for health care professionals working with fathers with cancer when planning and developing future interventions.

### **1.2 Research Question**

The research question is a descriptive one with the aim of understanding the individual's personal experience. Quite simply it is: What are the major areas of psychosocial concerns, individual anxieties and coping responses for fathers with testicular cancer?

### **1.3 Overview**

Having worked as an oncology social worker and counsellor with cancer patients and family members for over 20 years, I was asked to consult on a project to develop an intervention for families when a father had cancer by the Children and Families Team at the Tavistock Centre. Many studies have been conducted when the mother is the cancer patient and a variety of interventions both individual and family have been developed, however, a majority of these studies and interventions address the family needs when the mother has breast cancer (Barnes *et al.*, 2000; Friedman *et al.*, 1988; Lewis *et al.*, 1989; Walsh *et al.*, 2005). Research exclusively from the perspective of men who are fathers is very limited. Moreover, given my experience counselling individual men with cancer, I questioned whether a family intervention would in fact address the major areas of psychosocial

concerns and individual anxieties for these men. The team agreed this would be an important phenomenon to explore before we began the process of planning an intervention.

It was decided that in order to explore in depth the experience for men, it would be best to choose one type of cancer which primarily effected men who were at the stage of having children; thus even though the sample size would be small, the study would be internally consistent with a coherent argument (Smith, 2007). The most common cancers in the UK for men between the ages of 25 to 49 are testicular (15% of cancers for the British population between 25 to 49), malignant melanoma (11%) and bowel (9%) with prostate cancer contributing only 4% of the total in men in this age group ([www.cancerresearchuk.org/cancer-help/](http://www.cancerresearchuk.org/cancer-help/)). Therefore, testicular cancer, which also has an excellent prognosis, was deemed to be the optimal diagnosis to investigate. Moreover, a substantial amount of research had already been conducted which established that men with testicular cancer had a range psychosocial concerns (Arai *et al.*, 1996; Carpentier *et al.*, 2011; Chapple & McPherson, 2004; Dahl *et al.*, 2005; Gordon, 1995; Incrocci *et al.*, 1999; Moynihan, 1987; Reiker *et al.*, 1985; Schover and von Eschenbach, 1984). However, this research did not specifically explore the areas of concerns for fathers with cancer. Therefore, this study was designed to explore their psychosocial concerns, individual anxieties and coping responses and defence mechanisms. To clarify, for the purpose of this study, I will define these terms as follows:

- Psychosocial concerns pertain to the interactions between the social and the psychological,
- Individual anxieties are the subjective experiences of the individual including internal tension, apprehension, worry and unease (Maxmen, 1986, p. 203),
- Defense mechanisms are the automatic unconscious mental operations which are employed to preserve an individual's psychic equilibrium (Milton *et al.*, 2004 p. 20).

With the support of a consultant oncologist in the Urology Department of a large Cancer Centre, I was able to receive approval from both the institution's Committee for Clinical Research (CCR) and the Local Research Ethics Committee (LREC). I recruited the participants from the testicular cancer outpatient clinic. (I will provide more specific details in the methodology section.) I interviewed ten men with school age children who had

completed treatment for testicular cancer at the point they were asked to participate in the study. (Some men unexpectedly required additional treatments after they had agreed to participate.) The interviews were transcribed and the data analyzed utilizing IPA methodology and NVivo 9 software. Psychodynamic concepts were utilized as the theoretical framework to develop interpretations of each of the men's experience.

The focus of this study was to encourage the men to give a brief narrative about their experience of having cancer as a father from the point when they felt that something might be wrong to the present (hence the BNIM method of interviewing was employed which will be discussed in more detail in the methodology section.)

Given that the research question was to explore the participants psychosocial concerns and individual anxieties as well as their coping responses, I have structured both the individual case studies and the cross case analysis chapter by exploring each of the these three topics, or domains, separately. Obviously, there is no clear dividing line between concerns, anxieties and even defence mechanisms. For example, many of the participants were worried about how having cancer would affect their employment. They were concerned both about the reaction of colleagues as well as how they would continue to be able to perform. This relates to their sense of identity and job performance; in other words they had both psychosocial concerns and individual anxieties. I have, however, chosen to include work concerns under the psychosocial concerns and challenges to identity under individual anxieties. Obviously, the boundaries are artificial and only useful as a means of ensuring a comprehensive understanding of the participants' experience.

While I wrote detailed case studies on all ten participants, only five of the studies will be presented in full in this dissertation. I believe this sample will provide a comprehensive picture of the lived experience of the individual participants. All of the responses from the participants will be included in the Cross Case Analysis chapter. In order to ensure that all the concerns and anxieties were presented, I selected the five studies based on the rather complex cross case analysis procedure which carefully examined how much evidence a particular case study had regarding each theme (this procedure will be discussed in the Cross Case Analysis chapter). The first four studies I have chosen not only had the most evidence of a particular theme (i.e. fear of recurrence and late diagnosis) but also had the

most themes. However, while the fifth study (Don participant 1002) did not have the most evidence for the most themes, he had a particularly interesting and unique struggle both with his faith and finding meaning and therefore I have included his case study within the body of the dissertation.

I also recognize that while I have endeavoured to grasp the meanings of the experiences of all the participants, I have not discussed how their culture or background may have impacted on how the participants responded. While we did have participants from different ethnic, religious and social backgrounds (see Table 5.2), a thorough discussion of the impact of culture and difference on how patients respond to a cancer diagnosis is beyond the scope of this dissertation. Instead the focus is to explore the experience of being a father with cancer within the individual's own social environment.

After the individual case studies, I will present the cross case analysis. In order to ensure that the cross case analysis is not simply a listing of the case findings, it is essential to keep the participants' contextual meaning while still trying to ensure a systematic and comprehensive exploration of the phenomenon. Therefore, I have chosen to broadly follow the cross case analysis procedure developed by Robert Stake (2006) which systematically links evidence from their interviews, to interpreted themes to general cross case assertions. Finally, I will conclude with a discussion of the future implications of the findings from this study.

#### **1.4 Background on Testicular Cancer**

In order to develop an understanding of the concerns and anxieties which are particular to men with testicular cancer it is helpful to have a basic knowledge of the disease itself. According to Cancer Research UK, approximately 2000 men a year are diagnosed with testicular cancer in the UK. It is not known exactly what the causes of the cancer are; although, it is more common in men who have had a testicle which failed to descend. Additionally, men with a brother or father who have had the disease are slightly more at risk. It is also more common in white men than African-Caribbean or Asian men and occurs more commonly in wealthier social groups ([www.cancerresearchuk.org/cancer-help/type/testicular-cancer](http://www.cancerresearchuk.org/cancer-help/type/testicular-cancer)).

Treatment for testicular cancer is usually very successful. During the 2005-2009 periods, the five year survival rate for testicular cancer in England was 97%, not age standardized. Therefore, for testicular cancer a five year survival rate is effectively a “cure” rate ([www.cancerresearchuk.org/cancer-help/type/testicular-cancer](http://www.cancerresearchuk.org/cancer-help/type/testicular-cancer)). The treatment will depend on the type of cancer (either teratoma or seminoma) and whether it has spread. In people with early-stage disease surgery alone may cure the cancer but often chemotherapy or radiotherapy will also be given to reduce the risk of recurrence ([www.macmillan.org.uk/Cancerinformation/Cancertypes/.../Testicularcancer](http://www.macmillan.org.uk/Cancerinformation/Cancertypes/.../Testicularcancer)).

The two main types of testicular cancer are seminoma and teratoma. The major differences are the rate of onset and spread of disease as well as the age of men at the time of diagnosis. Seminomas most commonly occur in men between 25 and 55 and have a more indolent course. The majority of these men present with localized disease. Teratomas, on the other hand, affects younger men from 15 to 35 years with disseminated disease. The staging of the cancer describes the size of the tumour and whether it has spread beyond the area of the body where it started. A detailed explanation of the staging system is beyond the scope of this paper ([www.macmillan.org.uk/Cancerinformation/Cancertypes/.../Testicularcancer](http://www.macmillan.org.uk/Cancerinformation/Cancertypes/.../Testicularcancer)).

Patients who undergo surgery, chemotherapy and radiotherapy may suffer from some side effects. According to Cancer Research UK, if a man has one testicle removed there will be no long-term side effects, however; if both testicles are removed they will become infertile and require testosterone replacement therapy. Similarly, if men require a lymph node removal, they may also become infertile and experience retrograde ejaculation ([www.cancerresearchuk.org/cancer-help/type/testicular-cancer](http://www.cancerresearchuk.org/cancer-help/type/testicular-cancer)). Men who receive chemotherapy may have a lower resistance to infection, loss of appetite, hair loss, nausea, decreased sex drive and again their fertility may be compromised. However, on completion of chemotherapy most men appear to be able to return to normal sexual activities but in some cases may become permanently infertile ([www.macmillan.org.uk/Cancerinformation/Cancertypes/.../Testicularcancer](http://www.macmillan.org.uk/Cancerinformation/Cancertypes/.../Testicularcancer)). Men who require a course of radiotherapy may experience the following short-term side effects: tiredness, sore skin, sickness, diarrhoea and temporary sperm damage

([www.cancerresearchuk.org/cancer-help/type/testicular-cancer](http://www.cancerresearchuk.org/cancer-help/type/testicular-cancer)). In short, men may experience unpleasant short term side effects during the treatment stage and for awhile afterwards with the main long-term side effects being infertility and potentially a loss of sex drive which can be treated with hormone therapy.

Despite the excellent prognosis of this disease and limited long-term side effects from the treatments, there still appears to be considerable psychological morbidity even up to five years after their diagnosis. Both social variables such as unemployment and lack of outside support as well as individualistic factors such as the emotional states may be responsible for this (Moynihan, 1987). In order to examine these considerations, I will turn now to a literature review.

## **Chapter 2: Literature Review**

### **2.1 Introduction**

It is generally recognized in the psycho-oncology literature that from the point of diagnosis through the treatment of cancer, patients are faced with a number of challenges and changes in their lives. In order to obtain relevant literature, I performed computer searches using Medline and Psychinfo. Most of the articles were found in either cancer journals, medical journals or family and health journals. Additionally, a hand search of the bibliographies of the articles led to further studies. Academic text books were also utilized particularly for the theoretical background material.

From this literature search, numerous articles were found which addressed the psychological impact of cancer on the individual and their families (Cooley & Moriarty, 1997; Kristjanson & Ashcroft 1994; Lewis *et al.*, 1989; Wellisch 1985.) Moreover, in recent years, several studies have been done examining the efficacy of specific interventions for both individuals and families (Bressi *et al.* 2005; Carlson *et al.*; 2000; Moynihan *et al.*; 1998; Neilson-Clayton & Brownlee, 2002; Ostroff *et al.*, 2004).

In light of the extensive literature that has already been conducted, it is helpful to narrow down the most relevant studies to the topic of fathers with cancer by dividing the studies into two categories: first, the studies which have explored the impact of cancer on the family and second the studies which have discussed the psychological impact of cancer on the individual (particularly men). It is then helpful to make even further subdivisions and examine which studies have been done using qualitative methods and which have been done using quantitative methods. By dividing the studies into these categories, I hope to show that while a vast amount of research has been done on the psychological impact of cancer on the patient and family, there is still a lack of qualitative information from men, particularly fathers, about their specific concerns and anxieties.

### **2.2 Quantitative Family Studies**

It is now commonly recognized that the diagnosis of cancer is a family affair (Cooley & Moriarty, 1997). Numerous quantitative studies have been conducted to examine the impact of a cancer diagnosis and treatment of an adult on the family. The major areas of

concerns for the family which have emerged from these studies include: role changes, financial strain, communication problems and family functioning and coping styles. Because I anticipated that some if not all of these concerns would arise in the course of the individual interviews, it was helpful to carefully examine the studies which identified these. Not only was the content of these studies useful in developing a knowledge base to work with when interviewing and interpreting the data, but also reviewing the identified concerns helped to establish what had been explored exhaustively in the research and what topics might need further in-depth investigation. Therefore I will now look at each of these areas of concern in detail.

### 2.2.1 Role Changes

The stressful nature of role changes experienced by families of cancer patients is well documented. In a study by Wellisch (1985), families reported that transitions to new roles may be awkward, difficult and take time. Additionally, Pederson and Valani (1988) concluded that difficulties may develop in relationships because of the reassignment of housework, child care, and other duties since individuals' goals are being put aside. The role shifts seem particularly difficult when the cancer patient is the family coordinator and determines family interactions (Cohen *et al.*, 1977; Welch-McCaffrey, 1988). Therefore, it is not surprising that Vess and colleagues (1985) concluded that families who had the ability to adapt to changing roles before the onset of cancer were more capable of coping with the adjustment. Clearly, adjustment to role changes is one of the major areas of concern facing families with cancer; therefore, it will be discussed again from a slightly different perspective when reviewing the qualitative research.

### 2.1.2 Financial Strain

Financial strain can have a profound impact on the family system (Ostroff *et al.*, 2004). Not only might the patient be out of employment for an extended amount of time, but also the cost of transportation, increased child care expenses and additional home care costs may have a drastic impact on families' savings. This will of course lead to emotional stress for both the patient and the well spouse.



### 2.2.3 Communication Difficulties

Communication difficulties, both within the whole family system as well as the husband-wife dyad, are another common concern reported in the psycho-oncology literature (Clipp & George, 1992; Mathieson, *et al.*, 1991; Northouse & Northouse, 1987; Sabo, 1986; Spiegel *et al.* 1983; Walsh *et al.*, 2005). Looking first at communication within the family, how the family communicated with each other and reacted to the patient with cancer is influenced by what the family members' assumptions were before the person was diagnosed with cancer (Wortman & Dunkel-Schetter, 1979). If they felt that they should avoid thinking or talking about negative aspects of situations, the family members may continue to avoid discussing the patient's difficulties thus preventing open communication (Northouse & Northouse, 1987). Similarly, Spiegel and colleagues (1983) in their study of 54 women with metastatic breast cancer concluded that the family is a crucial factor in patient adjustment and therefore, "conspiracies of silence" may be extremely harmful. Walsh and colleagues (2005) had similar findings in a study of 204 young women with breast cancer who indicated that communication avoidance within the family systems was a major problem.

Communication with a partner was also identified as a major source of concern and has been reported in several studies with women with breast cancer (Sabo *et al.*, 1986; Spiegel *et al.* 1983; Walsh *et al.*, 2005). In a study by Walsh and colleagues (2005) mentioned above, the women reported that the most problematic and stressful issue was communication avoidance with the partner. More specifically, in a study on the psychosocial well being and age related differences in quality of life for women with breast cancer, Spencer and colleagues (1999) found that in comparison with older women, younger women reported poorer communication problems with partners, more problems related to sexual functioning and more partner-related concerns. This is of particular relevance to this pilot study with its focus on younger men.

Turning now to studies which questioned men about the impact of cancer on their life, Sabos and colleagues' (1986) study on the male role for women with mastectomy also found a similar conspiracy of silence whereby the husbands felt obligated to keep their own feelings at bay in an attempt to protect the wife which only fostered denial and ultimately

led to blocked communications. Schover and von Eschenbach (1984) conducted a study on the impact of testicular cancer on marital quality. In their sample of 121 men, 47% of the men reported that the experience of cancer had brought them closer together, 28% saw no change and 25% believed that cancer had impacted negatively on their relationship. The data showed that the couple who had been married for a short time (mean four years) were more likely to break up than those who had been together for a longer time (mean seven years). Unfortunately, the study did not provide greater detail on specific communication patterns or what had caused the break-up (Schover & von Eschenbach, 1984).

Given the reported lack of honest communication between couples facing cancer, it is not surprising that the research by both Clipp and George (1992) and Mathieson and colleagues (1991) provided support that if the couples were having difficulty maintaining open communications about the illness then the marital relationship may deteriorate. However, it should be noted that almost all of these conclusions about communication problems were based on research studies done on female patients and spouses who had completed questionnaires or answered questions in semi-structured interviews. The only study on male patients by Schover and Von Eschenbach had in fact drawn the opposite conclusion that the experience of cancer had brought the couple closer together. Additionally, the majority of the studies were done with women with breast cancer which, given the comparatively poorer prognosis for younger women, may have a more profound effect on the women's self-esteem, sexual feelings and fears about death. While testicular cancer may pose challenges to men's self-esteem it has a better prognosis and thus may lead to different communication issues.

#### 2.2.4 Family Functioning Coping Strategies

The final major areas of concern discussed in the quantitative family literature were the issues of family functioning and coping strategies. In these studies the terms coping strategies or family functioning were usually referring to the "work" that the family members have undertaken to deal with the impact of cancer and the use of external coping strategies and/or supports (Kristjanson & Ashcroft, 1994).

Of particular relevance to this pilot study was the research done by Lewis and colleagues (1989) discussing the family's functioning with chronic illness from the spouses' perspective. The data were obtained from standardized questionnaires from 48 fathers with young school-age children whose mother had breast cancer, diabetes or fibrocystic breast disease. Results of the study found that marital adjustment was significantly affected by both the father's level of depression as well as by the wife's type of disease. Spouses of women with breast cancer had significantly higher levels of marital adjustment than did partners of women with other diseases and had to make adjustments within the family including improving communication skills and discussion in order to feel they were coping well with the illness. Additionally, these fathers were more at risk for suffering from depression which would also impact on their marital relationship; however, this depressive behaviour did not impact on the father-child relationship. This may reflect an attempt by the father to filter his behaviour through the marital relationship (Lewis *et al.*, 1989).

Although this study is fairly old (1989), because it focuses on the father's perspective (albeit it as the spouse) it is one of most informative and relevant articles for this study. Not only did the findings corroborate with the other quantitative studies highlighting communication problems, role changes and family coping styles as primary concerns for the father and family, but it also discussed how these factors were interrelated. Of particular interest was that counter to the prediction, the fathers' level of depressive behaviour did not directly affect the father-child relationship or the family's level of coping or functioning. However, the marital relationship was affected. This research begs the questions: how would the marital relationship and the father-child relationship be effected if the father was the patient?

To briefly summarize the quantitative research discussed above, clearly, a tremendous amount of research has been conducted on the impact of cancer on the family. However, in most of the studies (Spencer *et al.*, 1999; Spiegel *et al.*, 1983; Walsh *et al.*, 2005) the females were the patients. Moreover in the slightly older studies with men (Lewis *et al.* 1989; Pederson and Valani, 1988; Sabo *et al.*, 1986; Schover and von Eschenbach, 1984) the findings were somewhat limited. Therefore I will now turn to the qualitative studies from the perspective of the male patient.

## **2.3 Qualitative Family Studies**

Several of the major concerns for families which were discussed in the quantitative studies are also addressed in the qualitative studies. While the research methods were different, the findings were similar in that role changes, communication problems and family coping and functioning were presented as primary areas for concern for the cancer patient and their family. However, because the methods were different and not limited to results from questionnaires some of the areas were discussed in more depth and other areas of concern emerged. For example, there was more discussion on making meaning of cancer in life and feelings of isolation and connectedness (Robinson *et al.*, 2005). I will first examine the studies which addressed similar concerns and then move on to the articles with slightly different findings

### 2.3.1 Role Changes

In the literature review, many of the studies which discussed the impact of cancer on the family from a qualitative approach were discussing the results and findings after a family intervention (Bressi *et al.*, 1997; Neilson-Clayton & Brownlee 2002; Robinson *et al.*, 2005; Thastum *et al.*, 2006). In these articles the authors had done an extensive literature review themselves, devised an intervention and then discussed their findings usually based on both questionnaires and interviews. The interventions were all short term and family based with relatively small sample sizes. In these studies unlike the ones above, some of the patients were men. The authors all agreed that the presence of cancer required changes that would affect the whole family. Communication problems and changes in roles were reported in a majority of the studies as major areas of concern and in slightly more descriptive detail than in the studies discussed above.

According to Bressi and colleagues (1997), the diagnosis of cancer, which is often experienced and also communicated as a death sentence, may trigger a crisis which will disrupt the homeostasis of the family who will no longer be able to function in their usual way. This disruption in the family' functioning and the impact on role changes was also discussed at length in a very comprehensive study by Thastum and colleagues (2006), with 17 fathers with cancer and 24 mothers. The authors found that having a parent with cancer

in the family seemed to influence the levels of depression of the mother more than the father regardless of whether the mother was the patient or the well spouse. The authors were then surprised to find that mothers, but not the fathers, became significantly less depressed during the counselling period. While the issue of role changes was discussed at length in this article, the authors did not discuss the ages of the children which may have also had an impact on the mothers' responses.

Theoretical writings on families indicate that stress may be greatest when a family is in a transition from one developmental stage to another. It is at this point that family dysfunctions are most likely to occur (Friedman *et al.*, 1988). Therefore it is not surprising that Wellisch's study (1985) on acting out adolescents when a parent has cancer found this to be a particularly difficult time for families to adjust to role changes. Wellisch emphasized not only does the adolescent experience overt changes such as taking on additional household chores, but also there may be subtle role shifts between the adolescent and both the well and the ill parent. The adolescent is pulled in a reverse direction from the natural course of emotional separation from the family and brought into an intense relationship with his parents. The parents must be sensitized to the role shifts which may lead to acting out behaviour (Wellisch, 1985).

### 2.3.2 Communication

I have already presented above the quantitative studies which have discussed communication concerns primarily with women with breast cancer; however, in the literature on the topic of the impact of cancer on the family and the interventions, more studies seemed to discuss cases where men were the patients. Similar to the studies on women with breast cancer, these studies did emphasize the importance of open communication. Bressi and colleagues (2005) emphasized that in many families communication patterns must be changed and individual family members must find new ways to communicate that "what is unsaid is not unfelt". In other words, avoiding talking about a topic such as the fear of death does not mean the fear goes away. In the study by Thastum and colleagues (2006) discussed above, the participants reported that the main benefits of the counselling seemed to relate to the more open communication and sharing of illness-related problems because it increased the mutual understanding between parents and

children. It is interesting to note that in these qualitative studies improvements in communication and adaptation to role changes were reported in interviews by patients and family members alike as some of the most beneficial outcomes of family focused interventions. Therefore, one can draw a link from the extensive exploration of the major concerns for families with the development of interventions addressing these concerns. Two concerns, however, which were not discussed at length in the quantitative research but were discussed more in the qualitative research, were the feelings of isolation and trying to find meaning in the cancer experience which we will turn to now.

In a study by Robinson and colleagues (2005), the authors designed a case-analysis protocol to learn about the personal perspectives of family members who participated in therapeutic treatment for cancer. The participants included two families one where the father had cancer and the other where the mother was the patient. The results of this study found three overwhelming themes: the balance between isolation and connection, beliefs about the meaning of life and death and finding balance between old and new world views. The researchers felt that the families made progress when they were able to develop a synthesis between the extremes of the old world and the cancer dominated view of the new world (Robinson *et al.*, 2005).

Similarly, Wright and colleagues in their book *Beliefs: the Heart of Healing in Families and Illness* concluded that how families deal with the illness depends on the beliefs about the illness confronting them (Wright *et al.*, 1996). Additionally, Gosselin (1989) in an article on giving meaning to cancer asserted that difficulties occur when family members hold too tightly to existing beliefs about cancer and do not allow new information to alter their outlook. Thus it seems that if clinicians are better able to understand the current context of the family and their belief system they will be better situated to offer effective interventions.

Robinson and colleagues (2005) asserted that the ongoing tension between isolation and connection was one of the core concerns in the families' experience of cancer. The researchers noted that feelings of isolation were very common and difficult for the participants. These feelings seemed to emerge from a perceived lack of support (Robinson

*et al.*, 2005). Becvar (2005) in a commentary on cancer goes one step further in explaining the cancer patients' feelings of isolation. She asserts that feelings of isolation are understandable given two prominent characteristics of our society: individualism and an intense fear about death. She asserts that a "cancer phobia" which often manifests itself as a persistent fear for one's health is also accompanied by a sense of shame with the diagnosis and a tendency to want to avoid others with a similar disease (Becvar, 2005). Clearly feelings of isolation and drawing meaning from the cancer experience are important concerns for the patient and family members. While these ongoing struggles may have been touched upon in the discussion of communication concerns in the quantitative studies above, it is through the in-depth interview process and the analysis of case studies that full weight of these particular struggles can be felt.

Above I have discussed in depth the major concerns facing families with cancer. I will now turn to more individual concerns and anxieties and review the literature on the impact of cancer on men in general and fathers in particular. I will categorize the studies as I did above and first focus on the quantitative work and then move to the qualitative studies and case analysis.

#### **2.4 Individual Quantitative Studies**

Literature discussing concerns and anxieties exclusively for men with cancer is comparatively limited. In the quantitative research the authors tend to "measure" the patients' psychosocial symptoms by relying on specific outcome measures which have been shown to be informative at detecting the clinical effectiveness of interventions. While these studies may accurately evaluate the efficacy of an intervention, they have a limited yet sometimes helpful insight into the anxieties of men. The study conducted by Moynihan and colleagues (1998) is a case in point.

Moynihan and her colleagues designed a research study to determine the efficacy of adjuvant psychological therapy in patients with testicular cancer. They asked newly diagnosed patients to participate in a randomised trial for psychological support. Of the 184 eligible men asked to participate, there were 73 men (40%) who agreed to participate in the intervention. The researchers used a battery of questionnaires to evaluate the

psychological well-being and psychosocial adjustment of the patients. Topics which were covered in these questionnaires included: anxiety, depression, mental adjustment to cancer (which includes fighting spirit, helplessness, anxious preoccupation, fatalism and denial). From the baseline questionnaires it was determined that the men who did agree to participate had more psychosocial dysfunction prior to the intervention.

The researchers based their decision to use adjuvant psychological therapy as the treatment intervention because, according to Vingerhoets and colleagues (1990), men are regarded as having a problem focused coping strategies; therefore, they want to focus on regaining control. Adjuvant psychological therapy, which uses cognitive and behavioural approaches, had been found to be helpful in regaining control (Moore & Greer, 1989). However, from the results of the follow up questionnaires no evidence of benefit was observed after the treatment and there were no statistically significant differences in outcome between those who participated and those who declined (Moynihan *et al.*, 1998). The authors emphasized that the efficacy of different types of interventions does differ depending on the disease and therefore concluded that interventions should be systematically evaluated within the specific context.

I would offer a few additional comments about drawing conclusions from this study. First, while it offered a lengthy discussion on the statistical methods used to analyze the data and why these methods were or were not accurate; they only very briefly discussed what the psychosocial factors were and why they felt these men would benefit from this particular intervention. They pointed out that the men who agreed to participate did have higher baseline levels of psychosocial symptoms which they felt suggested that these men felt they needed psychological support. However, the authors did not make the link of why they felt that the psychosocial symptoms that were reported by these men would benefit from this type of intervention. Instead, the authors justified using the adjuvant psychological therapy model based on a study by Vingerhoets that men have a tendency towards focused coping strategies because they want to regain control. The authors argued that Adjuvant Therapy helps regain control. The authors themselves admitted that an inappropriate intervention cannot be discounted (Moynihan *et al.*, 1998).



Clearly, there are limitations to this study particularly with regards to trying to tease out major areas of concern and anxieties for men with cancer. However, I have included it partly because in the cancer literature it is widely accepted that questionnaires given to participants do address the major areas of psychosocial concerns. Yet it seems that one of the limitations of a quantitative study such as this, which may be extremely statistically accurate and methodologically sound, is that not much is revealed about the actual men who participated in the study.

## **2.5 Individual Qualitative Studies**

On the other hand, Moynihan (1987) conducted a much earlier qualitative study with a formal assessment of the psychosocial concerns of testicular cancer patients. Moynihan recognized some of the difficulties in embarking on retrospective psychosocial study including the lack of a true “control group” and the problem of a woman herself, as the researcher, seeking to understand a very private male world. In order to overcome these obstacles, she conducted open-ended interviews where the patients would, up to a certain point, direct themselves. By using specific interview techniques where the patients gave their own accounts, the responses did not depend solely on the way the question was asked but more importantly on the relationship between the researcher and the patient. Moreover, the balance of power was consciously shifted with the interviews being carried out in the patients’ home and not in the hospital setting. It was believed that patients may tend to put on a “best face” and tell a “public account” story which they had repeated numerous times to the hospital staff if they were in the hospital. Moynihan found that she could get the more “private accounts”, when the patient had been invited to tell a story rather than asked structured questions in the comfort of their home (Moynihan, 1987).

Moynihan’s study found high levels of psychosocial morbidity in patients which was surprising to the researchers given that the men had excellent prognoses. The main concerns reported by the men included the men’s reticence to talk openly about their worries particularly within intimate family circles. Men also mentioned a loss of libido at the time of uncertainty and during treatment. Even well after the treatment at the interview men still reported this. Most men did not report body image as a worry; however, the researchers wondered if that was because men were reticent to reveal subtle feelings about

how the loss of a testicle may undermine their masculinity. On the contrary, men were very open about their concerns regarding unemployment which was associated with high levels of psychological distress. Men felt that they had been discriminated against at work and were very concerned about the possibility of being financially dependent on others.

Moynihan's study, albeit extremely insightful and informative, is comparatively old (1987) and as I have mentioned repeatedly, the number of more recent quantitative studies on the needs, anxieties and concerns of men is extremely limited. Therefore, when trying to gain information from qualitative studies about specific individual concerns I broaden my literature search to include articles which interviewed both men and women. Within this remit one study of particular interest was by Leydon and colleagues (2000) on the patients' information needs.

The purpose of this study was to explore why cancer patients do not want or seek out information about their condition beyond what has been volunteered by the medical staff during the time of their illness. The results found that while all patients wanted some information at the point of diagnosis and treatment not all wanted additional information throughout the cancer trajectory. The authors found three overarching attitudes to the patient's management of their cancer which limited their desire for and efforts to obtain information; faith, hope and charity. The patients, with different degrees, displayed faith in their doctors with the attitude that the doctor knows best. A sense of hope pervaded in all 17 narratives and for some of them this was closely linked to fear. Patients created a façade of hopefulness particularly in advance cases. Men rarely wanted to speak to other men about their experiences and felt pressure to preserve and put on a brave face. This attitude was linked to an avoidance of additional information because men continued to maintain hope through silence. Finally, with regards to charity, even in the face of terrible situations, all the patients reported having been influenced by thoughts of others who may be seen as being less fortunate than themselves (Leydon *et al.*, 2000).

It is interesting that in a study supposedly on the straightforward topic of information needs, the patients revealed in their interviews such powerful strategies of coping with their illness. While the concept of hope does appear on some of the quantitative research

questionnaires, neither the concept of faith nor charity do. Therefore, this study not only reveals some important areas of concern for male patients, but also shows the benefits of a systematic analysis of in-depth interviews. Additionally, this study shows the importance men place on maintaining a “brave face”, this type of behaviour is consistent with some of the studies on masculinity and illness which will be discussed in the next chapter. Hopefully, what has become evident in this discussion of available research and literature on the concerns and anxieties of men with cancer is that there is a need for further in-depth exploration.

## **Chapter 3: Masculinity, Gender Roles and Testicular Cancer**

### **3.1 Introduction**

Above we have examined numerous studies and articles exploring potential challenges and coping strategies for patients and family members with any type of cancer in order to establish a solid foundation of understanding about the impact of cancer on families when a parent has cancer. However, because the diagnosis of testicular cancer is an illness which threatens men's reproductive organs and potentially sexual function, it may also affect men's thoughts about themselves as men (Gordon, 1995). Therefore, it is also beneficial to explore how this diagnosis may impact on men's views of their masculinity, self-concept, self-image and gender roles. In order to do this it is helpful to provide a very brief description of the historical development of theoretical models and theories of masculinity. I will then provide definitions of specific concepts and discuss relevant research studies which explore the unique concerns, anxieties and coping strategies which men face when confronted with a chronic or critical illness with a particular focus on the complicating factors of masculinity, gender and sex roles. I will then turn to the limited amount of literature which specifically addresses these concerns, for men with male cancers.

I will conclude this section by describing a label that I have applied to the specific set of coping strategies which I identified in the participants' interviews which I have called the "Masculine Way of Handling Illness" (MWHI). I believe that a majority of the participants in the study employed a range of defense mechanisms and coping strategies to not only manage their concerns and fears about their illness but also to ensure that they maintained their sense of masculinity and self-concept. Therefore, for simplicity and clarity, I refer to this strategy as MWHI which I will describe in detail below.

### **3.2 Background**

Moynihan (1998), in her article on theories in health care and research, reminds us that by understanding theories of masculinity we will be in a better position to thoroughly understand the experience of young men with testicular cancer and how practitioners and researchers perceive and respond to them. In order to understand the current trends in

theories of masculinity it is helpful to briefly examine the historical development of these theories.

Most sociologists have moved on from the positivist perspective that masculinity and the male sex role are signified exclusively by the male anatomy (Moynihan, 1998). There has been a shift towards the constructionist theories. From this perspective, Courtenay (2000) proposes that men think and act in certain ways because they have adopted certain concepts about masculinity from their culture (Courtenay, 2000. p. 1387). In other words, according to the social constructionist point of view, male gender roles may be defined by and made up of social interactions and beliefs within societies which may vary across cultures (Moynihan, 1989). For example, there is the Western myth that real men are hard, strong, successful and are reluctant to admit to being ill (Moynihan, 1989).

Research and theory generated by feminist scholars in the 1960s and 1970s was also influencing the current views of gender, masculinity and health issues (Sabo & Gordon, 1995. p.4). Historically, feminist scholars have emphasized the concept of patriarchy and social hierarchies have been and continue to be male dominated. Rather than challenge this concept, Sabo and Gordon (1995) suggest that acknowledging this phenomena and recognizing that patriarchy and contemporary patterns of gender relations can be helpful in understanding cultural customs, family relations and even men's health and illness (1995, p. 2). They suggest that academics adapt an "inclusive feminism" approach combined with the socio-cultural approach which will help to facilitate a more thorough understanding of how men perceive their bodies and their psychosocial adjustment to their illnesses (Sabo & Gordon, 1995. p. 3). Connell (1987), whose work on masculinity is frequently cited, similarly combines elements from both the social constructionist and feminist approaches to develop his theories of hegemonic masculinity which will be discussed in more detail below.

What is relevant to this study is the importance of understanding and acknowledging what the current models seem to have in common. That is the emphasis on the importance of understanding the individual within his social context. There is no "right" theory nor is there a "right" way to understand the links between men's views of themselves, their sex

roles and their sense of masculinity and how they respond to their illness. However, these theoretical models provide a foundation for understanding each of the participants in this study and then developing assertions about the similarities amongst them.

### **3.3 Definitions**

As mentioned above, the benefits of the BNIM methodology is that the participants reveal the issues and concerns that are relevant to them rather than having the researcher choose possible topics. In this study, what became apparent was that being diagnosed with testicular cancer poses challenges to men's sense of self. While no participant directly stated "my masculinity was challenged", by carefully examining both the verbal and nonverbal communications shared during the interviews, it became evident that the men were confronted with issues regarding their sense of masculinity, identity and gender/ male sex roles. In order to ensure that these terms are applied consistently throughout the rest of this study, it is helpful to provide specific definitions.

Gender, according to social scientists, is different than sex. While sex refers to the biological differences between male and female, gender refers to the cultural meanings that are attributed to the biological distinctions which are learned via socialization, social conditioning and cultural adaptation (Sabo & Gordon, 1995). Furthermore gender, according to the constructionist perspective, is not static; it is a dynamic process which is produced and reproduced through people's actions (Courtenay, 2000. p. 1387). Moreover, health-related beliefs and behaviors can also be understood as a set of strategies for constructing gender (Courtenay, 2000. p.1388). In other words, individuals' beliefs about and their behaviors around health related issues can also be seen as a means of demonstrating and reinforcing gender roles. For example, when responding to illness men may act in a manner which reinforces their strongly held beliefs and may dismiss their health needs and take more physical risks in order to maintain the traditional male role (Courtenay, 2000).

Gordon (1995) draws on the works of Brannon (1976) and Harrison and colleagues (1992) to provide a description of what he refers to as the traditional male sex role. According to

Brannon the central characteristics of the male sex role in American society can be summed up as:

1. No sissy stuff: the need to be different than women.
2. The big wheel: the need to be superior to others.
3. The sturdy oak: the need to be independent and self-reliant.
4. Give 'em hell: the need to be more powerful than others, through violence if necessary (Gordon, 1995. p. 249).

Gordon suggests that individuals incorporate some of these characteristics into their personality in order to maintain their roles within society. Furthermore, he summarized additional key characteristics as outlined by Harrison that men “evaluate life success in terms of external achievements rather than personal and interpersonal fulfillment” (Harrison 1992 as cited in Gordon 1995. p. 249). For the purpose of this study I will similarly use these characteristics to describe the traditional male sex role.

Recognizing that male gender roles are a constructs of traits, attitudes, beliefs and behaviors (Helgeson, 1995), one can see the similarity with the concept of masculinity which is also influenced by society, history and class and which may change over time (Connell, 1995). Hegemonic masculinity describes the “idealized” form of masculinity whereby men are strong, self-reliant, and limit their emotional responses (McCaughn *et al.*, 2012). It is now accepted, however, that there are multiple forms of masculinity some of which are marginalized and some stigmatized (Chapple & Ziebland, 2002. p. 655). For the purpose of this study, when utilizing the term hegemonic masculinity, I will be referring to the stereotypical view of masculinity which includes characteristics such stoicism, courage, provider, sporty, self-reliant and inexpressive (Helgeson, 1995).

The other terms which are important to identify and clarify are identity, self-concept and self-image. One’s identity defines, locates and differentiates the self from others and develops both in stable roles and in changing situations (Charmaz, 1995. p. 268). Because people are confronted with illness, problems and incapacities, one’s identity can be challenged. Identity dilemmas occur when one loses valued attributes, physical capabilities, social and professional roles and is unable to continue to pursue hoped for goals. This can result in the loss of valued identities and the positive definition of the self (Charmaz, 1995.

p. 268). Similarly, self-concept is defined as a collection of beliefs about one's own nature, unique qualities and typical behavior; it is a mental picture of oneself: a collection of self-perceptions (Weiten, Dunn & Hammer, 2012). In contrast, self-image is more focused on the physical aspect or the idea of one's appearance (Pearsall, 1999). Men's self-image can be challenged and undermined when confronted with an illness. The body is one of the central foundations of how men define themselves and how they are defined by others (Gerschick, 1995. p. 185). Therefore, a man's view of his body is closely linked with his self-image which can determine how he feels about himself and how he believes he is seen by others.

### **3.4 Men, Illness and Masculinity**

In the literature review section, I presented the key areas of concerns and anxieties which were described for men with cancer in both qualitative and quantitative studies. In this section, I will expand on these concerns to further explore additional concerns found in relevant literature for men with chronic or critical illness which are closely linked to the concepts of masculinity and sex roles. While the studies described in this section were not on men with cancer, the findings can be helpful in further informing our understanding of challenges facing male patients.

The literature revealed two key challenges: First, illness can threaten male identities and masculinity. Second, because the characteristics of the traditional male gender role are inconsistent with the capacity to reach out for social and emotional support, some men fail to gain the support they desire or need (Helgeson, 1995. p. 76). I will elaborate on these two challenges.

Being diagnosed with a chronic or critical illness can be a devastating experience for men. The experience involves shattering the very basic assumptions about the self and the world (Helgeson, 1995. p. 86). A man discovers that he is vulnerable. Up until that point, a man's masculine identities had been established in the participation of the gender order whereby he may have taken for granted his masculine identity (Charmaz, 1995. p. 68). Suddenly, an illness can prevent a man from participating in work, sports, leisure and sexual activities, all of which may be ways of validating masculinity. They may feel a shift in power



relations with some and start to have self-doubts about masculinity (Charmaz, 1995. p. 268). Consequently, men with physical disabilities or illness may find themselves situated on the margins of mainstream society (Sabo & Gordon, 1995. p. 12). Moreover, because strength and physical activity are key components of masculinity; men confronted with illness may experience difficulties constructing a new workable masculine identity (Sabo & Gordon, 1995, p. 12). Therefore, men must learn to deal with the presence and pressures of hegemonic masculinity which demands strength at a time when they may be feeling weak (Gerschick & Miller, 1995. p. 184).

Research done by Helgeson (1995) on men confronted with coronary heart conditions and Gerschick and Miller (1995) on men with long-term disabilities describe strategies and adjustment techniques that men have employed to cope with the challenges to their masculinity and gender roles. While men did not necessarily define their masculinity in the exact same way, Gerschick and Miller found that there seemed to be three dominant frameworks their participants employed to cope with their condition in relation to their views on masculinity (1995, p. 187). The three frameworks were:

1. Reformulation where the men redefined masculinity in their own terms.
2. Reliance where the men relied on particular attributes that they could still hold onto.
3. Rejection where men would renunciate the old standards of masculinity (Gerschick & Miller, 1995. p. 187).

Once the participants were able to acknowledge that their future was uncertain, some participants were able to reformulate masculinity and reappraise what was important to them. Some men who had spent too much time at work decided to spend more time with their families (Charmaz, 1995) while others found that work was the one area they could continue to feel competent in and therefore placed more emphasis on their employment (Gerschick & Miller, 1995). Either way, these men confronted with challenges found illness as an opportunity for reevaluation, redirection, reconstruction of self and change (Charmaz, 1995, p. 278). Alternatively, men who relied on existing attributes put an emphasis on control, independence and strength. These men struggled to feel comfortable with their manhood and felt an inability to meet the predominant standards of masculinity (Gerschick & Miller, 1995). Finally, men who rejected the traditional ideals of masculinity

created their own principles and practices. They relinquished some of the identities of the past self as a means of marginalizing the effects of the illness (Charmaz, 1995) and then created alternative masculinities identities which provided them with a supportive environment (Gerschick & Miller, 1995. p. 199). The authors recognized that these frameworks are not mutually exclusive and that most participants employed a combination of strategies at different times to cope. However, the framework is a helpful reference for exploring how men adjust to challenges regarding illness and masculinity.

Another challenge for men confronted with chronic and critical illness, is that men often do not receive the emotional and practical support they need. The characteristics of traditional male gender role and masculinity with the emphasis on self-control, toughness and autonomy may prevent men from expressing emotions and reaching out for assistance (Kilmartin, 1994). Men are socialized to believe that expressiveness is inconsistent with masculinity (Balswick & Peek, 1971) and may avoid self-disclosure and admission of vulnerability (Helgeson, 1995). Thus they may refuse to admit pain or feel it is inappropriate to seek help as it might signify weakness (Helgeson, 1995. p. 86). For these men, the consequences of having a chronic or critical illness are much more than just the physical symptoms.

However, just because men are reluctant to ask for support does not mean that they do not receive it or benefit from it (Helgeson, 1995. p. 96). A recent study by Oliffe and colleagues (2009) found that men with prostate cancer did benefit from the experience of participating in a support group. Additionally, men's desire for information, their need for control and their interest in problem focused solutions, suggests that men are more amenable to interventions and support groups which have an educational focus (Helgeson, 1995). However, while men clearly struggle to reach out and gain support from other men, in Helgeson's study the single greatest predictor of recovery was the extent to which men disclosed and felt supported by their partners. Patients who felt comfortable sharing their concerns with their spouse reportedly recovered better from heart attacks (Helgeson, 1995. p. 90).

### **3.5 Men, Testicular Cancer and Masculinity**

The physical consequences of the diagnosis and treatment of testicular cancer pose unique challenges to men. In particular, after surgery men not only lose a testicle and have scars but in many cases they suffer from sexual dysfunctions (Gordon, 1995. p. 246). Additionally, men who require further treatment have reported having a loss of sexual activity, difficulty reaching orgasm and erectile dysfunction (Schover & von Eschenbach, 1984. p. 252). Thus not only do the side effects from treatment impact on the men physically but the challenges are further complicated by issues relating to masculinity and body/self-image due to the cancer site. Three main concerns for men with testicular cancer which are reported in the current literature include (1) sexual dysfunctions, (2), challenges to masculinity and self-image, (3) decision to have a prosthesis. These concerns will now be discussed in detail.

Because of the excellent prognosis for testicular cancer patients, there are an increasing number of young men who must cope with the long-term effects of their treatments (Schover & von Eschenbach, 1984). There is evidence to suggest that up to 30% of survivors report experiencing some problems with sexual function, body image, and infertility as a result of the treatments (Gordon, 1995. p. 248). Additionally, in a study by Reiker and colleagues (1985), they found that a sub-group of the men who reported sexual impairments had also reported having difficulty discussing their concerns and attempted to conceal their emotions. For these men, the authors suggest that because the men had internalized the traditional sex role model, they were unable to express and discuss their concerns with surgeons who may have been able to offer assistance (Reiker, 1985, p. 1124). Schover & von Eschenbach (1984) found that the ability to function sexually was a crucial factor in marital happiness and sexual dysfunction was a major stress factor for men whose marriages did dissolve after the treatment. Moynihan (1987) emphasized the importance of overcoming the stalemate of doctors and patients being locked in perpetuating male gender myths in order for the patients to be able to talk honestly to their doctors. While seeking relief for issues regarding sexual dysfunction through counselling or support groups may not be an option for some testicular patients, particularly those who are locked into traditional male role behavior (Reiker *et al.*, 1990), perhaps these men may now find some vital, useful information on the internet.

Men reported and admitted feeling less masculine immediately after surgery and during the treatment phase (Gordon, 1995). This is the point at which patients were unable to function normally sexually. However, for the majority of men when normal functioning returned, they reported that the feelings of loss of masculinity disappeared (Gordon, 1995. p. 252). However, even over time their negative feelings about their body image and feelings of shame and stigma remained. Because of the stigma and fears about being judged by others, men may struggle with the decision as to whether they should disclose their diagnosis to other men or not (Bullen *et al.*, 2010).

Gordon (1995) found that the men in his study employed two different strategies to cope with the challenges testicular cancer posed to their masculine identities which is similar to the strategies presented by Gerschick and Miller. The first strategy was to define their cancer ordeal as a means of reaffirming their version of masculinity. The second strategy was to develop a new, less traditional view of masculinity (Gordon, 1995. p. 254). With regards to the first strategy, for some men surviving the cancer ordeal provided an opportunity to test themselves and demonstrate an ability to “put up a good fight”. Not only did they feel more self confident having overcome a life threatening illness but they also did so in a “tough” way perhaps by returning to work or sports as quickly as possible (Gordon, 1995. p. 255). Similarly, men who chose to disclose did so in a way that was influenced by perceptions of idealized masculinity (Bullen *et al.*, 2010). Surviving cancer provided an opportunity to face up to a difficult challenge courageously. Thus men were able to maintain the image of being strong and tough (Bullen *et al.*, 200). In effect the men were able to maintain a secure sense of their masculinity by exhibiting some of the key characteristics of the traditional male sex role (Gordon, 1995. p. 259).

The other strategy that the participants in Gordon’s study employed was to define masculinity in non-traditional terms. The men moved away from the traditional view of masculinity and described their responses to their illness as becoming more emotionally expressive, more relationship orientated and becoming more concerned about the well being of others (Gordon, 1995. p. 263). However, Gordon recognizes that these two strategies were not mutually exclusive and in most cases the men who admitted to adopting

new characteristics did so while still holding on to their original view of gender roles and masculinity (Gordon, 1995. p. 261). Clearly, the participants in Gordon's study as well as other patients facing the challenges of testicular cancer must devise a unique set of coping strategies and responses which fit into their individual view of masculinity as well as their own self-image.

For some patients, who are struggling with negative body image, one option is to have a surgically implanted prosthesis. Although testicular implants have been available to men since 1941, relatively little is known about men's perceptions of these implants and the decision making process (Chapple & McPherson, 2004). Choosing whether to have one is an option that all men undergoing orchidectomies face and one which is unique to a diagnosis of testicular cancer. Most studies have found that the majority of testicular cancer patients choose not to have prostheses implanted (Moynihan, 1987; Gritz *et al.*, 1989; Chapple & McPherson, 2004). The men decided against having a prostheses because they thought that the loss of a testicle was not obvious, was not a long-term threat to their masculinity and that living with one testicle was comfortable (Chapple & McPherson, 2004. p. 655). Additionally, men who were married claimed that they and their wives felt good about the husband's body image without the prosthesis (Gritz *et al.*, 1989). However, patients who opted for one explained they did so for reasons such as loss of masculinity and changing self image, social stigma, body image and, for men not in long-term relationships, concerns about sexual encounters (Chapple & McPherson, 2004. p. 661). Clearly the decision to have a prosthesis is quite complex and men are influenced by worries about self-image, body shape, social relationships and feelings of masculinity (Chapple & McPherson, 2004. p. 662). In order to make an informed choice, men need to be provided with thorough, accurate information and given ample time to contemplate the pros and con in order to come to a decision that is right for them.

### **3.6 Masculine Way of Handling Illness**

Clearly men confronted with illness in general and testicular cancer in particular may struggle coping not only with the physical effects of their illness but also the challenges it places on them regarding their views of masculinity and sex roles. Different authors have identified and explored different strategies that men have employed to cope with these

challenges (Gordon, 1995; Gerschick & Miller, 1995; Helgeson, 1995; Bullen *et al.*, 2010). The authors have provided frameworks in which to understand the interplay between masculinity and sex roles and illness. These strategies and frameworks combined with the analysis of the ten participants in this study enabled me to recognize a pattern of coping strategies and defense mechanisms. The participants in this study seemed to employ coping strategies and defense mechanisms which helped them to cope with their illness AS WELL AS maintain their own sense of masculinity and gender role. The most common defense mechanisms employed to cope with both included: denial and avoidance, maintaining a stoic façade, minimizing, intellectualization, in some cases humor and projection. (Examples will be provided in the case studies). While I recognize that these defense mechanisms are not exclusively used by men, what is important to note is that the benefit of employing them was twofold: it enabled the participants to hold onto their sense of masculinity and self while also providing a means of dealing with the physical and emotional challenges of their disease. I acknowledge that Masculine Way of Handling Illness may not be a technically precise definition, nor do I presume that this strategy applies to all men confronted with cancer. However, it was a general trend that I noticed for the men in this study. Hopefully, when reading the individual case analyses, the evidence to support this concept will become clearer. Moreover, having described the concept, it should be helpful in understanding the lived experience of the fathers with cancer.

## **Chapter 4: Theoretical Framework**

### **4.1 Introduction**

Having a specific theoretical framework for a psychosocial research study is essential in order to make direct links from the empirical findings to the conceptual conclusions. In order to do this, the researcher must select an explicit theoretical framework to guide the study (Cooley & Moriarty, 1997). I have chosen to utilize the psychodynamic model with particular emphasis on Kleinian theory. The key to psychosocial research which is informed by psychoanalytical concepts lies in the belief that in addition to the facts and feelings openly communicated by the participant, it is also essential to consider the unconscious communications, dynamics and defences that exist in the research environment. Psychodynamic theory is particularly well placed to explore these unconscious but revealing factors. Thus, utilizing psychodynamic concepts to interpret the data from the interviews will hopefully ensure a more thorough understanding of the participants' experiences.

While a full discussion of psychodynamic theory is beyond the scope of this dissertation, it is helpful to highlight the basic psychodynamic concepts including the major anxieties and defences as presented by Melanie Klein. At the same time I will also incorporate some of the psychotherapy literature on cancer albeit extremely sparse in the hope that these articles can exemplify the benefit of exploring the cancer patient's situation from a psychodynamic perspective (Burton & Watson, 1998; Goldie, 2005; Hess, 1995; Moylan & Jureidini, 1994). Finally, I will conclude this chapter with a discussion of the benefits of utilizing psychodynamic concepts to inform psychosocial research.

### **4.2 Psychodynamic Theory**

At the heart of all psychodynamic therapies is the premise that links are made between early childhood experiences and relationships and the patient's current character structure and symptoms. The patient's emotional response to the therapist (transference) and in turn the therapist's emotional response to the patient (countertransference) are a major source of learning. These key patterns of feelings and behaving are repeated from early childhood into adulthood and may be unconscious. It is the therapist's role to identify some of these patterns and when appropriate make interpretations (Burton & Watson, 1998).

Klein's differentiation into two basic groupings of anxieties and defences can also be helpful when trying to orientate clinical work. The two basic positions, the paranoid-schizoid and depressive positions, can be compared along specific characteristics of anxieties, defences, mental structures and types of object relations. In the paranoid-schizoid position anxieties are of a primitive nature whereby the infant hates and fears the "bad" object which leads to feelings of persecution while in a parallel way loves the good object. The chief defences are splitting, projection and introjections and idealization (Steiner, 1992). The use of these defences can be seen in clinical practice with cancer patients.

Goldie (2005) in his book *Psychotherapy and the Treatment of Cancer Patients* provides an explanation of his therapeutic relationship which shows signs of the patients' use of introjection and idealization. He describes his relationship with the majority of his cancer patients:

I was accepted as a person who could accept them and their fears. It was reminiscent for some of them of a very early relationship with another – often a parent – that could contain them. I was frequently taken in – introjected- by the patient as a processor of bad feelings (Goldie, 2005, p.35).

Goldie goes onto explain that in many cases he only saw the patients a few times yet they found these meetings very helpful. By being able to mobilize very primitive defences at an extremely stressful time the patient was able to "take in" some of the good from Dr. Goldie who had become the all good, loving and caring parent figure.

Moving now to Klein's second position, the depressive position represents an important developmental advance whereby the whole object is recognized and the infant feels ambivalence which leads to a shift in primary concern for survival of the self to a concern for the object which it depends on. Thus the anxieties are around feelings of loss and guilt which will then enable the experience of mourning to take place (Steiner, 1992). In this stage the individual will develop reparative capacities in hopes of preserving his object. Another important mechanism of defence in the depressive position is projective identification whereby the individual unconsciously projects his feelings or experiences



into another who then finds he has to cope with these feelings on behalf of the first individual (Moylan & Jureidini, 1994).

A clinical example of the use of projective identification occurred by the staff of nurses on a bone marrow transplant ward. Moylan and Jureidini (1994) described how they had been asked to consult on a ward which they described as being full of uncertainty about death. They felt that the staff was frequently on the receiving end of powerful unconscious projections from their patients and because of the very stressful environment, the staff was often unable to process these projections. Therefore, the staff in turn bombarded the consultants with primitive emotions. The consultants ultimately felt unable to be the “all-powerful mother of childhood who could make the world right again...” And instead they found themselves feeling helpless, just as the staff did (Moylan & Jureidini, 1994, p. 236).

Goldie’s work with cancer patients and Moylan and Jureidini’s experience as consultants, exemplify how psychodynamic theory can be helpful and illuminating in clinical work with cancer patients.

#### **4.3. Psychosocial Research**

In addition to enhancing our understanding of clinical work with cancer patients, psychoanalytic theory can also help to add depth to the understanding of participants in research studies. It is precisely because individuals have personal views about their world and attach latent levels of meaning to their ideas that within qualitative research there is traditionally a rejection of the view that truths can be established. Instead, the focus is shifted to take into account the uniqueness of individuals within their environment (Hollway & Jefferson, 2000). With this perspective in mind, research which can facilitate the exploration of both the spoken and latent meanings for participants while incorporating concepts and principles from psychoanalytic theory is, therefore, well placed to bond the split between the “individual” and “society”.

Since the 1990s in the UK, psychosocial studies which seek to understand the emotions as well as illuminate core issues within social sciences have become increasingly popular (Clarke & Hoggett, 2009). While psychosocial studies are still in the developmental phase,

they are increasingly informing new methodologies in the social sciences which encourage the use of free association and biographical interview methods as a means of uncovering the unconscious communications, dynamics and defences that exist in the research environment. These approaches have the unique capacity to explore the researcher/researched relationship thus generating knowledge about these interactions (Briggs, 2005, p.15).

In a further effort to incorporate key fundamental principles of psychoanalytic theory into informed practice research, Hollway and Jefferson (2000) introduce the concept of the “defended subject” in research studies. In order to better understand the defended subject, they suggest the incorporation of the fundamental psychoanalytic proposition that anxiety is inherent in the human condition and precipitates defences against threats which are largely unconscious. A core psychoanalytic concept is the premise that individuals’ dynamic unconscious which defends against anxiety significantly influences individuals actions, lives and relations (Hollway & Jefferson, 2000, p.19). Traditionally, psychoanalysis examines how individuals responded when feeling threatened and what defence mechanisms they employ as well as focusing on the emotionality and the process of relationships (Briggs, 2005).

The concept of the defended subject then is particularly relevant to the participants of this study, all of whom are facing a life threatening illness. Cooper (1982) insightfully comments that for patients confronted with Hodgkin’s disease (a form of cancer) “Somewhere, in even the most carefree or apparently coping personality, will lurk the fear of imminent death” (p. 613). Thus for men who may be employing defenses to cope with some of the most primitive fears including the fear of death itself, the prospect of being able to utilize a methodology which encouraged the understanding of the defended subject seemed particularly relevant. Patients are repeatedly asked to provide their medical histories to a range of health care professionals; therefore, in a research interview, the respondent potentially could present a rehearsed set of generalizations to the researcher. In keeping with the defended subject approach, we see the possibility of the participant employing a defensive strategy utilizing intellectualization and avoidance to control potentially painful and frightening concerns (Hollway & Jefferson, 2000). Hence

incorporating the concept of a defended subject provides a means to see past or “below the surface” of the routine responses.

I have discussed how psychosocial research utilizes these psychoanalytic concepts to explore the unconscious dynamics and defences at play. However, and what is vital, is that these concepts not only help to understand the participant, they also shed light on the research process, like the analytic process, as a whole. Through a psychoanalytic lens we see that the research subject can only be known through the researcher because together they are co-producers of meaning (Clarke & Hoggett, 2009). In other words the affective dynamics of the research encounter are influenced by what the social researcher and the participant bring to the interview. Thus proponents of psychosocial research have established the need for a reflexive researcher who is engaged in sustained self reflection throughout the research process (Hollway & Jefferson, 2000). I will discuss my experience as a reflexive practitioner in more detail in Chapter 12.

A prominent feature of psychoanalytically informed research is the emphasis it places on gathering data not only from the verbal communications but from non-verbal forms as well. This is similar to the clinical setting of the client and analyst where the therapist recalls the detailed interactions between herself and the client in the session as a means of understanding the internal world of the client. Similarly, if the researcher is keen to explore both the conscious and unconscious communications of the interview, the choice of interview technique is a vital ingredient. For the purpose of my study I turned to the BNIM method which is a clinical case study approach to interviewing. This approach is both consistent with the emphasis on reflexivity in the interview while also allowing for the development of an understanding of the unconscious dynamics at play, particularly the individual’s defences against anxiety (Hollway & Jefferson, 2000). This particular approach seemed to fit neatly with the aim of my study. I will discuss my particular choice of interviewing and analyzing in the next chapter on methodology.

#### **4.4 Rationale for the Study**

Having now reviewed relevant literature, it is evident that both the family as a whole and the patient as an individual face a multitude of concerns and anxieties which they will cope

with in a variety of different ways. While there has been a vast amount of research on these topics from the perspective of mothers with cancer, it is evident from the literature review that less has been done from the perspective of fathers. A psychosocial study designed to explore in depth the concerns, anxieties and defences of fathers with cancer utilizing psychoanalytic concepts should provide a unique, detailed and informative understanding of these men. Moreover, this study will hopefully be relevant to clinicians in that it will provide a deeper understanding of the men's concerns as an individual, as a member of a family and within his environment and thus be useful in supporting the patients and their families as well as designing helpful interventions.

## **Chapter 5: Methodology**

### **5.1 Introduction**

In this section, I will discuss my decision to conduct a qualitative study over a quantitative study and then explain the importance of establishing a trustworthy qualitative research model in order to ensure that the study has a “scientific attitude” which is valid and reliable. Next, I will address why I decided to utilize two different methods, the Biographic Narrative Interpretive Method (BNIM) and the Interpretative Phenomenological Analysis (IPA) to interview and then analyze the data and how these models were well suited to work utilizing a psychodynamic theoretical framework. I will then consider ethical factors which had to be addressed. I will also present the approval process at the Cancer Hospital where I conducted the study and explain the decision to have a sample size of ten men. I will conclude with a discussion of the recruitment process and the demographic details of the participants.

### **5.2 Qualitative verses Quantitative**

Having decided that the purpose of this study was to explore the areas of concern and individual anxieties of this population, the next decision was which methodology to employ: qualitative or quantitative? Traditionally, quantitative methodologies have been based on the standard philosophical view of natural science which is also closely linked to positivism. The key feature is to obtain objective knowledge based on experience which is separated from values (Robson, 2011). It has often been proposed that quantitative research is “hard” science and is considered higher in the hierarchy of research and the best method to deploy (Woolgar, 1996, p.11). Particularly in an era when social workers, as in other professions, are being bombarded with the demands of producing evidence based practice (EBP) in order to meet regulatory audits and inspections (Briggs, 1995), the desire to investigate and focus on emotionality may be met with skepticism. Luckily, this perspective has been severely challenged in recent years (Fuller and Petch, as cited in Briggs, 1995) with a shift to appreciating the value of understanding and exploring a phenomena in depth (Stake, 2006). Needless to say, my study was not looking to establish empirical regularities or truths, nor was it interested in turning information into measurable

data. Hence, a quantitative design was ruled out because I was interested in understanding the experiences of service users.

Qualitative research is vital in the realm of social science research because of its quest for understanding the meaning of experience, actions and events as they are interpreted through the eyes of the participants as well as allowing for the research to be sensitive to the complexity of the behavior and meaning in the context of the participants' world (Henwood, 1996). Qualitative research has typically been associated with the social constructionism paradigm which emphasizes the socially constructed nature of reality. Meaning does not exist in its own right but rather is constructed by humans interacting in interpreting their world. Social constructionism is different and distinct from social constructivism which is more focused on the individual and how they construct and make sense of their OWN world (Robson, 2011). Compared to a quantitative framework, the qualitative paradigm seemed closer to addressing the methodological needs of my study to explore men's experience. In particular, acknowledging the role of social constructionism in helping to define the concept of "masculinity" was a major component of understanding men with testicular cancer as discussed above (Moynihan, 1998).

While it is beneficial to understand the distinct theoretical models which underpin qualitative research, I needed a more specific methodology to explore the lived experience of fathers with cancer. Hence I recognized the need to find a particular methodological framework which would ensure a scientific attitude so that my research would meet the scientific criteria expected within the medical community while also ensuring that the interview approach would allow deeper exploration of emotionality and inter-subjectivity. Hence I decided to employ two methods: IPA and BNIM. However, before exploring these methods in more detail it is helpful to explain how I incorporated a scientific attitude into my research design in the hopes of producing a valid and reliable study.

### 5.2.1 Scientific Attitude

Qualitative design methods can be criticized because of their absence of a "standard" means of assessing reliability and validity which could be directly replicated (Robson, 2011). However, it is still possible to design a study which has a "scientific attitude". According to Robson (2011) a scientific attitude requires the authors to:

1. Systematically consider the nature of the observations and the role of the investigator.
2. Sceptically subject interpretations and assertions to challenges and disconfirmation.
3. Follow an ethical code of conduct.

If these criteria are met then the study is potentially more valuable because it is of a good quality and a socially responsible contribution to scientific research (Robson, 2011, p.15).

Below in the discussion of the choice of interview methods, I will examine the first point the role of the investigator, and later I will address the third point the importance of ethically conducted research in this study. What is important here is the second criteria of “skeptically” subjecting ideas to disconfirmation and scrutiny. When searching for a qualitative methodology to analyze the data, I was determined to find a method that would allow for both the discussion and presentation of the lived experience of the participants as well as stand up to challenges. Qualitative researchers usually recognize that their findings carry opinion; however, they are hoping that their studies may “not win over a critic but ... be persuasive to critical friends” (Stake, 2006, p.41). Smith suggests a few strategies for attempting to ensure studies withstand the keen eye of skeptics. In particular, he suggests:

- Internal coherence – concentrate on a sample that is internally consistent (i.e. a small sample size of men all with the same cancer diagnosis).
- Presentation of evidence – present enough raw data to ensure that reader can interrogate the interpretation (i.e. link all identified themes and interpretations to specific quotes from the text).
- Independent audit or close supervision - allowing someone else to follow the chain of evidence (i.e. present cases in supervision and research seminars).
- Triangulation – using different sources to tackle the research question (i.e. an extensive literature review).
- Member validation - taking the analysis of responses back to the participants to comment on the findings (i.e. sent report of findings to all participants for feedback) (Smith, 1996, p.194).

I incorporated these sensible strategies into my research design with the hopes of ensuring a valid and reliable study albeit from a qualitative perspective. It is helpful to look at the concepts of validity and reliability in more detail.

### 5.2.2 Validity and Reliability

When considering what constitutes a good quality research study and whether it is credible, it is beneficial, according to Robson, to consider what might be a threat to validity (2011). He presents a useful typology with three types of threats to validity in qualitative research; description, interpretation and theory. With regards to description, he emphasizes that the main threat to validity lies with inaccurate or incomplete data. In order to avoid this, all of the interviews in this study were audio-tape and transcribed verbatim. NVivo 9 software was used to keep track of transcripts as well as literature sources.

The next threat to providing a valid interpretation is by forcing a framework on the interview rather than allowing for an interpretation to emerge. Accordingly, throughout the analytic process, I relied on colleagues in and my supervisors to challenge and then support my interpretations. Additionally, the participants were emailed a short report of the findings and asked for their comments and response. Three participants responded confirming that they agreed with the identified themes. One participant replied “Your synopsis sums up all the points we discussed very well, so nothing to add except well done!”

Finally, a main threat to validity, according to Robson (2011), is the researcher’s preferences and bias which may interfere with the interview and later on the focus of the study. For example, in the interview the participant may try to give an answer because they think the researcher wants to hear something. The researcher must be aware of their own biases, for example, how their social identity and background may impact on their research. For the purpose of ensuring validity, it was important to avoid this type of bias again by utilizing close individual and peer supervision throughout the data analysis process.

Reliability in fixed design or quantitative research consists of using standardized instruments which can produce consistent results; however, this is problematic for qualitative researches. Technically, because qualitative methods are not standardized it is extremely difficult to apply the same tests. The researcher, therefore, needs to ensure the reliability of their methods and research practice by thorough, accurate and careful record keeping which can be shown to others in forms such as field notes, transcripts and tapes and research journals (Robson, 2011). All my field notes, transcripts and journals have



been kept in a secure location which is readily available for verification. The transcripts were re-read with the tapes by a colleague to ensure accuracy.

Hopefully the concepts or validity and reliability have been incorporated in the design of this study to ensure a trustworthy and credible design with a scientific attitude.

### **5.3 Biographic Narrative Interpretive Method (BNIM) and Interviewing**

Having determined that the psychosocial case study approach best suited the needs of my study, I was then introduced to the Biographical Narrative Interpretive Method (BNIM) developed by Wengraf and Chamberlayne (2006). One of main strengths of the BNIM method is its ability to enable the researcher to explore the latent levels of meaning (Chamberlayne & Wengraf, 2006). Additionally, it encourages eliciting narratives from the participants in an uninterrupted way thus helping to minimize the possibility that the facts of the story become more important than the person telling the story (Clarke & Hoggett, 2009). This interviewing strategy was particularly appealing because it encouraged both conscious and unconscious communications which psychodynamic theory was well placed to interpret.

The authors of the BNIM method argue that not only do we need to understand our personal histories; we also need to understand the context around them – both the psychological and the social (Chamberlayne and Wengraf, 2006). In order to encourage participants to explore their experience with the researcher they developed a method that includes a very specific interview process which is comprised of two sub sessions.

- In the first sub session, the participant is asked only one question and then asked to take his time and answer the question in detail. The interviewer does not interrupt and allows him to take as long as he likes.
- In the second sub session, the interviewer follows up with approximately 5-7 questions asking for the participant to elaborate on specific points.

This very open first question invites the participants to describe and then explore their experience. Unlike structured interviews, by focusing on eliciting narratives the hope is that participants will express perspectives that may have been suppressed and reveal what is

important to them. This method was appealing to my research with cancer patients who have become accustomed to telling their medical history to health care professionals thus having a “public account” which lacks emotion and personal details. An additional benefit is that this method encourages men to present what is important to them, not what the researcher thinks will be important. This proved to be extremely valuable in my study where men discussed topics and shared concerns which had not been anticipated or expected. The question I asked each participant was:

*As you know the purpose of this study is to learn about your experience as a father with testicular cancer. Therefore, in a moment I will ask you to tell me about your experience including all the events and emotions that were important to you from the time you suspected something was wrong to date. I will not interrupt and you can take as long as you like. So, when you are ready can you please tell me about your experience.*

An additional appeal of the BNIM method is the structure of the interview. After the initial open ended question, in the second stage of the interview the researcher asks five or six very specific questions based on what the participant has shared in the first stage. Rather than following up with a feelings or emotions question, the interviewer asks for a specific incident or what Wengraf (2006) calls a Particular Incident (PIN). For example, instead of asking “How did you feel about having to rely on your wife to take on more responsibility with the children?” I asked “Do you remember a specific time when you had to rely on your wife to do something with the children instead of yourself?” This line of questioning often leads to untapped emotions. In this example, I suspect the answer to the first question would have been something along the lines of “It was fine. My wife is capable.” Instead the respondent told a story about how his wife had to read a bedtime story to his son which had always been one of his very favourite parts of the day. The participant found his eyes welling up as he recounted this incident. Not only did I find this a very poignant vignette, but it also demonstrated that the participant had in fact struggled with role changes. The use of both the open-ended question combined with the strategy of asking for PINS seemed to be particularly well placed for encouraging the men to discuss what was important to them while also eliciting the emotions attached to their experiences.

The BNIM method has two distinct lines of interpreting and processing the data: one of which is the actual chronological events and the other is how the participant told the story.

In order to analyze the interviews, the researcher engages a panel of several colleagues to help explore the key themes which emerged. While I could see the benefits of this process in providing an in-depth understanding, in order to meet the requirements of hospital's committee for clinical research, the sample sized needed to be ten men. Therefore, I knew that practically this process of data analysis was not feasible. Yet, I wanted to utilize the very effective interview method; therefore, I decided to employ the BNIM interview method combined with IPA method of data analysis.

#### **5.4 Interpretative Phenomenological Analysis (IPA) and Data Analysis**

Interpretative Phenomenological Analysis (IPA) is a qualitative research approach that is committed to the examination of how people make sense of their experiences. While it originated and is best known in the field of psychology, it is increasingly being chosen by other disciplines in human, health and social sciences (Smith *et al.*, 2009). IPA has three distinct components which are reflected in the name.

##### **Key Components**

1. Phenomenological – the study is concerned with the “thing” itself, the researcher wants to learn about the lived experience of the participant in their own terms.
2. Interpretative - this component of IPA is informed by hermeneutics theory of interpretation. The researchers take the view that the participant is trying to make sense of his experience. It is an interpretative endeavor of the researcher trying to make sense of the participant making sense of his experience.
3. Idiographic – IPA is committed to the detailed examination of a particular case. IPA studies usually have a small number of participants and the aim is to reveal something of the lived experience of the participants (Smith *et al.*, 2009).

In short the IPA methodology wants an insider's perspective. The researcher wants to learn what it is like to stand in the participants' shoes. However, they are also standing alongside them and taking a look from a different angle and become reliant on the interpretative (Smith *et al.*, 2009). This methodology seemed the ideal approach to analyze the data. Moreover, it invited the incorporation of psychodynamic concepts as a means of interpreting the data and developing themes thus allowing for a more comprehensive and insightful understanding of the participant's experience. And finally, it was ideal for a small sample size.

The IPA method is specifically designed to utilize purposive sampling which is representative of the service users rather than the population at large. The emphasis is on exploring the users' concerns and providing him with an opportunity to "give his voice" (Larkin *et al.*, 2006). This again blends well with psychoanalytically informed research which is very strong in providing in-depth discussions of individual cases in a way that illuminates the internal world of the participant as well as allowing for case comparisons. Generating categories and themes grounded in the text enables the development of comparisons within and across cases (Briggs, 2005). Because both the BNIM method and IPA are so focused on the individual, I originally planned a sample size of five. However, because most of the studies conducted at the cancer hospital are quantitative, I was strongly encouraged to have a sample size of ten in order to ensure approval. I have, therefore, interviewed and analyzed ten participants but each case study is quite long and many of the themes re-emerged in the cases. Thus I will present only five of the case studies in the body of the dissertation while still including responses from all ten in the cross case analysis chapter.

Another appealing quality of the IPA methodology which reflected a scientific attitude was the systematic process of analyzing the data. The IPA data analysis method sets out a structure to develop themes which are grounded in specific examples from the data. There are five stages of analysing process which included:

1. Read and re-read notes and transcripts.
2. Initial noting: examine the semantic context and language used; look at descriptive content, explore the conceptual content.
3. Develop emerging themes.
4. Search for connections across themes.
5. Look for patterns across cases (Smith *et al.* 2009).

Although this process was time consuming and labour intensive, I hoped to ensure that the identified themes accurately depicted the participants' experiences. Moreover, this

approach adheres to both Robson's (2011) scientific attitude and Smith and colleagues' (2009) strategies for producing high quality qualitative data which systematically provides the "evidence" which is directly linked to the interview text that can be scrutinized by the sceptics!

## **5.5 Ethical Considerations**

When conducting research, the wellbeing of the participant should be paramount when developing and carrying out any type of research study; ethically the researcher must follow a code of conduct (Robson, 2011). In this section I will present some key features and practices which are recognized as fundamental guidelines that have been employed in an effort to ensure the well being of the participants.

In order to conduct this study, in addition to approval from the Committee for Clinical Research (CCR) ensuring scientific significance, I was also required to gain approval of the Local Research Ethics Committee (LREC). (See Appendices 10 and 11.) While this is an important organizational tool which attempts to support both the health care professionals as well as the ethical well being of the participants, it is only one part of the equation. Ethical issues should be considered throughout the whole research process from the research design, recruitment, interviews, data analysis and presentation (Clarke & Hoggett, 2009). Some of the key features and practices include the following:

1. Avoid harm,
2. Obtain informed consent,
3. Ensure confidentiality and anonymity,
4. Handle the data with care,
5. Provide access to necessary support (Smith *et al.*, 2000, p. 54).

There are two aspects to avoiding harm. First, one must always consider the extent to which exploring experiences may awaken or stir up a strong emotional response (Smith *et al.*, 2009). We knowingly are asking our participants to share and reveal not only their verbal concerns but also to allow us to interpret their responses in an attempt to understand their experiences. Thus as ethical practitioners we must endeavor to ensure that not only do we provide a containing "safe" space to share their experiences, but also in the event that

the interview is upsetting we ensure that the participants have access to additional support (Smith *et al.*, 2009). In the case of this study, if the men had required additional emotional support, I had secured the commitment of the Department of Psychological Care to provided free psychological support. Luckily, this situation never arose.

A second aspect to avoiding harm requires that in our role as psychosocial researchers, we should also be aware of the complexities that develop within relationships. It is our professional responsibility to keep our countertransference feelings in check; hence individual supervision and the research seminars were vital in helping me to identify my own feelings and to be sensitive to my responses in the interviews.

The issue of informed consent is taken very seriously in medical institutions. Specifically, I was required:

- To explain the trial and to provide information in writing in the form of a Patient Information Sheet. There must be an opportunity to discuss this information.
- To ensure that the potential participant understood the information they have been given; therefore, they were encouraged to ask questions.
- To be given time to think about joining a study, to talk with your family or friends, or the GP ([www.royalmarsden.org/cancer-research](http://www.royalmarsden.org/cancer-research)).

All of the above procedures were carefully explained in the study protocol and demonstrated how important the hospital views informed consent. However, in this study it was also important to ensure that the men understood what they were participating in (Smith *et al.*, 2009). Unlike the majority of clinical trials in the hospital, I was asking them to share and explore their emotional experience. Thus when I met with them the first time I also explained the nature of the study and how the results would be disseminated. This leads us to the next fundamental principle – ensuring confidentiality and anonymity.

The nature of biographical methods makes the feasibility about concealing a person's identity more complex (Hollway & Jefferson, 2000, p. 90). What is particularly challenging is that the very details of the case which make it interesting and relevant also make it difficult to secure the participant's anonymity. Therefore, I decided to only include relevant data to the discussion at hand. Thus if the theme being explored in the text related to concerns about children, then the ethnicity, profession and age of participant may be

omitted. If on the other hand, the theme being explored related to concerns about work, then the number and age of children might be kept out. In this manner in the body of the study relevant details are presented but always with an eye at ensuring the anonymity of the participant.

With regards to handling the data with care, there are simple practices such as ensuring that all raw, unedited data and transcripts are only seen by the research team (Smith *et al.*, 2009). However, there is more to this principle than the safe keeping of transcripts, Dictaphones and laptops. Additionally, as researchers we have a “duty of care” to our participants. They have entrusted us with their personal thoughts and feelings and it is our responsibility to ensure that we actually listen to them rather than making the data “fit” into our preconceived ideas and research questions (Smith *et al.*, 2009, p. 20). Additionally, and very importantly, occasionally participants share particularly poignant and heartfelt vignettes or even contentious issues. It is the researcher’s responsibility to recognize when these should be omitted completely (Smith *et al.*, 2009). There were certainly topics which the participants did mention during our interviews or after the Dictaphone was turned off which I have chosen not to include in this dissertation because of their very personal nature.

Finally, I had to be prepared to halt the interview if necessary. This may seem straight forward, and yet having recruited a participant, found a venue, driven to the interview and then spent close to two hours in a meeting, this potentially could have been more challenging than one expects. Again, luckily this situation did not arise. Clearly, it is vital that the ethical principles are firmly established and the well-being of the participant is viewed as vital in order to ensure that the research process falls within the established code of conduct.

## **5.6\_Recruitment**

Having identified the patient population I was interested in studying (fathers with testicular cancer), I then approached a consultant oncologist in the Department of Urology at a cancer hospital. Luckily, he agreed to be the Chief Investigator and sponsored my research; I then embarked on the process of writing a research protocol. The study was approved by the Committee for Clinical Research (CCR) in November 2009 and the Local Research Ethics Committee (LREC) in March 2010. My honorary contract was approved in September

2010 and I began soon after. I identified the men who met the inclusion criteria by reviewing the clinic list and checking the medical records. The criteria included:

1. Having children between the ages of five and 12 at the time of diagnosis.
2. Having completed their treatment six months to two years previously.
3. Having a good prognosis.
4. Speaking English.
5. Living in England.
6. Not being cognitively impaired as judged by the consultant in charge.

Once a potential participant was identified, I would confer with a consultant to ensure the patient was cognitively and emotionally fit to participate in the study. After obtaining his approval, I would approach the individual in the waiting area of the clinic. After briefly presenting the nature and details of the study I would hand the patient a Patient Information Sheet (see Appendix 7) as well as a letter of agreement and an SAE. Additionally, I would ask for their email address. If I had not had a reply in two weeks I would send a follow up email with one additional reminder in another two weeks. If I did not have a response, I would not ask them again. When I received the signed letter of agreement I would contact the participant to arrange a date, time and venue.

I began recruiting in October 2010, held the first interview in November 2010 and the final interview was in April 2012. In total I approached 28 patients in order to recruit ten participants. I believe that the recruitment process took over two years not because men were not willing to participate, but rather because testicular cancer is a young man's disease; therefore, 51% men were single with no children. The total number of men attending the clinics was 1431. In total there were 28 (2%) eligible men; had we included children all ages there would have been 77 men (7%).(See Table 5. 1.)

Given the nature of the study and the recruitment process, I interviewed the first ten men that agreed to participate, and did not actively seek out men from different ethnicities and cultural backgrounds. While we did have four men who identified their nationality as non-British (See Table 5.2), I appreciate that this study does not specifically address the impact of culture and ethnicity on the men's responses to their cancer diagnosis. However, the study does endeavour to understand each individual's unique experience within their own social context. In this manner, I hope to demonstrate a capacity to adhere to the social work



values of understanding and appreciating difference. An in-depth exploration of the impact of culture and ethnicity on a patient's response to cancer would be an interesting future research study.

**Table 5. 1: Exclusion Criteria**

Criteria	Number	%
Married	703	49
Single	728	51
Cohabiting	57	4
Divorced/Sep	37	3
Treatment > 2	294	21
In treatment	41	3
Child too young	38	3
Child too old	33	2
No children	74	5
Wrong Diagnosis	25	2
Other	48	3
<b>Eligible</b>	<b>28</b>	<b>2</b>

All participants signed consent forms and were reassured of confidentiality prior to their interviews which were audio recorded and transcribed. The participants had been diagnosed with one of the two types of testicular cancer: Seminoma or Non Seminoma (such as Teratoma). For treatments, all of the men had undergone an orchidectomy and some had chemotherapy, radiotherapy or both. The interviews were held in the homes (3), at the hospital (4), and at the Tavistock Centre (3). The participants had children ranging in age from 5 to 21. All the men had either two or three children except for one who had one son at the time of the interview and was in the process of adopting a second son. Two of the men had adopted their children. The men were from a range of ethnic backgrounds, professions and education levels. (See Table 5.2.)

**Table 5.2: Participant Demographics**

	Number	%
<b>Disease</b>		
Non-seminoma	3	30
Seminoma	7	70
<b>Treatment</b>		
Orchidectomy only	2	20
Orchidectomy/chemo	3	30
Orchidectomy/radiation	1	10
All three	4	40
<b>Nationality</b>		
White British	6	60
Asian	1	10
White other	3	30
<b>Education</b>		
Secondary School	1	10
College/university	9	90
<b>Married</b>		
6-10 years	5	50
11-15 years	1	10
20+ years	4	40
<b>Employed</b>	10	100
<b>Children</b>		
One child	1	10
Two children	5	50
Three children	4	40
Adopted	2	20
Daughters	10	
Sons	12	

It is now time to meet the participants. The participant chapters are in the order of how I met them.

## **Chapter 6**

### **Participant 1002: Don**

#### **6.1 Introduction**

At the time of the interview, Don was a 35 year old computer analyst who had been married for eight years and had two daughters (seven and five). He was diagnosed with Stage 1 Testicular Seminoma and had an inguinal orchidectomy with no further treatment except surveillance (appointments every three months for five years). During the course of the interview it became apparent that his major psychosocial concerns were:

1. Lack of adequate information and feeling somewhat “alone” with his disease,
2. Work related issues,
3. Physical changes/prosthesis,
4. Worries about his children,
5. Family conflicts.

He also struggled with two main underlying anxieties: a crisis of his faith and a fear of death. Don dealt with these concerns and anxieties with a variety of coping responses and defense mechanisms including:

6. Masculine way of handling illness,
7. Good cancer bad disease,
8. Learning to cope with the conveyor belt mentality – depersonalization,
9. Finding meaning on his cancer journey.

I will explore these concerns, anxieties and responses by referring to specific verbatim quotes as I track the issues through the course of his interview.

#### **6.2 Psychosocial Concerns**

##### **6.2.1 Information and Isolation**

Don was not one to complain. His concerns and anxieties became increasingly apparent not by what he said or how he said it but by how often he referred to it. For example, with regards to obtaining information, he never actually said that he did not receive enough information from the doctors. Instead he repeatedly mentioned how quickly the doctors came and went and how his wife found most of the information they needed on the internet. For instance, Don began the interview by saying:

*I saw the surgeon, registrar, I'm not sure and they described the operation really, really quickly. And again you've got to try and get all your questions in as fast as you can before you forget and also ask questions based upon what they're saying which is just hard.*

In this excerpt Don was not actually complaining about the doctors but simply stating that he struggled to have all his questions answered. Clearly, however, this was not quite enough information so he then relied on his wife. This became more evident in the second sub session of the interview when he said *"Yeah so she did all the research, whatever research she found I'd look over it as well"*.

Don seemed to accept that this was part of the process and never reprimanded the doctors for not spending more time with him. However, it was not until the end of the interview when discussing what type of interventions might have been helpful, did it become evident that he felt quite alone with his disease and wondered if his feelings were "normal." Yet he did not think it was appropriate to discuss his emotional concerns with the doctor. Don mentioned his desire to speak to other men in a similar situation several times which suggests that having established a relationship with the interviewer; he was finally able to raise the topic of his feelings of isolation and whether his concerns were "normal". This is in keeping with a commentary by Becvar where she found that participants in studies gain a dimension of support as they interact with investigators who are interested in knowing about their experience (2005).

Moreover, feelings of isolation are common in testicular cancer patients as documented by Carpentier and his colleagues (2011) in their study on the perception of masculinity and self-image in young male testicular cancer patients. They point out that having testicular cancer made the survivors feel different and alienated from others. With this in mind, it is interesting to note that what Don did make very clear by the end of the interview was that although the doctors always answered the questions he asked, and his wife was extremely helpful in researching the facts of his disease, he would have genuinely welcomed the opportunity to learn more about other men's experiences.

### 6.2.2 Work Concerns

Don believed that he was “lucky” with his work situation on two counts. First, he was diagnosed and then had his surgery at the end of the December so he did not have to miss too much work. Secondly, his boss’s daughter had had cancer so he gave Don support while keeping appropriate boundaries. However, what was interesting with Don regarding his workplace was that it actually became the venue where he felt it was important to share his experience. Because Don did not consider himself the gregarious type, he shared his experience in a different way. He explained:

*...once they deemed that an operation had to happen then I started telling people at work and it’s...and friends and family although it’s a weird thing to bring into conversation. A lot of times I found it easier to type rather than talk, so messaging or instant messaging and telling people that, I think the main reason for me doing was yeah I think security in numbers possibly but also I want people to be aware that this stuff goes on and it can come get you when you’re not expecting it. And if anything comes out of it I want people to become more aware.*

This quotation shows that by nature Don was not an extrovert; however, he firmly believed that he had an important message to share. Therefore, he communicated via emails and instant messaging. Moreover, the phrase “safety in numbers” suggests that he thought it was helpful to have the support of others. By sending out emails, he was attempting to decrease his feelings of isolation in his work environment. This attempt to reach out and minimize his feelings of isolation with his work colleagues was revealed again later in the interview when he states:

*So if anything comes of this if I’ve got more and I actually had people coming out of the woodwork and saying, oh yeah I’ve had this, I’ve had this... suddenly you find out a bit more about them which surprises you in a way but then you don’t normally talk about things of a personal nature.*

This quotation indicates that Bob hoped to share his experience to ensure that his colleagues would not suffer what he had as well as finding it helpful to make connections with people. Similarly, in a qualitative study of 58 long-term survivors by Foley and colleagues (2006), they found that for many patients, cancer was a positive experience which had fostered a greater appreciation for life. Moreover, the cancer experience amplified the person’s pre-existing inner strengths (Foley *et al.*, 2006). One feels that with Don who was typically a shy man, having cancer motivated him to reach out to others. Importantly, in this quotation he began by saying “if anything comes of this”, using the

present tense which would indicate that he was still hopeful that his experience would have had an impact on his colleagues and other male friends.

### 6.2.3 Concerns for Children

Of all the topics Don raised, his concern for his children was the one subject that he raised the most often. At the very beginning of the interview, Don mentioned how the night before his surgery he made a video for his daughters “just in case”. I will discuss the nature of the video in more detail below in the section on his underlying anxieties; however, it is important to mention here because it was one of the first topics Don introduced which indicates that even though the experience was more than a year previously, the making of this video for his daughters was at the forefront of his mind. Other than the fact that he was not able to pick up the girls and cuddle them for about a month, Don did not think his illness impacted too much on his daughters. However, what became evident was that while Don did not think it was appropriate at the time to discuss “cancer” with his daughters given their age, he was beginning to question when he should tell them. In the beginning of the interview he said:

*And even now to this day they don't really know what happened and there's no need, I just say I was sick. Mentioned, I never mentioned to them what cancer was or anything like that just that I was ill and that was far easier to work around, especially that young and I think given my stage there was no need to elaborate too much on what cancer is...luckily I didn't have any further treatment it was just the one. And yeah I go for checkups every so often but again I say I'm going to see the doctor at the hospital, they don't really, they're never asking questions about it and I'm OK with that.*

From this quotation, one might assume that Don had decided not to tell his daughters because they were too young and that he was comfortable with this decision. However, there is a suspicion that he might be wondering how long he could “get away” without telling them since he had to go to a Cancer Hospital every three months. Later on he stated:

*So they didn't really, they never asked why I was sick or how I was sick and if they did I'm not quite sure what I would have told them, but no I think I got away with it because of their age, if it happened now yeah I think I give them the information... I can't remember whether I say I'm going to the hospital, I just say I'm going to see a doctor I think, I don't actually tell them I'm going to hospital. I think hospital builds images of serious illness...*

In this quotation, Don seemed to struggle with his words and the concepts. He was recognizing that if it happened now he would probably have to provide them with more detailed and accurate information. Ironically, just as Don was given little and scarce information from the medical staff, he was similarly providing minimal details to his own daughters. Yet, unlike the doctors he was questioning how he was handling providing information to his girls. However, by the end of the interview when he was asked what intervention might have been helpful he revealed how much he was mulling over what and how to talk to his daughters. He stated:

*I almost need to work out what I should have told them and what I shouldn't tell them at that age, which probably goes back to my individual counselling or the family counselling. I, we took it as a decision upon ourselves that they shouldn't get involved, I think I will tell them in later years but I think it would be useful to find out what you tell a child that age and then making a decision on whether you actually, I think as a couple my wife and I would like to find out what people think about telling children this age.*

Again, this quotation showed that Don felt slightly isolated with his situation and believed that he would benefit from speaking to someone about what and how to tell his children. (Isolated not in the sense that he is alone, because he did have the support of his wife; instead they as a couple were on their own.) He seemed relatively comfortable with the decision that they made not to tell the girls but he recognized that the situation had changed now that the girls were getting older.

It is of particular interest to note that once the interview was officially complete, I had a lengthy discussion with Don about how to discuss his condition with his daughters. Lewis and colleagues (1989) in their study of the impact of breast cancer on the spouse and family point out that the behavior of the father affects the ongoing development of the child. Therefore, it seemed appropriate to suggest ways to assist Don in communicating with his daughters. I suggested that he might introduce the concept of "tumors" with pictures of happy face and sad face cells and how a stack of sad face cells could be "cut" out of him. We discussed how honest, age appropriate information was important particularly since he would continue to be a patient at a cancer hospital. Don returned to a clinic appointment three months later and explained that he and his wife had drawn the pictures with their daughters and they both felt relieved that they were no longer keeping a secret from their girls. By tracing his comments through the interview, it became apparent that his concern

for his daughters had changed from not being able to physically hold them, to being able to verbally share with them his experience. Don's struggles with sharing concerns with his family were also apparent in his relationship with his parents.

#### 6.2.4 Concerns for Wife and Family

Unlike the supportive relationship Don had with his wife, what became evident throughout the course of the interview was that Don was struggling with how his parents responded. He tentatively introduced the topic at the beginning of the interview, and then referred to them numerous times with increasing frustration, disappointment and even guilt. He started by saying:

*I spoke to my mum and dad and they ramped up my fear level because suddenly they're saying oh you should go for a second opinion, you should go for, what if they've got it wrong...you had to beat them down a bit but knowing that they're trying to look out for you, so you're trying to just, yeah keep perspective about the whole thing and not get too freaked out about it.*

This quote shows that Don had conflicting feelings about his parent's response. On the one hand, he was annoyed that they "ramped up" his fear level while on the other hand he acknowledged that his parents were looking out for him. In some ways, Don's parents seem to have struggled with his condition in the classic five stages of loss as described by Kubler-Ross. Kubler-Ross' stages are:

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance (Kubler-Ross, 1969).

When Don initially told his parents about his condition, in order to absorb the news they used a temporary defense of denial, suggesting that the doctors made a mistake and that Don should go for a second opinion. Unfortunately, while they were struggling with their own loss of a healthy son, Don was trying to come to terms with his illness. Hence there was a conflict between the support that his parents were able to provide and the support that Don was hoping for.



This conflict continued after Don had the second opinion and was told again that he did have testicular cancer and needed surgery immediately. Don described that his parents went into a “blind panic” and flew off to Italy visiting churches and going to masses. Again we are reminded of the Kubler-Ross’ stages where Don’s parents are both angry (acting in a blind panic) while also bargaining. Don explained they came home with “various religious ointments and symbols”. They were trying to find a way out of the situation and make a deal with God that if their son used these ointments that God would save him. This is a common coping response when confronted with such a loss; however, what makes the situation difficult was that Don was feeling that his parent’s style of coping was being forced upon him. When he described how they flew off to Rome to visit churches he stated:

*But I felt almost, I felt almost bad that I didn’t as if I was, if I wasn’t so grateful for my parents being, taking all these steps and visiting things and yeah it, I know they meant well and, but I thought they were a bit, I felt personally it was a bit over the top.*

This quotation shows that Don was clearly struggling with his feelings about his parents. He felt guilty that he was not grateful to his parents but perhaps he was also feeling disappointed that they left him to go to Italy rather than just staying at home and taking care of him; something that would have been less “over the top”. When dealing with loss, according to Kleinian theory, the individual can work in the two modes paranoid-schizoid or the more mature depressive mode (Hinshelwood, 1991). In this situation Don seems to be working from a depressive position where he is truly struggling with the guilt that he feels for the others with whom he is identified with. Yet at the same time he was also coping with the realities of his illness. He therefore, seemed to try and appease his parents by putting on the ointments they brought him while relying on his wife for the practical and emotional support he needed. Again relating to the Kubler-Ross stages both Don and his parents seemed to have achieved a state of acceptance, but they reached this stage through very different paths.

## **6.3 Individual Anxieties**

### **6.3.1 Physical Changes, Challenges to Self-image and Prosthesis**

Don did not spend much time discussing the physical impact of his disease except in two areas. First, after the operation he was not able to drive and pick up his daughters. And

second, he did mention being offered a prosthesis. While neither of these topics seemed to dominate his reflections about being a father with cancer, the content of how he presented them in the interview does indicate they had an impact on his overall experience.

With regards to the physical impact that the surgery had, Don explained that he was not able to carry his daughters or to drive after the surgery both of which only lasted for a couple of weeks. He seemed more concerned about how his daughters would respond to him not being able to give them a cuddle than he was about how he physically felt. Similarly, he was more bothered about being a burden on his wife than he was about being in pain.

When describing how he was asked about the prosthesis, it became evident that Don did in fact struggle with the decision and again would have benefitted from more information from the doctors. This is similar to the findings by Lynch and Pryor (1992) in their study on the patients' perception of prosthesis. The authors concluded that patients who have lost a testis should be made aware that a cosmetic substitute is available. They will then be able to make their own informed decision on the desirability of such a replacement (Lynch and Pryor, 1992). The key here being "informed" choice; Don does not seem to have been provided with adequate information. He explained that the doctors had mentioned the prosthesis twice...

*... once on the day of the operation which threw me back a little bit, I think I knew a bit beforehand, on the day they said yeah you can have a prosthesis and I said, oh OK. And so looking back I don't know actually what that was in terms of what it was made of or I think they said silicone although I'm not 100% sure.*

This quotation indicates that he did not know much about the actual prosthesis when he went into surgery. At first he seemed to be very accepting about not having the prosthesis put in particularly given the negative press about silicone. However, later on he commented:

*So when they got all the results together she mentioned it again so I could do it anytime I like and it's not like that was my one chance I can come back in a few years I suppose and revisit it so OK that's an option to have. But I didn't, yeah they did mention it but it's not something which I was too worried about at the time.*

The fact he mentioned that it was still an option indicates that he was still considering it. Body image is an important aspect of why men choose to have prosthesis with concerns about self-image and a desire to look “normal” being particularly important (Carpentier *et al.*, 2011, p.743). While Don was a reserved and private man and therefore did not disclose too much about how he felt the physical changes impacted on his self-image, the fact that he mentioned the topic several times during an interview about being a father with cancer combined with the ambiguity of whether he would still have the procedure done in the future, suggests that the physical changes did impact on his self-image. Certainly, Don would have benefited from more information and time to discuss this topic with the doctors.

### 6.3.2 Crisis of Faith

Whenever Don discussed his parent’s reactions, he then followed up with comments about his thoughts on God and religion. Don seemed almost envious of his parent’s unwavering faith and belief that God would help them through this crisis. He would describe an action that his parents had taken then described his own quandary. For example, in sub-session two when asked to follow up on his comments about his parent’s response he said:

*Yeah I’m a churchgoer I do believe in God and a powerful being of some sort but I don’t know I look at it in a little bit of a different light, I don’t look at it so much as a, well ... If God is a parent your parent doesn’t be cruel... If you were a parent and your child is I don’t know, you don’t make your child ill you want to make sure you have your best for your child so... I think where I’m going with this is that there was, you don’t wish ill upon your child so and equally you don’t have to get someone to beg you to be good to your child. Which is kind of what my mum getting all these oils and stuff, begging God to take it away from me it just sounded a bit weird.. If I was a parent you wouldn’t get anyone else, well I am a parent but I don’t need anyone else to tell me not to be, to tell me to be good to my child no, I just make sure the best is possible.*

In this lengthy excerpt, it is evident that Don struggled to find the words to describe how he felt and feels. He doesn’t complete his sentences, he changes verb tenses, and he even leaves out words. This struggling with expressing himself is perhaps a reflection of how much he is struggling with the question why would God, who is supposed to be like your parent, make you ill? Additionally, he was wondering why his parents should have to beg God to take care of him. He was genuinely questioning what kind of God would do this. This quote was then followed up with his second quandary:

*...and then there's other questions of why I got it in the first place, there's all other things but it's just that one perspective was an interesting one.*

Again, Don was sharing some of his deepest fears: what kind of God would do this and why to him? Halstead and Hull (2001) in a study on women with breast cancer describe that the cancer diagnosis may challenge patients' belief systems and thus they look for meaning in the experience which may help them to redefine their lives and live with the realities and uncertainties of being a cancer survivor. Similarly, Don's belief system was challenged at the time he was diagnosed and treated and he was continuing to struggle with these issues even at the time of the interview. He later goes on to say:

*... it could have been a lot worse, I've got through this and yeah it's, yeah I got, this whole thing was a bit of a religious waking or revisit at a different level because sometimes you just do religion for the sake of, you just kind of go through the motions. And so this in way it got me to re think it and I don't think a bad thing has come of it ...*

Again we see in this quote the broad question of what kind of God would let bad things happen and why had he chosen Don. Clearly, Don was trying to adjust to his cancer diagnosis while also trying to make sense of the illness in his life. These struggles shook his very foundation of being a devoted churchgoer, and left him feeling more fragile and vulnerable. I will discuss below how he ultimately addressed these anxieties by finding meaning in the experience.

### 6.3.3 Fear of Death

Only twice during the interview did Don explicitly admit that he was frightened about the possibility of death as a result of having a life threatening disease. However, the manner in which he did suggests that his fear of death was his deepest anxiety. Both times he mentioned his fears, his eyes welled up when he was speaking and he tried to make light of his actions. He explained that the night before he went into surgery:

*On the day yeah, on the evening actually I got a bit morbid, I decided to make a video thinking I'm not coming back, so I look back on it now and smile a bit. But at the time it's again building in all the fears that you're hearing...*

After that sentence Don changed the subject and went on to describe all the statistics that he was given which were supposed to make him feel less anxious. There are several important points that can be drawn from this quote. First is that from this description there is the appearance of the defense mechanism of reaction formation whereby Don was saying that he can smile but actually the last thing he was doing was smiling in fact he had become tearful. He was trying, unsuccessfully, to minimize the depth of his fears. By thinking about it in psychodynamic terms, when confronted with his greatest fear, death, Don immediately resorted to comforting himself with statistics. Hence, there is an element of regressing back to a paranoid –schizoid defense, whereby he was minimizing his anxiety by splitting his cancer into the “good” cancer with the “good statistics”. This was an attempt to remind himself that he was safe and healthy. Interestingly, by employing this primitive defense, it highlights the depth of his anxiety about the fear of death and leaving his family.

A second key point is related to his family. Charmaz (1995) in her study on men with chronic illness describes how most married men during crisis and its immediate aftermath felt tremendous affirmation of their valued identities in the family as they awakened to death. Furthermore, the wives provided their husbands with a containing link to both past and future identity through the intensity of their involvement in the present (Charmaz, 1995, p. 272). Don’s primary focus when confronted with undergoing surgery was that he left a video for his wife and daughters in the event something went wrong. In other words his identity as a husband and father were paramount in his mind, and made him more frightened about the prospect of no longer being there for his family. When I followed up in the second sub-session and asked him to describe the video in more detail, he said:

*...it was a video for my kids if I never saw them again, I never, we take pictures and do video but never really say anything, never really take, it was just in case you take that two or three minute time out just to, so I did it yeah. Yeah it was the, the percentages got the better of me even though I knew I was going to be all right... it's dead straight. But yeah I just, I took the worst case scenario yeah. So I just felt, ended up just talking to the kids and my wife...*

In this excerpt Don was again struggling to complete his sentences, as if even a year later he did not want to admit that he was making the video because he was terrified of dying and leaving his wife and daughters. Yet the use of the phrase “dead straight” followed immediately by the “worst case scenario” indicates that death was very definitely on his

mind. Moreover, as Charmaz describes above, Don was making a video to ensure that his daughters and wife would have a link to him in the future. Additionally, Don's wife was his major support whereas he struggled with his own parents, which again links to Charmaz's comments that men feel an affirmation to their identities in the family. Thus it appears that even confronted with his greatest fear; Don seemed able to find coping responses and defense mechanisms which helped him through his ordeal.

#### **6.4 Coping Responses and Defense Mechanisms**

In analyzing Don's interview, four main coping responses emerged:

1. Masculine way of handling illness: denial, minimization, stoic façade,
2. Good cancer bad disease,
3. Depersonalization – conveyor belt mentality,
4. Finding meaning.

These will each be discussed in detail.

##### 6.4.1 Masculine Way of Handling Illness

From the point when Don first suspected something might be wrong through to the end of the interview, he engaged in help seeking behavior and coping responses that were influenced by what has been referred to as an “idealized” perception of masculinity. For example, Don admitted that he put off going to see the GP; he assumed that it would all be fine. However, like the participants in the study by Bullen and his colleagues (2010) on men with penile cancer, Don faced the challenge of trying to preserve his image of being the strong, resilient “sturdy as an oak” idealized male (Bullen, 2010, p.935). He achieved this by minimizing some of the details as well as emphasizing how quickly he recovered. When describing going to the hospital for surgery, he stated that he “checked in” and compared it to going on a holiday. He also reported that within a couple of weeks he was back to normal. He states:

*So that was it. More of an inconvenience than anything else but that (not being able to pick up his daughters) soon latched off and once I got my strength back I was back playing sports and stuff and again it didn't feel like, it didn't even feel like it happened.*

Don emphasized that he quickly returned to the manly activity of “playing sports and stuff”. He minimized the whole surgery by saying it was an “inconvenience” and yet he

admitted that the night before the surgery he had made a video for his family in case something went wrong. Clearly, this contradiction indicates that the surgery was more than an inconvenience.

Also like the men in Bullen's study (2010), Don faced the challenge of seeking support and disclosing his condition while at the same time remaining stoic. As discussed above when examining Don's experience at work, he managed to balance his need for support and the necessity of disclosure by resorting to emails rather than speaking to his colleagues. In this way he projected an image of a man who was "getting on with it", which helped to reinforce his sense of masculinity at a time when his masculinity was being challenged.

Even Don's description of how he relied on his wife as his main source of support and for finding information, hints of a man who was attempting to cope with his diagnosis in an idealized masculine way. He explains that she, unlike his parents, understood the struggles he was undergoing regarding his faith. Bullen states:

*The results point to the need for support that is appropriate within a masculine context. ..In this study the centrality of wives/female partners in providing support was a key finding. The data suggested that rehabilitation was possible for men in strong, supportive relationships which provided reassurance of a continued, if re-constructed, masculine role (Bullen et al., 2010, p. 939).*

Certainly, the supportive relationship that Don had with his wife enabled him to obtain the support he needed while also feeling that his sense of masculinity was maintained.

#### 6.4.2 Good Cancer/ Bad Disease

As discussed above in the information section, Don felt that the doctors were concise and helpful yet they provided a minimal amount of specific information or emotional support. Don implied that the doctors did not spend too much time with him because they had more urgent and serious cases to deal with. He compared himself to others when he described going for his three monthly clinic appointment. He stated:

*Yeah and so every three months I'm almost reminded that I've had a cancer close call rather than, I almost forget day to day that there was even a problem... and then when I go into the hospital you see people around who are, you kind of take in a big deep breath and thank yourself for where you are right now and hopefully you'll be able to get beyond that. But you see other people who aren't so, who are*

*further along... so it's a bit scary ...But yeah I now just dive into a book and then just keep, stay there and just don't think about, don't let anything else cloud my thoughts.*

Clearly, Don was very aware that he was extremely lucky compared to many of the patients at the hospital in that he had an excellent prognosis. However, rather than dwell on how ill some of the people around him were, Don lost himself in a book. This sense of being fortunate with the type of cancer Don had was mirrored in how the medical team treated him. As Menzies-Lyth (1960) explains in her article on nurses and the functioning of social systems as a defense against anxieties, in some institutions social defenses develop over time as the result of the collusive interaction of the members. These defenses, which are usually unconscious, become a key aspect of the structure of the organization and its external reality which both old and new members of the institution accept. Don acknowledged that the doctors seemed to have little time for him because they were busy with more difficult cases. His description fits with Menzies-Lyth's argument that the members of institutions develop mechanisms to cope with very anxiety provoking work. In this case, one might speculate that the medical team had developed a system whereby in order to ensure that they had the emotional stamina to assist all patients, they reserve their expressive support for more advanced and difficult cancer patients. Don as a new member of the institution, for the most part, accepted this defense when thinking about the other patients and did not challenge it. However, when he described how he felt that he was on a conveyor belt, he did show some frustration with the medical team's attitude towards him.

#### 6.4.3 Depersonalization and the Conveyor Belt Mentality

There are numerous examples during the course of the interview where Don described how from the moment he found out something was seriously wrong throughout the course of his treatment that he felt like he was on a conveyor belt. This metaphor deserves careful consideration. First, it suggests that Don felt that he was not treated like an individual person, instead he felt like an object. And second, that as a part of an object on a machine he actually had no control of his life. Instead he was in the hands of the medical team that were there to help him survive his life threatening illness. While these feelings of being depersonalized and out of control may in part come from Don's own individual anxieties, there was also an element of how the staff within the institution was treating him which contributed to these feelings. Institutional defenses, as described by Menzies-Lyth, have



been discussed above; however, what is important to note here is the impact they had on Don. He said:

*So I got the information, they booked me in, I went, that's when the conveyer belt started so I went from there, went to get my X-ray, went to get the bloods done, in between all of that I was making phone calls and contacting my employer.*

It is as if Don had become part of the machine and was being propelled down the assembly line. Because he felt himself to be a part of the conveyor belt, he was reluctant to ask for additional support and instead complied with the rules of the machine, which was clearly evidenced above when discussing how his wife helped provide the information that he needed rather than to ask the doctors. Initially, as a defense, he tried to ignore his fears and concentrate on the physical tasks at hand. Yet the fact that Don mentioned the conveyor belt term numerous times indicated that perhaps he was not “ok” with how he was handled by the system. He even described how he tried to make a joke with the nurse right before surgery but “it didn’t go down too well”. Don was trying to make a personal link with a staff member who felt the need to maintain a professional distance right at the moment when Don was feeling most vulnerable, just as he was being put under anesthetic. Don was vacillating between showing that he was a terrified individual seeking comfort with trying to maintain the tough exterior as a defense against his fears. The institution seemed to encourage the “stoic” male response.

However, ultimately at the end of the interview Don openly admitted that he would have liked support and an opportunity to discuss his fears. He mentioned numerous times how helpful it would have been to speak to either a counsellor or someone who had been through it to find out that he was not alone; other men had felt similar things. This suggests that he was struggling with being depersonalized by the health care professionals who had in fact increased his feelings of anxiety rather than attempt to comfort him.

Because Don was reluctant to complain or ask for additional support, it was understandable why Don employed the coping mechanisms and defenses he did. It was only towards the end of the interview, when Don believed that his feelings were being listened to that he shared the fears and concerns that he had been suppressing during his treatment phase.

#### 6.4.4 Finding Meaning

By the end of the interview, Don seemed to have identified two main areas where he felt that the experience of having the cancer had profoundly changed him. First, he felt his unwavering and blind belief in God had been replaced by a more thoughtful and individual faith. He stated:

*I like to think I've got more higher picture that someone's put through all this for some reason rather than trying to do things to fix it up short term. So whatever's happening is happening and hopefully it will just sort itself out yeah, yeah I think that's it.*

Don believed that there is a long-term reason why he has been put through this challenge and therefore he should accept that small things will sort themselves out and instead he should focus on what is important to him, in particular his wife and family.

The second area where Don felt his experience had changed him was his determination to try and ensure that other men are more aware of male cancers and that they do not have to be so alone with it. He stated:

*Having had this experience I want men to be more aware and not get, not do what I did for the first month and just kind of hide it, yeah it's nothing. So if anything comes of this if I've got more and I actually had people coming out of the woodwork and saying, oh yeah I've had this, I've had this.*

In this quotation, Don shows his determination to ensure that other men do not make the same mistake that he did. As Charmaz (1995) succinctly states “By making illness an ally, men can use it as an opportunity for reflection and change” (Charmaz, 1995, p. 278). Don had broken out of his comfort zone of being a reticent man in an effort to help other men. This provided him with a deeper acceptance of why he had been put through the challenge of coping with cancer.

#### **6.5 Conclusion**

For Don, who initially presented as a very private and reserved man, having the opportunity to discuss his experience at length allowed him to think about the experience as a whole. He agreed to participate in the study in the hope that in some way it might help other fathers with cancer in the future; however, by the end of the interview there was a sense that participating in the study had also helped Don to make some sense of the entire

experience. While he clearly had thought about many of the above topics at length individually, by exploring his thought and feelings in a safe and contained environment, he was able to shed light on his fundamental areas of concern; for him particularly: concerns for his family, lack of information and feelings of isolation and frustration with the conveyor belt mentality. The underlying anxiety which was revealed only by carefully dissecting the text was his fear of death. This fear was heightened by his own struggle to come to terms with his faith which clearly had shaken his sense of identity. Yet even with all these concerns and anxieties, Don with the support of his wife and his personal coping responses had survived the challenges he was confronted with and felt a stronger person because of it.

## Chapter 7

### Participant 1003: Bob

#### 7.1 Introduction

Bob was a 40 year old mental health care professional who had been married for 14 years and had three children (one son nine, and two daughters seven and five). He had been diagnosed with a Mixed Germ Cell Tumor and had undergone an orchidectomy but chosen not to have a dose of chemotherapy. Although Bob was initially diagnosed approximately two years prior to the interview and thus he believed that he was hazy with the details, what is evident from this interview is that most of Bob's feelings were still felt quite acutely. Even with the benefit of hindsight, for the most part, he did not seem to be trying to make sense of his experience, instead he used the interview as an opportunity to vent the strong feelings that he had during his experience and were still with him. Four major concerns dominated the interview including:

1. Lack of information,
2. Physical consequences and issues around a prosthesis,
3. Work issues,
4. Concerns for his children.

By paying close attention to not only what he said but how he said it, Bob's underlying anxieties around the fear of death and annihilation also become evident. In order to cope with these concerns and anxieties, he employed specific responses and defense mechanisms including: re-evaluating his life, splitting his cancer into the good cancer but bad disease, handling his illness in a "masculine" way, intellectualizing and establishing his own hierarchy. Below I will first discuss his major concerns and anxieties and then explore his coping responses.

#### 7.2 Psychosocial Concerns

##### 7.2.1 Lack of Information

Although Bob had suspected something was wrong for several months prior to visiting his GP, once he did have his initial consultation he was diagnosed and went into surgery quite quickly. Because of this, there was little time for him to process what was happening and to be open to receiving information. These ambivalent feelings are revealed in the following excerpt from the beginning of the interview:

*So there were all these bits of wanting information and then not being sure about how people are because I know that people have different attitudes to wanting information and some people don't want to know a lot and some people want to know everything. And the medics have to take a judgment about how to explain the information and will you be able to understand it. And I thought if you treat me as if I'm stupid or ignorant I might get irritated. But they didn't, so that was all that was fine.*

Bob seemed to be projecting his own conflicting feelings about wanting information and struggling with how much he really wanted to know onto “some people”. He was also setting down the beginnings of another theme that he was very concerned with being respected and on an intellectual par with the “medics”. (I will explore this hierarchical theme more below.) Bob admitted at this point that he had only briefly looked online because he said that he would rather rely on the information provided to him by the doctors. This is in keeping with a study done by Leydon and colleagues (2000) on cancer patients’ information needs and seeking behavior. They found that while all patients wanted basic information on diagnosis and treatment, not all wanted further information at all stages of their illness. Their attitudes in part stemmed from their faith in the doctors’ medical expertise which precluded the need for patients to seek further information themselves (Leydon *et al.*, 2000). Similarly, Bob was hoping that he could establish a good relationship with a prominent doctor who he could discuss his condition with at length. This was evident in the following excerpt:

*But I thought I only want good quality information. I only want different people with whom I have relationships. I don't, there's no point getting stuck with bits of information that might not be reliable and might be ambiguous and that I can't interrogate. So I didn't look on the internet.*

The difficulty for Bob in trying to obtain information through people that he respected and had good relationships with was the structure of the clinic process. When Bob was seen in the clinic for his follow up appointments, he was examined by different doctors. Therefore, it was extremely difficult for Bob to ever establish a relationship with one person. Thus he was effectively establishing criteria for obtaining reliable information which could never actually be met. This begs the question did he really want the information or was this a form of avoidance? While it is impossible to definitively answer this question, what is evident both from what Bob described and his attitude towards the

medical community is that Bob felt he was not given adequate information. This is particularly evident in the discussion of having prosthesis and the physical consequences of his surgery discussed in more detail below.

### 7.2.2 Work Concerns and Challenges to Identity

Of all the concerns that Bob expressed during the interview, his anger and frustration about the response he had from his bosses was by far the strongest and was still keenly vivid in his mind. His very strong reaction provides us with a clue that perhaps the frustrations he described with management may actually be revealing underlying concerns about his identity. He started the interview by describing that he wanted to be open and honest with his colleagues and bosses; however, by the end of the interview his descriptions became more heated and negative, revealing his underlying anger. In the beginning he stated:

*So I just thought, oh I'll just tell everybody and just told everybody that it was fine for anybody to know and then people will just all find out like that. And it was all, it was fine. People were very sweet and supportive and concerned and I had that funny thing of being a bit disembodied again and like watching me talking about myself having cancer to these people.*

In this excerpt there is not even a hint that Bob had any issue about telling colleagues; instead it seemed that he wanted to be open with and supported by his colleagues. However, almost immediately afterwards he began describing the difficult relationship with his current manager.

*And he's all just very chronic and nonsensey about us moving and me making a request for flexible working and him through his inadequacy felt a need to be overly controlling said no to my request for flexible working. But absolutely no good reason, just because I think he wanted to feel powerful and in control...*

One might speculate that Bob was accusing his boss of being inadequate and needing to be powerful and in control because he was feeling so out of control himself. He used very strong language such as “overly controlling” and “absolutely no good reason”, to express how emphatically he felt that his boss was being unreasonable. Moreover, what is important to note is that the difficult situation with his boss started when he was first diagnosed but continued to the present. At the time of the interview, Bob was still suffering the consequences of what he believed to be his unjust treatment. One possible explanation for Bob’s strong reaction to management was that having been confronted with complicated problems, Bob might have been experiencing an identity dilemma. Charmaz

(1995) points out that identity dilemmas result from losing valued attributes, physical functions and social roles (Charmaz, 1995, p. 268). Certainly, for Bob the loss of control over his body and having to publicly explain his condition may have led to an identity dilemma and concerns about his self-concept. This dilemma combined with the lack of support from “management” may have led to Bob’s strong, angry reactions. His frustration was further exemplified towards the end of the interview when Bob returned to the topic of work yet again.

*And she was fine...but then this other boss person was just very rigid and concrete. And she’s a psychologist. You’d never believe it...And I thought that’s f... awful.*

Again he was discussing how unfair management was about his working from home. However, this excerpt is slightly confusing because initially Bob referred to his boss as “he”; however, in this excerpt he talks about “she”. Then later on he went on to generalize that management was not helpful. This would indicate that more than one person in positions of power had left him feeling frustrated, angry and out of control. He was articulating this even more categorically by using profanities. He wanted to make a stark contrast between how he had been coping with his disease compared to his bosses. Again, perhaps in an attempt to maintain his past identity as the stoic male in control of his life, he made a point of demonstrating that he was still capable of being the provider with the “give ‘em hell attitude” who was still more powerful than others (Brannon, 1976. P. 22). He sums it up towards the end of the interview by saying:

*But my colleagues have been lovely. It’s just management that’s been shitty really.*

In this excerpt there was stark contrast between how his colleagues’ responded compared to management. Moreover, even though his surgery was more than two years before the interview it was evident that the ramifications were still impacting on him. This was emphasized not only in the strong language that he used, and the verb tense of being both past and present, but also in that throughout the course of the interview he repeatedly returned to this subject. His work concerns, frustrations with management and how it impacted on his identity and self-concept were some of the most challenging obstacles that he faced.

### 7.2.3 Concerns for Children

It is interesting to note that although this study was described to all the participants as

exploring the impact of cancer on men who are fathers, Bob spoke very little about his children. When he did it was either to describe how he and his wife told them or in the context of what it would be like for them if something happened to him. In the beginning of the interview he explained:

*Did we tell them? Just I, there's something wrong with it. Just there's something wrong with my testicle and it's got to be ripped out. I hadn't been, I hadn't been ill or looked ill or anything so I think, I think we were fairly matter of fact about it. That seemed to be fine. And we didn't actually talk about cancer for another couple of years.*

He then goes on to describe how after the surgery he started attending clinics at the hospital. In this context, the brief but extremely blunt reference to his surgery seems quite harsh and lacking any emotion. He explained that he and his wife were matter of fact and since there were no physical signs, they could avoid telling the children anything about "cancer". The choice of words, however, hints at signs of anger particularly when combined with the lack of emotion. Bob commented that the only direct impact his cancer had on his children at the time was that they couldn't jump on him.

Then in sub-session two when I specifically asked if he could tell me more about when he told the children that he had cancer, he said:

*I can't remember who it was this time who had cancer because it was some time after, this was after ... cancer had already been diagnosed and we were talking about somebody else's cancer I think. And so, yeah so there are more or less dangerous or untreatable cancers and so I was going, oh you remember I had that lumpy testicle, that was a kind of cancer. But it just happens that it's not a very dangerous kind of cancer and so I was very true to them.*

This excerpt shows that not only was it important to him to be reassuring to his children that he was physically safe, but also he wanted to be honest with them. He then described at length his thoughts about what would happen to his children if he died. This will be discussed in more detail in the section below about his fear of death and annihilation. What is significant here is that from his direct quotes related to the children, Bob seemed to place a great deal of importance on providing his children with an age appropriate explanation of his condition that gave them enough information without "lying" to them but also without frightening them. He and his wife agreed to this strategy and therefore, he did not discuss it extensively in the interview. He seemed to feel confident that they had handled the situation well. Therefore, unlike his work situation which had ramifications on his present



life, he did not seem to feel the need to vent any unresolved feelings. He did, however, discuss in more detail his concern for his children in the context of what their life would be like without him which will be explored when discussing his fear of death and annihilation.

### **7.3 Individual Anxieties**

#### 7.3.1 Challenges to Self-image, Prosthesis and Physical Consequences

For Bob it was not only the actual prosthesis or physical consequences of his surgery that upset him but also and quite profoundly the lack of information, support and respect that he would have liked around these issues. These feelings were best exemplified in the context of learning about the prosthesis and being examined, perhaps because that is when Bob was at his most vulnerable. This was particularly evident in an excerpt where Bob described being seen by a young female doctor.

*There had been a couple, there were a couple of young women and she didn't want to be uncomfortable. If I'm just a body and my genitals are just organs and you, and have no other significance that's fine. But if you, when you start being shy about my genitals that makes me feel quite uncomfortable.*

In this example, it was not the fact that Bob no longer had a testicle that bothered him, it was the way that the female doctor responded to him that made him feel uncomfortable. Interestingly, throughout the interview he did not describe the female doctors as doctors but rather as “a young women”. This suggests that he might have perceived them as young women and not in their professional capacity. This, of course, would explain why he felt uncomfortable and why he projected feelings of “being shy” onto the doctors probably because he in fact was feeling shy and vulnerable. Similarly, even in describing these events to me, a female researcher, he may also have felt uncomfortable.

Bob stated later in the interview that he didn't “feel angry with my body for letting me down”. Moreover, he explained that within two weeks of the surgery he was able to go back to fencing even though he was still a bit sore. So clearly, even with hindsight he acknowledged that for him the physical consequences were not severe. Moreover, he wanted to convey to me, that he was still the strong resilient male who could bounce back physically. However, it was the emotional response both by the female doctors and him that had the more long lasting impact. This was also evident when discussing how the doctors asked if he wanted a prosthesis.

*So I had, I met the surgeon there and he said, oh so they did the who are you and your date of birth and stuff and he said, oh do you want me to pop a, do you want me to pop in a prosthetic one for you? And I thought son of a, it was at the last minute really. I said, well I don't know. What would you suggest like? He said, well, he said to be honest he said they're not really the same shape, weight or size as a real testicle. And I thought that sounds improbably, that sounds improbably bad. I think he just meant there's only, there's just, there's like a generic prosthetic testicle. I don't know because they don't, he didn't offer me an egg box of gonads to choose from.*

Bob's choice of language is sarcastic. Choosing the verb "pop" emphasized how in Bob's mind the doctors were minimizing the procedure. His response feels quite angry: "son of a" but he stops himself from finishing his sentence. His blunt almost crass description of a "box of gonads" also hints at sarcasm and anger. He felt the doctors were dismissive and negative. Later on he described that he was "fine" not having prosthesis; however, during the interview about being a father with cancer, he described how little information and time he was given to decide if he wanted prosthesis five times. This would suggest that he was not fine with his decision; instead he was angry and resentful that he was not provided with more information and an opportunity to carefully consider it. Similarly, in the study conducted by Adshead and colleagues (2001) exploring testicular implants and patient satisfaction, they concluded that a majority of the 71 men wanted the option of an implant and wanted to see sample implants (Adshead *et al.*, 2001, p. 560). Bob's reactions were certainly reflective of these conclusions. Moreover, given the anger with which he presented this topic as well as the number of times it was addressed, one might also speculate that the loss of his testicle and lack of having a new one had raised some issues regarding his sense of masculinity (this topic will be discussed below when addressing Bob's coping responses).

Bob was fortunate in that he did not suffer too much pain post- surgery, nor did he have to undergo any additional treatment. Therefore, the actual physical impact of his disease and treatment were comparatively limited. However, what was clear was that during his treatment and even two years later he still felt quite angry and frustrated.

### 7.3.2 Fear of Death and Annihilation

For Bob there seems to be two distinct fears related to death and annihilation. First, he described several times the fear that he might actually die from this disease; although statistically that was unlikely. And second, was the fear of annihilation in the literal sense of the word meaning “complete destruction of something” (Webster Dictionary). Turning first to his fear about his possible death, Bob initially mentioned the possibility of dying from the disease in the context of how unlikely it was. He stated:

*...so there's a 40% chance of it coming back at the time of my surgery and then only a 5% chance of it coming back after a year. And even if it does come back then there's chemo with a 92, 98% chance of curing that. And even if that doesn't work it's a, they can give you another course of chemo and it's more than, it's more likely that that will work so to me the chance of dying becomes astronomically, well becomes extremely remote...*

The fact that Bob repeated statistics three times suggests that he was trying to make a point, perhaps even convince himself. Rather than being confident that his chances of dying were “astronomically” remote, perhaps this was an example of reaction formation whereby Bob was saying one thing when actually he was feeling extremely vulnerable.

These fears of death resurface only a few minutes later when he stated:

*We'd got this nice three week family holiday planned in America in August and I'm thinking, oh God. I hope it's, if it's not clear we'll have to cancel the holiday...I probably still won't die but it will be awful. The main hurdle was am I going to die... It wasn't until I met the Prof I think that I really felt assured and maybe helped.*

This quote suggests that he had not felt as confident of his survival as he had first suggested. By describing the order of events, he remembered the concerns that he was plagued with at the time; the main concern being the possibility of dying. Again his preoccupation with the possibility of dying is evident again only moments later when he returned to the subject and stated:

*...And I'm somebody who probably was kind of destined to die a bit young. That's a weird idea to me...my Dad died at 57 which seems young, so I'd obviously, oh shit, if I live, maybe another nine ...19 years would be quite good.*

This quotation links together his own increased vulnerability to death with the fact that his father had died young. The combination clearly left him deeply frightened which was emphasized again by saying “oh shit” and then contrasting it by saying 19 years would be good. His loss of confidence in living a long fulfilling life is similarly described by

Charmaz (1995) who discusses the concerns of men with chronic illness and states that “while in crisis, men see living and dying as discrete categories. Their sense of betrayal by their bodies evokes anger, self-pity, and envy of the healthy. A once certain future now looks uncertain, even ended” (Charmaz, 1995, p. 270). This progression from stating positive statistics with assurance to reflecting on the untimely death of his own father revealed the deteriorating belief in his long-term future which had been replaced with a fear of his own death. These thoughts of dying became even more frightening when Bob started to ponder what the world would be like without him, if he were annihilated. Later in the interview he stated:

*I wasn't concerned about any of that when I thought, if I thought I was going to die. That I only cared about Julia and the kids and how they would, how they would get on without me and not just the loss but just the lack of support. I wanted to be there. I wanted to be there to be a husband and a dad...*

On the one hand Bob stated that he only cared about Julia and the kids but then in the next sentence he stated that he wanted to be there. This obvious contradiction emphasized the point that he was frightened of the thought of not being alive and in the lives of his wife and children. Klein in her discussion on the development of infants describes disintegration and the fear of annihilation as one of the most primitive states. She writes about the infant's ego and the anxiety which is “ a fear of annihilation (death) and takes the form of the fear of persecution ...experienced as an uncontrollable overpowering object...the anxiety of being destroyed from within” (Klein, 1946, p 4-5). This description seems to aptly apply to Bob who was terrified of being out of control of the cancer within him and thus projected some of his anger onto the “useless medics” who he felt were persecuting him partly by not providing the information he needed. His strong language established his anger and the adamant words he chose combined with the repetition that he “wants to be there” confirmed that he found the thought of a world without him truly terrifying. And yet he tried to minimize these fears as he went on to discuss someone else who died of a different type of cancer. This is one example of how Bob employed the defense mechanism of intellectualization to ward off his underlying anxieties. Now I will present the other defenses and coping strategies that Bob employed to manage his fears.

## 7.4 Coping Responses and Defense Mechanisms

Clearly from the discussion above, in spite of the reassuring statistics of testicular cancer, Bob resorted to several different coping responses and defense mechanisms in order to help cope with the emotional and physical impact of his disease. In particular he re-evaluated his life and made changes, he differentiated or split his disease into the “good cancer/bad disease” category, he minimized many of his concerns and tried to employ the defenses which fall into the category I have described as the masculine way of handling illness, including utilizing statistics and intellectualization as well as developing a hierarchy where he could feel above it all.

### 7.4.1 Re-evaluating Life/Finding Meaning

Both Bob’s actions and words indicated that one of his major coping responses was to look at his cancer experience as a catalyst to re-evaluate his life and to draw some meaning from his experience. During the course of the interview, he revealed that after he had completed his treatment, he had moved from the city to the countryside and started working four days a week. He explained that these changes were not just to benefit him but for his whole family. His strong desire to redefine what was important to him was evident from the beginning of the interview when he said:

*I wasn't thinking, you know there's those stories and films about other people who they think they're going to die and find out they're going to die and all the things they want to cram in. I didn't want to cram anything. I wasn't concerned about that at all. I was only thinking about normality, just normal life because actually it made me realise I think that my immediate family and having a normal life with them was overwhelmingly what mattered to me. And I thought that's valuable. If I, if I'm OK and I probably will be ... I knew that straightaway, that, especially if I didn't have to have chemo. Then really appreciating those kinds of more simple things in life ... there'd be something for me to cherish ...*

Bob’s response of re-evaluating what was important in his life is a common response for many men who are faced with a life-threatening illness. Charmaz, for example explains that:

*When men acknowledge continued uncertainty, their reappraisals bring reflection and self-appraisal. Men who had attended much more to their work than to their families decide to devote more time to the latter. Men who describe themselves as driven by their Type A behavior believe that they have to relinquish it before it kills them (Charmaz, 1995, p. 273).*

This appears to be the case with Bob who on the one hand stated that he “knew” that he would be “OK”, and yet as discussed above, was still struggling with his deep fears. Bob responded to these fears by trying to find some meaning in having gone through this experience. Bob believed a “valuable” outcome from his experience was deciding to spend more precious time with his family. As Charmaz (1995) points out, Bob’s response of re-evaluating his life is common in men with life threatening illness. Similarly, Bob employed another defense which was common with the participants in this study: the “good cancer, bad disease” response.

#### 7.4.2 Good Cancer/Bad Disease and Minimizing

From the beginning of this interview, it was apparent that while Bob knew he had cancer, there was an element of minimizing the impact of the disease because he was told it had a very good prognosis. In the first moments when asked what his diagnosis was, Bob responded:

*Oh, oh what was my diagnosis? A mixed cell germ or something it said on the, it was a mixed tera seminoma teratoma, is it, or something like that.*

Even allowing for a two year time lapse since Bob had been diagnosed, it is interesting that he could not remember the exact type of cancer he had. While on the one hand, this might suggest that he was not taking his cancer too seriously; perhaps he felt it was not a “real” cancer. On the other hand, from the discussion above about his fear of death and annihilation, this might imply that Bob was deliberately trying to minimize a situation which he had found very challenging. Another example of his minimizing behavior occurred later when he was describing how he was first diagnosed and then he described how he “tottled” on down to A & E where he met a “nice young man” who told Bob that he suspected that he did have testicular cancer but not to worry because they “could take care of that”. Thus from the very beginning of Bob’s experience there was a splitting of suspecting that he had cancer, a life threatening disease, with an almost blasé attitude of “but don’t worry you will be fine”, as if he had a common cold. This attitude was evident when Bob stated:

*So testicular cancer as cancers go is just a great cancer to have whereas brain tumors are not and at the same time, just after I was diagnosed with testicular cancer my brother-in-law’s cousin’s husband was diagnosed with a brain tumor... and he was told he had a year to live.*

Bob, like many of the medical professionals and patients around him, frequently compared testicular cancer to other cancers as a means of coping with the illness. It enabled both Bob and the medical staff to focus on his positive prognosis. Courtenay (2000) points out that institutional structure often cultivate stereotypical forms of gender enactments which encourage behaviors among men. These behaviors reinforce the strongly held cultural belief that men are more powerful and less vulnerable than women (Courtenay, 2000, p. 1394). Both Bob and the medical staff seemed to promote the behavior that Bob had the “great” cancer which could easily be dealt with by a strong man. As such Bob incorporated this institutionalized defense that he was a sturdy man who had the “good” cancer into his personal coping mechanisms. This is particularly evident in the very last moments of his interview when he stated:

*It was all a bit self indulgent and a bit intellectualized because I never really thought I was going to die...I basically always thought I was going to be fine... It would probably have been quite profoundly different if I wasn't sure, yeah, if there was more uncertainty. Do you want another cup of tea?*

The discussion above suggests that Bob had seriously struggled with his fear of death; however, the fact that Bob moved from discussing thinking about dying to offering me a cup of tea in the space of a few short sentences, suggests that the defense of minimizing the type of cancer he had into a “good” cancer was an extremely important coping response for him. As shown above, throughout the interview he returned to this theme numerous times which indicates that he had adopted this attitude in order to positively cope with his true underlying anxieties. In this quote, Bob also used the term “intellectualization” and I will turn now to explore his use of intellectualization as a defense.

#### 7.4.3 Intellectualization and Statistics

In the discussion above regarding Bob’s deep fear of death and annihilation, I provided an example where he cited very detailed statistics about his chance of survival. This was just one of numerous times throughout the interview where Bob presented very specific statistics. This suggests that one of Bob’s major coping strategies was rather than exploring his emotional responses to the threat of his disease he removed the emotions from the equation and concentrated on the facts and statistics. This form of intellectualization is defined as:

*Intellectualization is the overuse of abstract thinking, which unlike rationalization, is only self-serving in aiming to reduce psychic discomfort. Alcoholics use intellectualization when they quibble over the definition of alcoholism as a way of avoiding their drinking (Maxmen, 1980, p. 68).*

Bob's reliance on the statistics became an extremely important source of reducing his psychic discomfort particularly, as discussed above, his underlying anxieties about annihilation and death. Moreover, when he was faced with the decision whether he should have chemotherapy after his surgery, he yet again turned to statistics to reassure himself that he had made the right decision. The doctors had explained to him that there was some vascular invasion so they were considering giving him chemotherapy which has some health risks. Bob stated:

*..Basically they offered chemo so the chance of the cancer coming back is 2% rather than 40%, but if you're unlucky enough to be one of the 40% there's a 98% cure from the chemo anyway. So I thought, well I'm not, if I go for the prophylactic chemo I'm not really using all the, I'm not really using all the risks, that I'm not using the probability of it being OK that I have if you multiply the risk. So I decided not to and that was a fairly straightforward decision.*

While on the one hand Bob seemed confident in his knowledge of the facts, on the other he repeated himself a few times which suggests that he was not quite as certain as he made out. Choosing between subjecting one's body to a chemical which has severe side effects or having a 40% chance instead of a 2% chance of recurrence was probably not straightforward for Bob. Yet throughout the course of the interview, Bob returned to the statistics and emphasized that all of his decisions were based on facts not emotions. Intellectualization is a common defense mechanism employed by men confronting an illness and in this case not only did it help him cope with his fears but also to maintain his self-concept of being a strong decisive male.

#### 7.4.4 Masculine Way of Handling Illness and Hierarchies

Above theories of masculinity were discussed in general and hegemonic masculinity in particular. What is relevant in this interview is twofold. First, Bob in what would be described as a typically hegemonic masculine way, downplayed the emotional concerns raised when confronted with an illness. Secondly, Bob has employed what Sabo and London (1992) describe as intermale dominated hierarchies. Looking first at how Bob responded in a traditionally hegemonic way, in the second sub-session of the interview, I



asked Bob to elaborate on his Bob's comment that his wife would have made him go to the doctor much sooner if she had known about his problem. Bob's response was:

*I can't be bothered to go to the doctor and it probably will be OK. It's probably nothing or I think in my case I think it was probably more than avoidance of bad news. I think if I'd thought more about the possibility of it being serious I would have gone...*

In this quote Bob seems to have engaged in a practice that has aligned himself with his view of masculinity. He wanted to appear stoic, strong, and limit his emotional responses. This type of behavior, according to Connell (1995), is a form of idealized masculinity. Bob wanted to differentiate himself from his wife who he believed would have responded more emotionally and encouraged him to go see a doctor immediately. Throughout the interview, Bob described his wife as the emotional, dependant type. This pattern of setting himself apart and almost above his wife was also evident when he dealt with some of the other female professionals or "medics" he encountered, as discussed above. Moynihan (1998), who conducted numerous studies on men with testicular cancer, points out that for many men it is hard to accept becoming ill and to express their fears and needs. This seems to have been the case with Bob who was also reluctant to show any signs of vulnerability and instead attempted be above it all. These feelings of needing to appear as the stoic male may have been further reinforced by the fact that I was also a female and thus during the course of the interview and trying to enter his very "private male world", Bob felt the need to hold fast to the hegemonic male role and to present himself accordingly (Moynihan, 1987).

Sabo and London discuss the concepts of hierarchies and how men may resort to this type of behavior. They state:

*The prevailing cultural definitions of masculinity or hegemonic masculinity are essentially ideological constructions that serve the material interests of dominant male groups. Hegemonic masculinity reflects, supports and actively cultivates sex inequality (i.e. men's domination of women), but it also allows elite males to extend their influence and control over lesser-status males in various intermale dominated hierarchies (Sabo & London, p. 8, 1992).*

I presented above how Bob felt about the female doctors and his wife. However, there are further examples when perhaps Bob was an attempting to cultivate a sense of inequality even amongst other male medical professionals. Certainly this was evident in the following

situation immediately before his surgery when he was being examined by one of the junior doctors. Bob described the situation:

*And he was puzzling and fretting over the notes and I said it's the right side. He said it doesn't, well it doesn't say here which side it is. And I thought, well I do know which side it is... I'm not happy that it doesn't say which side it is but I don't want to wait another week or so whilst you work out which side it is. So I made him, I made him, I stood over and dropped my trousers and made him with a felt tip pen draw a big arrow, right it's that side, do it there.*

Bob was extremely, and understandably, annoyed that the doctor did not know which testicle was being removed. However, both how he described what he did and the actual action indicate that Bob wanted to show that the doctor that he was in charge, he knew what the doctors should have known. He later described the junior doctors as “underlings” which has a derogatory connotation of being inferior. This attitude was even more apparent in the following quote when Bob was waiting to receive results from his blood work.

*...you know there could be any number of benign explanations or maybe not. So you start, you're stuck with that. And then this guy came in and as a clinical psychologist I'm a bit chippy about doctors anyway. I'm a bit chippy, I hate doctors, so you start to see how the things, how things work and you've got this flea pit of junior doctors who are, do it. It looks like they're doing a stint, doing a few months, doing a rotation at the hospital. And they really don't know anything about testicular cancer.*

This quotation is from the end of the interview when Bob was reflecting back on his experience and was becoming increasingly agitated with some aspects of his care as well as more comfortable in revealing his true feelings about his experience. He had moved from referring to the doctors as “nice young men” to “flea pit of junior doctors”. Moreover, most of his verb tenses were in the present tense which would indicate that he still “hates” junior doctors and feels they “don't know anything”. He had also established himself professionally which he believed allowed him to be “chippy” about doctors. All of these points suggest that one of the main mechanisms Bob employed to cope with his illness was establishing hierarchies as described by Sabo and London (ibid). Establishing himself as higher in the pecking order perhaps was another means of coping with the challenges to his masculinity.

## **7.5 Conclusion**

At the start of this interview, Bob reported that he had been extremely lucky and the whole “cancer thing really wasn’t that big a deal”. However, by examining his interview in detail, it becomes evident that the whole experience had evoked some serious concerns and anxieties for Bob which he continued to struggle with. He reported concerns of being frustrated with the lack of information particularly regarding the prosthesis, being annoyed at the attitude of his bosses and struggling to deal with junior doctors. When discussing these concerns there is almost a paranoid-schizoid mode of functioning whereby Bob views some doctors as all good and some all bad. Similarly, his colleagues were extremely helpful but his bosses were useless which is suggestive of Bob utilizing the defense of splitting. He also employed the defenses of intellectualization and minimizing. However, just as an infant vacillates between the paranoid schizoid and depressive positions, so too did Bob fluctuate. Bob seem to feel that his masculinity had been challenged and thus he developed coping responses in the hopes of firmly establishing hierarchies in order to ensure that he felt more in control of his uncontrollable situation. Moreover, his very being was also threatened and his fear of death and annihilation were just below the surface. Therefore, he showed strong feelings of guilt about the possibility of not being there for his children and he also showed the need to mourn the loss of both his physical testicle as well as loss of no longer being the “strong, healthy” male as defined by the hegemonic terms of masculinity. Whether looking at the psychosocial concerns, his anxieties or his chosen defenses and coping responses, what is evident is that having cancer had a tremendous emotional impact on Bob and it was in fact a big deal.

## Chapter 8

### Participant 1007: Simon

#### 8.1 Introduction

This interview with Simon, a 43 year father of three sons, was overwhelmingly dominated by the concern that his sons (17, 14, 11) might be at risk for testicular cancer; therefore, the boys needed to be informed and repeatedly reminded of the necessity of checking themselves. Simon, a white British man, had been married for 21 years and worked as a project manager for a building company. Simon rode his motorcycle to the interview and was wearing his black leather jacket; then during the break between sub sessions he went up stairs and came down with teas for both of us. At the time of the interview, Simon had had an orchidectomy and was under surveillance. A few months after the interview, the cancer had spread to the lymph nodes and Simon went for radiotherapy; one year later he had no evidence of disease.

What was particularly poignant about this interview was that Simon's brother, father and grandfather all had testicular cancer. Needless to say, he and his wife were extremely concerned that their boys would similarly develop the disease. With this in mind, it is not surprising that the Simon openly discussed his concerns which were about his sons, his wife, and the lack of information. By examining the text more closely other concerns about his self-image, self-concept and sense of masculinity became evident. Moreover, while Simon never openly admitted a fear of death, he repeatedly returned to the topic of confronting the disease as early as possible in order to minimize the chance of recurrence. Simon had developed very adaptive coping responses which will also be explored in detail.

#### 8.2 Psychosocial Concerns

##### 8.2.1 Concerns for Children

Simon began and ended this interview with his concerns about his sons contracting cancer and mentioned it numerous times. Given the family history of testicular cancer, it was clearly and justifiably his primary concern. In order to understand what this actually meant for Simon, I have identified three specific concerns which Simon referred to when discussing his children: the fact that he had to tell his sons because it was hereditary, the

importance in convincing his sons to check themselves, and the unfortunate situation that at the same time Simon was diagnosed, his son had also found a small cyst on his testicle.

Almost every time Simon mentioned how he told his sons, he followed it with a few sentences about how testicular cancer has a particularly good prognosis. For example at the very beginning of the interview Simon said:

*...so really it's more concern for them, dad, brother, me, it seems genetically a defect somewhere along the line, so, and having three boys it's, it's a concern. But it's a very treatable cancer, there's, it's quite low level and treatable, as I've seen...*

In this quotation right away Simon shared that he was “more concerned for them” than for himself. Similarly, he went onto say that for a father the biggest issue is worrying about his sons. He emphasized the genetic link by stating who else in his family had the disease. He did this repeatedly throughout the interview. He would then immediately mention that it was a “treatable cancer” almost as if to reassure himself and to separate it from other types of cancers. This is a form of splitting, which according to psychoanalytic thinking as discussed above, is a defence mechanism used when an anxiety becomes intolerable (Moylan & Jureidini, 1994). Clearly for Simon the thought that his sons may also get the disease was almost unbearable; therefore, he had to reassure himself by splitting testicular cancer into the good type which could be treated.

Simon later went onto describe how he told his sons. He emphasized that he was very open with his boys. He stated:

*So we sort of like went quite deep into what it was and what's going to happen, I just kept reassuring them that yeah, everything's going to be done, I'm pretty sure that I'll be getting out of it in time... You mention cancer and obviously everyone thinks that's it, but that's not the case at all, so, but yeah, the youngest one, he didn't really have too much to say, the oldest son, as I say, he understood a lot more... So yeah, they were quite, I think with the information we gave them, they were fine with it, they were fine with it.*

This quotation is important for several reasons. First, he said “I’m pretty sure” which suggests that he wasn’t completely confident. This is followed by him emphasizing that the cancer they have is the “good one” and can be treated successfully. This was the first evidence of Simon employing the defence mechanisms of splitting whereby he splits the different cancer types into the ones where “that is it” and the other types such as testicular

cancer. Next, Simon recognized that his boys were at different developmental stages and thus they required slightly different approaches in how they were informed; however, they DO need to be informed. And finally he repeated twice that his sons were fine with it. This repetition of the positive would suggest that Simon was trying to convince himself that they were fine when in fact he was not sure.

Simon needed to find the balance between being reassuring to his sons that his disease was treatable and instilling in them the importance of checking themselves in order to ensure early detection. He did this by trying to be as direct and honest as he could. He stated:

*So because they know about dad, they know about my brother, so obviously I said look, it sounds like it's a hereditary genetic issue that you need to be very aware of. So I think I've scared them enough to make sure they keep checking. But so the pattern also, I said, it's not set, dad was 40, brother was 38, I was 42, it seems to be at the latter part of the scale, if that's anything to go by. So just check yourself, if you find anything down there, just don't be afraid, just deal with it...*

In this quotation Simon remembered the exact age of his family members when they were diagnosed. This attention to detail suggests that he was extremely concerned. Moreover, he was reinforcing the message that once the cancer was detected it could be dealt with effectively. He went on to describe at length the other times and ways that he had reinforced the message of the need to check themselves. This was particularly dominant in his mind because at the time of his interview his middle son had in fact found a testicular cyst.

Simon's son had an appointment the afternoon of the interview for an ultrasound to examine his cyst. Clearly, Simon was extremely worried not only about this particular incident but about the future. As Wellisch (1985) describes in his study on adolescents' behavior when a parent has cancer, one of the key questions is how families live in a constant state of uncertainty. In Simon's case he seemed to be trying to take control by ensuring his boys checked themselves and that they dealt with all medical conditions promptly and together. What makes this particularly challenging is normally adolescence is a time when the natural course is for emotional separation from the family and yet Simon's sons were being pulled in a reverse direction from the natural course and becoming more dependent on their parents (Wellisch, 1985). Luckily, Simon reported the next time he was in clinic that his son was fine. However, with all this transpiring it was

not surprising that not only was Simon worried about the response of his sons, but his wife was also struggling with this. Simon recognized how difficult it must be for her.

### 8.2.2 Concern for his Wife

Although Simon always referred to his wife as “the wife” which hints at macho-sexism, actually they clearly had a very strong relationship. Not only was she his major source of support but they seemed very concerned about each other. Simon’s concerns for his wife took on two major features. First he was worried that having to deal with his disease was quite demanding on her because she was also worried about the impact it had on their sons. Second, his wife was the recipient of Simon’s projections. Simon projected his own worries onto “the wife” who then felt the concern for him in the form of projective identification. (This defense will be discussed in more detail below.)

Very early on in the interview Simon mentioned his wife’s reaction. He stated:

*But it’s a very treatable cancer... now it’s hopefully gone, been cut out, dealt with and can, I can just spend the next five years monitoring it, and hopefully it won’t reoccur. So it put, it was no stress to me, other people were more worried than I was about it, in fairness, the wife was quite worried.*

This quotation suggests that Simon had again split his cancer into the “good” cancer which was very treatable and one that he can cope with because “hopefully” it won’t reoccur. However, immediately after that sentence he then spoke of his wife who he was concerned about. Throughout the interview he described how challenging the whole experience was for her and how much time she spent finding the information they needed about the disease.

Using psychoanalytic terms helps to illuminate Simon’s responses. There was a deep concern and even a sense of guilt that he was putting his wife through this difficult situation. In the treatment stage of Simon’s condition he seemed to be working from a paranoid-schizoid position whereby he split the cancer into good and bad in order to cope with a life threatening illness. Then when the imminent danger had subsided, he moved to a more depressive mode of functioning where his defence mechanisms included both feelings of guilt and projective identification. As mentioned above there is evidence of the use of projective identification whereby he had projected his fears onto “the wife” who became “quite worried”. Klein (1946) explains that projective identification is

where the individual unconsciously transmits his experience to another who then finds themselves having to cope with these feelings and emotions on behalf of the first individual. This seems to be the case with Simon and his wife. This use of projective identification enabled Simon to get rid of the worrying and troublesome emotions by evoking them in his wife so he could lose contact with them himself (Moylan & Jureidini, 1994).

The use of projective identification also played an important role in enabling Simon to maintain his sense of self and being the “man” in the family. This was particularly important to Simon who seemed to thrive on the hegemonic male image of riding a motorcycle, wearing a leather jacket and being the head of the family. By employing projective identification as a defence, his masculinity and self-concept were not challenged at a time when he needed it to cope as best he could. The use of projective identification is evident again in the following quotation:

*And when, she was finally sort of like, was relieved at the sort of two, two appointments at the Marsden when they said no, it's low level... everything seems clear now and you're in the clear... So I think at that point she could take a sigh of relief...*

Simon described “the wife” to be demonstrating all the emotions that one suspects that he was in fact feeling. Simon’s wife seemed capable of containing his anxieties in a similar way to a mother who “knows” when a baby is hungry or in pain and deals with it accordingly (Moylan & Jureidini, 1994). Moreover, Simon’s wife was also extremely competent and took it upon herself to look for the information they needed when the hospital was not particular forthcoming.

### 8.2.3 Lack of Information

During the course of the interview, there were two areas where Simon explained that he did not receive adequate information; they were: post-operative information and how and what to tell his sons. What Simon was not prepared for was how much discomfort he would be in after surgery and how long it would take him to recover. He stated:

*I've still not got full feeling down there, whether or not it will come back, obviously the doctor's got to get in there. Yeah and that, because I suppose that side of it was a surprise, because that bit hadn't really been explained to me.*



Not only does this quotation reveal that Simon had not received the information at the time of the surgery but also he still did not know if he would ever have feelings back. Simon repeated his frustration with the lack of aftercare several times during the interview and relied on his wife to find information on the internet. Thus not only was he physically uncomfortable when he was recovering but he was also anxious that perhaps something was wrong and worried that he was experiencing more pain than most men.

With regards to the information for his sons, Simon also repeated several times that they had to “go looking” on the internet; this was extremely frustrating for both he and his wife at a time when they wanted to be focused on Simon’s recovery. Moreover, not only did they not have much information what they did have was woefully inadequate. Simon stated:

*...I like the internet, I think it is great, but I think there’s certain things that you just let the professionals deal with, because I think there could be some false ... there’s a lot of crap out there that you don’t really want to pay attention to... more from the kid’s side probably, because it was a bit more, I suppose a bit of a shock tactic, because some of them (the websites) are quite graphic.*

In this quote, Simon explains that he would have preferred to have the information from healthcare professionals but since that was not forthcoming they went online. Unfortunately, this information was not particularly helpful. Simon uses the strongest word “crap” that he used throughout the interview which suggested that it really annoyed him that when trying to find ways to inform his sons about a disease there was no reliable information.

I found myself particularly touched by Simon’s description of the situation with his sons. Having teenagers myself, I know how challenging it can be to get them to listen. But in Simon’s case, the situation could be life threatening. While in previous interviews I had felt concerned about the lack of adequate information for fathers, this particular interview prompted me to start developing ideas to meet this need, even before the study was completed. These plans will be discussed in the Future Implications section.

### **8.3 Underlying Anxieties**

#### **8.3.1 Challenges to Self-Concept, Self-image and Prosthesis**

Simon seemed to preserve his self-concept by continuing to present the idealized image of masculinity including the strong and resilient man who was the “sturdy oak” for his family (Bullen *et al.*, 2010). While he never openly expressed concerns about his self-concept, by examining closely his words and actions, there is evidence that he had felt frustrated because he struggled to return quickly to his pre-surgery self. However, he did not feel the necessity to have prosthesis and seemed to preserve his self-image by ongoing behaviors such as continuing to wear masculine clothes and riding a motorbike. First I will explore the evidence to suggest that he did feel the need to preserve his identity and self-concept, and then look at his response to having prosthesis.

Simon found the post-surgery period surprisingly uncomfortable; moreover, he was not able to return to and recapture his former self. This was evident in the following quote when he stated:

*So it took about a good three months before maybe now I'm sort of like easing back into it, and how unfit you can get in three months.*

Simon was feeling frustrated in how long it took to become “fit” again. Being in shape was important to Simon and therefore, his aim was to reclaim the same identity that he had prior to his diagnosis. He also expected to go back to work quite quickly but was frustrated to find that it took about three weeks before he could even start back on light duties. Similarly, in his choice of clothing and riding his motorcycle there is more evidence of a man attempting to preserve the self by maintaining the essential qualities, attributes and identities of the past self that fundamentally shape his self-concept (Charmaz, 1995).

Interestingly, however, Simon did not seem to even contemplate having prosthesis. He stated:

*It was probably about a week before the operation, at one of the consults, he said had you thought, do you want a prosthesis? Straight away I said there's no point really, it's not, I'm not vain enough to worry about it, I'm never going to put Speedos on, so ... there wasn't really any call for it.*

This was the only mention that Simon made throughout the interview about the prosthesis. He seemed quite comfortable with his decision and there was no sense that this physical change had impacted on his self-image. This is in keeping with the study

done by Adshead and colleagues (2001) that found being in a steady relationship influenced the decision to decline an implant at the time of surgery; married men in particular felt it was less of a concern to have a symmetrical scrotum. This would suggest that what was essential for Simon to keep his self-concept was not his anatomy as such, although being fit was important, instead it was vital that he was seen as being a capable and an in control father and husband. For the most part, Simon maintained this concept. However, it is only through examining how often he mentioned the importance of catching the disease quickly, is there evidence that underneath this calm facade there was an anxious patient.

### 8.3.2 Fear of Late Diagnosis

On numerous occasions during the interview, Simon referred to the importance of catching and confronting his illness quickly. By repeatedly commenting on how important this was, this suggests how frightened Simon was of what might have been if he had not in his own words been “man enough” to take some action. For example at the beginning of the interview he said:

*And the fact that if I hadn't dealt with it how it could have obviously led to it being a lot more serious and a lot more treatment. The thing that comes to my mind is, from a man's point of view, especially in that area, is that you've just got to deal with it, and people I spoke to, friends and that said oh, you're so brave, I don't know how you can go through with it. And I said but its cancer, you've got to deal with it...*

This excerpt not only shows how frightened Simon was of what might have been but it also illustrates again, the importance Simon placed on confronting his illness in a “manly” fashion. Clearly, maintaining his self-concept was essential and that Simon’s coping was influenced by his perceptions of idealised masculinity (Bullen *et al.*, 2010). What was important to Simon was that unlike some men who might have avoided “dealing” with it and would have put themselves at an increased health risk, Simon was able to behave in a manner within the confines of hegemonic ideals and thus did not diminish his perceptions about his manhood (Courtenay, 2000). This is also in keeping with Gordon’s (1995) strategy of how men cope with challenges to their masculine identity by viewing surviving cancer as an opportunity to face up to a difficult challenge courageously and by minimizing the situation. In other words he was able to address

his deep fears in a manly way. The depths of his fears were also evident in the following quote:

*And it just so happens that I was going through that, and then also a friend of mine's ex wife, she was, she's passed away, she was totally riddled with it... I'm a case of dealing with it and getting on with it, she unfortunately must have known something was wrong, but didn't do anything about it...two weeks later she passed away.*

Interestingly here Simon does not refer to what type of cancer “she” had but still compares it to his own. He hypothesizes that she knew for a long time and did not do anything about it. Applying psychodynamic concepts again helps understand this quote in greater depth. The fact that Simon used the defence of “splitting” whereby he took the good action while she effectively took the “bad” action suggests a very primitive fear. In order to ensure that he had coped well with his disease, he had to project all the fear of being diagnosed when it was too late onto someone else and hold onto his belief that his actions had saved him. This improved his feelings of being in control and enabled him to avoid facing the underlying fears about what would have happened if he had not taken such swift action.

### 8.3.3 Recurrence and Death

Simon never actually mentioned the words “recurrence”, “death” or “dying” and yet his fears were evident throughout the interview. While Simon openly discussed the importance of early detection, he struggled to verbalize his fears about what would happen if his disease was not diagnosed early. His only direct specific reference to recurrence was towards the end of the interview when he said.

*But I'd imagine there's quite a few people out there, especially addressing the men, that would actually not deal with it...that's when it leads to the big problem that it gets passed down, starts going into the other areas, that's when it becomes harder to cure.*

The “big problem” of course is recurrence but he does not use medical terms even though he is a very well spoken man. Instead again he went onto the topic of how other men might not have dealt with it. This suggests that even with hindsight he was not capable of dwelling on what the “big problem” actually was, probably because it was too frightening for someone who liked to appear in control and coping well.

As Cooper (1982, p. 613) points out that “somewhere, in even the most carefree of apparently coping personality, will lurk the fear of imminent death.” This seems to be the case with Simon who was extremely concerned with catching his disease early. The closest he came to admitting that he had even contemplated what might have happened was the following quote:

*..It's more after actually, and what could have been, if left, that I thought about for a while. That's going away now as well, you've got those quite moments you just reflect on what you've just been through for the first four months of the year.*

Instead of recurrence or death, Simon refers to “what could have been”. This avoidance of using the words “death” or “recurrence” suggests that for Simon the fear of death was lurking somewhere but was too frightening to mention. It is only by examining how often he mentioned catching it early and looking closely at his word choice does it become apparent that Simon was in fact extremely frightened but had employed coping styles and defines mechanisms in order to deal with his disease.

#### **8.4 Coping Responses and Defence Mechanisms**

During the course of this interview it emerged that Simon had developed four main ways of coping with his disease. These were: separating his cancer into the good cancer/bad disease category, handling his illness in a masculine way (including the defences of projection and splitting as well as maintaining his self-concept), relying on the support of his family in particular his brother and using both intellectualization and humor. Above in the section on concerns for the children and his wife, I presented the use of splitting and the good cancer/bad disease concept. Similarly when discussing his concerns for his wife and the challenges to his self-concept I explored how by handling his illness in a masculine way he felt in control and more confident about the impact the disease would have on his life, thus these topics will not be discussed again. Instead, the focus here will be on his reliance on his family for support and use of humour and intellectualization.

##### **8.4.1 Family Support**

Simon and his wife told their sons together over dinner about Simon's disease. This is just one example of the open communication and positive family functioning that was

evident in Simon's family. Longitudinal and cross-sectional studies have demonstrated that good family functioning has been associated with lower levels of distress, depression and anxiety (Baider & De-Nour, 1988; Spiegel *et al.*, 1983). This certainly seemed to be the case with Simon and his family. Simon also relied on his brother who had testicular cancer eight years before. Simon stated:

*...having my brother there, and having him gone through it, and he was quite, that helped a lot. Because he told me the, like the stages that you were going to go through and then the treatment after the operation with the radiotherapy or chemo.*

Clearly, his brother was a "great comfort"; he mentioned him numerous times during the interview. When asked if he would have wanted any additional sources of support, Simon said that he did not need any because he always spoke to his brother. In Simon's case having family support played a major role in determining his quality of life (Ostroff *et al.*, 2004).

#### 8.4.2 Masculine Way of Handling Illness: Humour and Intellectualization

In addition to the use of projection and splitting, Simon also employed other coping strategies and defence mechanisms which fall in the category of what I have described as Masculine Way of Handling Illness because they allowed him to cope with his illness while also maintaining his self-concept. In particular he employed humour and intellectualization. He was not flippant but rather used jokes as a means of communicating what otherwise might be awkward or embarrassing to say. In terms of gender, humour plays an important role in men's social interactions and provides a strategy to self-disclose (Thorson *et al.*, 1997). For example, Simon's Speedo comments about why he did not need a prosthesis. Utilizing humour allowed him to express ambivalent feelings.

Not only did Simon use the humour in the interview, he also described how he incorporated it when trying to handle challenging situations with his sons: for example, when his son had a cyst they were given a trainee doctor and Simon reported:

*You have to laugh, yeah, when you've got a trainee you're going to make a joke of it, yeah? We had laugh, I think he's fine... they've all got to learn.*

Here Simon was trying to incorporate humour in order to both ease the difficulty of the moment as well as teach his son how to cope. As Oliffe and colleagues (2009) point out humour can be ego-enhancing by fostering a sense of mastery and it can help reduce anxiety. Certainly, Simon successfully felt more in control and less anxious when he was able to make his sons laugh. Additionally, the sharing of laughter was an indication of a degree of shared safety and showed the establishment of intimacy in interpersonal relations which also facilitated their communications (Oliffe et al., 2009, p. 923). By “making a joke” of it, Simon was demonstrating an adaptive coping strategy which helped them deal with an awkward moment. Additionally, it also set the example which Simon frequently referred to, one “has to man up and deal with it!”

### **8.5 Conclusion**

The interview with Simon was honest, humorous and informative which reflected his interactions with his family. He was particularly concerned about the impact that his disease would have on his sons both practically and emotionally. In order to best cope with this, he employed adaptive coping skills and defence mechanisms. While he never actually mentioned his fear of late diagnosis, recurrence and death, by examining the numerous times he repeated certain topics, as well as the complete lack of the mention of the word death or dying, Simon appears to be stoically holding onto his position as father, role model and provider who knew how important it was to man up and face his disease early.

## **Chapter 9**

### **Participant 1009: Nigel**

#### **9.1 Introduction**

Nigel, a 48 year old white British man, was the father of three boys who were six, 14 and 18 years old at the time Nigel was diagnosed. He had been married for 20 years to his wife, Sarah, who was a nurse. He had completed secondary school and worked in a prestigious position in the civil service. What dominated Nigel's interview was that unfortunately he had been misdiagnosed for the first six months and then experienced numerous medical mishaps which resulted in his disease spreading and the need for extensive treatment. Ultimately, he was diagnosed with Stage 2c right testicular seminoma with para-aortic and liver recurrence. I will begin by providing relevant details about the medical mishaps which colored his entire experience and hence the interview.

#### **9.2 Medical Mishaps**

In September 2008, Nigel began experiencing severe back pain which he reported to the GP who diagnosed rheumatism. However, the pain continued to grow and then in January 2009, Nigel also noticed a hardening of his testicle which he again reported to the GP who reassured him that it was scar tissue from his vasectomy. By February the pain was almost unbearable and Nigel's wife who was a nurse insisted that the practice try and address his pain; therefore, Nigel was referred to an orthopedic surgeon who immediately did a full body scan. At this point they found a large mass in Nigel's abdomen and the surgeon explained that he suspected lymphoma; therefore, Nigel was admitted into hospital. While in hospital, Nigel was unable to urinate and was thus visited by a team of urologists who asked if Nigel was suffering from any other symptoms. When he explained about the hardened testicle, the urologist replied that Nigel had been correct and the GP was wrong because in fact Nigel had testicular cancer. The hospital then explained they would not be able to operate for another week at which point Nigel, who had private insurance, made a call to one of his colleagues who had a contact in the press office of the hospital. Within one hour Nigel was in the operating room having an orchidectomy.



Nigel transferred hospitals and was almost immediately admitted to the private ward for a round of chemotherapy. Although Nigel reported that his treatment at the second hospital was excellent, unfortunately he relapsed and then had to undergo both radiotherapy and another round of chemotherapy. At the time of the interview, the oncologists were very hopeful and they confirmed that he had no evidence of disease.

### **9.3 Psychosocial Concerns**

#### **9.3.1 Lack of Information and Feelings of Isolation**

In light of the emotionally and physically taxing experience that Nigel had suffered for six months prior to his surgery, it is not surprising that Nigel then reported feeling “extremely unwell” and “extremely isolated” when he was admitted onto the ward for chemotherapy. Given the circumstances, it is not surprising that he repeatedly mentioned how exasperated he was with his GP who never provided him with any information about testicular cancer. The combination of not having adequate information from the beginning of his cancer experience and his feelings of isolation remained a constant theme through the course of Nigel’s treatment and was present at the time of the interview. Nigel explained that:

*I just felt completely isolated and I don't think that actually did my mental ability terribly good because it was quite, you're trying to cope with the cancer, trying to cope with the treatment, but then there's that isolation, that solitude, and I think possibly if I'd been able to share my experience with others in a similar situation on a ward that might have made a huge difference.*

This quote shows that Nigel was certainly struggling and feeling overwhelmed by his circumstances and thus was losing sight of his capabilities and his problem-solving strengths (Neilson-Clayton & Brownlee, 2002). There is a sense that the “solitude” was negatively impacting on his ability to cope. However, what is also revealing was that he repeated these feelings numerous times which suggested the depth of his feelings of isolation. Moreover, I found myself in the verge of tears several times, something that had not happened in the other interviews. I felt a real sadness for Nigel and wished that I had met him earlier on during his treatment. The fact that his words stirred such strong feelings in me suggests the depth of his feelings of isolation.

Nigel later went on to describe how he felt like a “prisoner” in his own room. Nigel explained that while he was in the hospital he desperately wanted to share his experiences with others who were in a similar situation; this belief of how helpful that would have been was still strongly felt at the time of the interview. Typically men do not openly discuss their cancer concerns with other men; however, men with prostate cancers have expressed a desire to disclose their feelings and vent their concerns about their illness with other men (Olliffe et al., 2009). Nigel wished that he had the opportunity to ease his feelings of isolation by speaking to other men. Instead, he had to rely on his wife which led to other concerns.

### 9.3.2 Concerns for Wife

According to Nigel while he was struggling in the hospital, his wife was managing everything else. He said:

*The person I felt really sorry for was my wife because she has no parents to turn to. She's got a brother but he lives in Hertfordshire, my mum and dad were focused on me, who was looking after her? And she had so much to contend with, she had the kids, she had me, she's trying to run the home plus she was, at that point she was also working as well and in the end we did say, something's got to give here and so she had to pull out of work for a couple of months because I could see her falling over. I said, you cannot fall over also but she found it really, really tough, really tough.*

Nigel had identified the multiple responsibilities his wife was managing on her own which he recognized was too much for her. He emphasized this by repeating how “tough” it was three times. He went on to explain:

*...because I was a private patient there was no recognition of the support that she or the kids might need that you seem to get on the NHS side but you didn't get on the private side. So we, I think there were times she felt completely isolated and in limbo and we know, having spoken to other patients that that's not the same, who were treated on the NHS side, that wasn't the same.*

Clearly, Nigel was concerned because his wife did not seem to be receiving the support she needed at a time when he was not in a position to be there for her because he was struggling to cope himself. He emphasized the point by saying “completely” isolated. This dilemma of being worried about his wife while lacking the stamina to support her was also evident when he discussed his concerns for his sons.

### 9.3.3 Concerns for Children

Of all the topics Nigel presented and themes that emerged in this interview, the overriding one was Nigel's concerns for his children. The three dominant themes were the huge impact that his diagnosis had on the whole family, his struggle to tell them when the cancer had recurred and his dilemma between taking care of himself while feeling guilty that he was not there to support his sons. I will focus on these three central themes.

At the very beginning of the interview Nigel explained:

*But the impact on the kids was quite considerable, it was one of the most difficult conversations I've had to ... I wanted to go home and see my children and tell them what was going on and tell my parents. ..trying to be as much, as reassuring as we possibly could be and then I kind of left and went off to hospital...*

Nigel admitted that this was one of the most difficult conversations he had; moreover, the fact that he wanted to go home before going to hospital even after waiting six months for a diagnosis showed how important it was that he speak to his children. He went onto explain:

*...but the impact it has on, not only just the person suffering cancer but the whole family, is amazing, is considerable, and I don't think people appreciate that, I really don't.*

This quotation succinctly encapsulates the overwhelming impact that cancer can have on the whole family and the accepted fact that a diagnosis of cancer is a very stressful event for both the patients and their family members (Edwards & Clarke, 2004). Nigel then went onto to explain that while he and his wife spoke to the boys together initially, over the course of the next two years, he was conscious that the boys were different ages and thus needed to be given slightly different age appropriate information. This became particularly important when he had to explain to them that the cancer had recurred.

Nigel mentioned numerous times during the interview how difficult it was to tell his sons when he recurred. A particularly poignant example was when he said:

*So, as I say, different messages for different age ranges but then there's obviously when it came back the second time much, much more difficult because you go up, you start or you think you've got over it and everything's going to be fine and then all of a sudden you get this complete bolt out the blue kind of thing ... and that was really difficult. Well are you going to be all right, are you going to die? I don't know.*

This excerpt not only showed how conscious Nigel was of the importance of talking age appropriately to his sons but also it emphasized how difficult it was for the whole family when he recurred. The family's cancer illness experience changes over time and it can be particularly challenging to cope with recurrence phase (Kristjanson & Ashcroft, 1994). Having witnessed Nigel suffer all the side effects of the treatment, his sons were then subjected to watching their father bear these ailments again as well as having the possibility of his death looming over them all. Teenagers in particular want to know more about the future and may ask "what if questions" which makes discussing recurrence even more challenging (National Cancer Institute, 2013). His sons' concerns about Nigel's possible death were evident again in the following quote:

*And, as I say, my son found it quite difficult I think and I think he just kept saying, are you going to die? And I said, no of course I'm not. And but trying to reassure a 13 year old as he was is really hard, really, really hard and the last thing I wanted to do was tell him something that actually you, that then becomes unrealistic or not true. And that's the approach we've always adopted with the kids, if we've got problems we confront them head on and we actually share the problems rather than try to bury them and hide them and this was no different.*

From this quotation, it is evident that Nigel was "really, really" struggling with what to tell his son. They had employed a very honest approach while also showing determination that they were "confronting" the illness. Telling the truth couched in hopefulness instead of trying to convince them of a good outcome which can not necessarily be guaranteed is a key strategy in helping children to live well with uncertainty (Harpham, 2004). When listening to Nigel discuss this struggle, I found myself wanting to reassure him that he had done well and offer words of advice. My strong desire to step out of role as the researcher suggests how strongly he was expressing his concerns. Not until after I turned off the Dictaphone did we discuss at length how to speak to his children and the limited resources available. When I left his home I found myself more determined to develop an intervention to help families communicate about cancer.

Even though Nigel and his wife seemed to have handled the situation with their sons admirably, Nigel still struggled with the fact that he also spent quite a bit of time worrying about himself. Nigel explained that both times he had chemotherapy: "You lose

your hair, you lose weight, you just lose, you just lose your dignity, it was, and it is horrible.” There is an overwhelming sense of loss. Not just at the physical side but of dignity. This was particularly difficult for him when trying to maintain his role as strong father. He went onto explain:

*I do not remember much about the last three or four months of 2009 if I'm honest so. There were times when I had to just shut myself out of what was going on and that included shutting the boys out as well and I was very mindful of that but it was my way of coping. It is, I couldn't be a dad, I couldn't be a dad they wanted to be at that, during that period so and I don't mind admitting it now.*

This excerpt poignantly exemplified Nigel's need to withdraw as well as his struggles of not being “a dad they wanted me to be”. Nigel admitted during the interview that he had to partially give up his role as father because at the time he could only focus on himself. For families coping with cancer it is not uncommon for the father to lose pride in providing for the family and in decision making. Men may also regress into an adolescent or even childlike role (Schover & von Eschenbach, 1985). This quote hints at these feelings of loss of pride and need to concentrate on the self in an almost adolescent manner. I will discuss in more detail Nigel's struggles with his self-concept but what is particularly evident from this extract and was that while Nigel was struggling with his own deep fears and physical battles, he was always concerned with how his illness was impacting on his wife and children.

What is particularly interesting is that while at the time of his illness Nigel felt incapable of acting any differently, when discussing his actions during the interview there was a sense of remorse. Applying psychoanalytic concepts, this is suggestive of a man who was struggling with the ambivalent impulses of the depressive position. Like an infant who recognizes that the breast which frustrates him is also the one that gratifies him and that both hatred and love can be felt for the same object, Nigel was displaying a capacity to shift his primary concern from the survival of himself to the people on whom he depended (Steiner, 1992). Ironically, Nigel's willingness to openly explore these complex feelings of loss and guilt during the interview, reflected a man who had shifted from a point where his fears were at their height (which I will discuss below) to a crucial stage of having the capacity for mourning and deep meaningful relationships (Menzies Lyth, 1960).

## **9.4 Individual Anxieties**

### 9.4.1 Challenges to Self-concept, Masculinity and Faith

Coping with his initial diagnosis, the treatments and then his recurrence all proved to be challenging to Nigel's faith and his self-concept. Nigel only mentioned once that he had a strong faith which he then questioned when his cancer returned. He stated "it does call into question ...whether you believe or not." This simple quote suggested that Nigel was struggling with his faith and how it fitted into his belief system. Similarly, Nigel was struggling with how he viewed himself. His job was quite important to him. He said:

*I've got quite a high profile job.... When it all happened I was the Deputy Director and so it's quite a pressurised job. I was, didn't know whether I was going to go back.*

Nigel was obviously proud of his career but was concerned at the time that he might not be able to return to it. He later went on to explain that he was "determined to get back to prove to myself, I think, what I could do." This determination to return to his professional role as well as his frustrations at not being the father that he wanted to be are suggestive of a man who had an idealized image of his masculinity as one which includes ideas of strength, coping, independence and man as the "sturdy oak". Nigel found being "weak" from the treatment both physically and emotionally draining.

Later in the interview, Nigel admitted that after he had recurred and was in hospital for further chemotherapy he had felt "depressed" and had "spoken to someone". While he said it was "not too helpful" and he had not told many people about it, he thought at the time he needed it. This was also suggestive of a man who was trying to enact his masculinity in different ways. In the hospital setting he was accepting of support, however, in the more social context of the interview and with friends he was reluctant to admit his need for support and returned to a more dominant, masculine identity (McCaughan *et al.*, 2012). Ironically, at the time when Nigel was feeling his weakest he was in fact given an award at work which while bolstering his self-concept as a capable man, also challenged his physical self-image.

#### 9.4.2 Challenges to Self-image and Prosthesis

For Nigel the treatment of his cancer drastically changed his physical appearance both in that he lost a substantial amount of weight as well as having a testicle removed. While some studies have shown that men deny that their illness had any long-term effect on their self-image, for Nigel it certainly seemed to have impacted on him (Gordon, 1995 and Moynihan, 1987). For example, Nigel, who normally weighed 11 stone, explained that while he was having treatment he received an award:

*And so I was given the award... all these people came down...what was funny there was clearly my appearance because I went down to about 8½ stone and I was determined though to get into a suit that day so I had a suit on and my appearance clearly struck a lot of people and...I suddenly realized people think this is the last time they're going to see me.*

Clearly, Nigel did not think this was “funny” instead, he felt quite upset. He had tried to maintain his professional stature by wearing his suit and yet what people saw was a very ill man perhaps on death’s door. Even reflecting back on this incident, Nigel seemed to struggle with how frail and close to death he appeared. The distance of two years had not lessened the impact he felt that the disease had on his self-image of the strong, successful professional. Similarly, he still had resentful feelings about not being asked if he wanted a prosthesis.

Nigel was never asked if he wanted a prosthesis, it was not mentioned at all; a fact which still bothered him. He said:

*I've give that quite a lot of thought actually and I'm not angry, that's the wrong word, that's the wrong expression, but I think I would have liked to have been offered the option. .. I would like to have discussed it with somebody at some point and said, right these are the options...I went through a period of feeling not whole and I don't know if that makes sense.*

In this excerpt we see that Nigel changed his verb tenses. This suggests that not only did he wish he had been offered the option of a prosthesis but he continued to feel that way at the time of this interview. This is in keeping with the study done by Adshead and colleagues (2001: p. 560) of 234 men who replied by questionnaire 91% felt that it was important to be offered an implant at the time of surgery. At a point when Nigel was struggling with so many losses and challenges, it seems very unfortunate that Nigel was not offered an implant which might have alleviated one of his concerns.

### 9.4.3 Fear of Death

Because of the lengthy time it took to diagnose Nigel, by the time he was being treated his cancer was fairly progressed and his prognosis was far from certain. Moreover he relapsed within a few months with the cancer spreading to the liver which was very serious. He described the meeting with his consultant where he was told of the progression of his disease:

*...he (the consultant) talked through what the treatment would be which would be more extensive chemotherapy and having been through it once I knew what was coming and somebody said to me it's like putting your hand in a fire and knowing you're going to get burnt and having to do it all over again. And he said that would be followed up by 20 sessions of radiotherapy on the liver... Unbeknown to me and it only transpired sometime later, while I was out the room my wife had a conversation with the doctor who gave me a 50/50% chance of survival so the fact that I'm sitting here today three years later is quite an achievement...*

This quote reveals two important themes for Nigel. First, he eloquently described how difficult it would be to go through the treatment again. His image of putting his hand in a fire poignantly captured both the physical and emotional anguish that he would have to experience when putting himself through rigorous treatments, again. Secondly, he candidly admitted how close to death he was and how grateful he was to survive. There was a real sense in this quote and several times during the course of the interview that Nigel was very aware of the real possibility of his death. This prospect was certainly darkening his view of the present while also shading his future which was no longer certain (Charmaz, 1995). His anxieties about his future were even more evident in the following quote:

*...(I) then started the 20 sessions of radiotherapy but I was extremely ill and there were times when I actually didn't know myself whether I'd actually wake up the following morning I felt so ill. There were times when, to be quite honest, I didn't want to wake up because I felt so ill.*

Again there is evidence of both the physical and emotional turmoil that Nigel was confronting. This is reminiscent of Freud's work after the First World War when he described our defensiveness against realizing the inevitability of our own death and explained that this defensive attitude to death 'has a powerful effect on our lives. Life is impoverished; it loses in interest, when the highest stake in the game of living, life itself, may be risked.' (Freud, 1915 in Menzies-Lyth 1975b, p 208). There is certainly a sense in



this quote that for Nigel during his treatment stage, his life was impoverished and he was not certain he wanted to continue. And yet he continued to fight. As he explained:

*...but the team at the hospital were fantastic, they were absolutely brilliant and I know (the doctors) got me through kicking and screaming... and touch wood I've been now, touch wood, still close monitoring but everything's heading in the right direction and you know so hopefully that will carry on.*

At a time when Nigel was confronted with the most fundamental anxiety of his own death and his struggle for survival, there was evidence of the primitive defense of splitting. The “all good” doctors became the caring protective parent who contained his unbearable fears. The doctors seemed to be bearing the tremendous responsibility when their patient was suffering (Moylan & Jureidini, 1994). Even with the benefit of time, Nigel still credited the doctors with helping him cope with his greatest fear and ultimately achieving his survival. Nigel was trying to recapture his past healthy self and “stave off death” and that by believing in his “all good” doctors and their resolve to cure him, he was able to maintain his own hope (Charmaz, 1995, p. 280). This is just one example of how Nigel utilized splitting as a defense; I will turn now to his other coping responses.

## **9.5 Coping Responses and Defense Mechanisms**

### 9.5.1 Good Cancer Bad Disease

Although Nigel had a very serious case of testicular cancer, there was still an element of him reassuring himself that he had the “good” cancer. While statistically it is evident that testicular cancer does have a better prognosis than most of the other types of cancer ([www.cancerresearchuk.org/cancer-help/type/testicular-cancer](http://www.cancerresearchuk.org/cancer-help/type/testicular-cancer)), Nigel also employed the splitting of his disease into the “one to have” as a way of coping with a frightening condition. For example, he explained that someone in his office was diagnosed at the same time with bowel cancer which spread to the liver. Unfortunately, this colleague died. Nigel quickly explained that he had testicular cancer which spread to the liver not liver or bowel cancer. Again, while this is medically accurate, there is also a sense that Nigel needed to make a clear distinction between himself and the colleague who had died. He went onto discuss how important it was to remember that each experience of cancer was unique and that it can be “destructive” to discuss or compare diseases. All of these facts are true and show that Nigel had a comprehensive understanding of his illness. But importantly by

repeating this distinction repeatedly, there was a sense that Nigel was trying to convince himself.

### 9.5.2 Writing and Withdrawal

Ironically, while distinguishing himself from other cancer patients helped him to cope on the one hand, on the other hand it exacerbated his feelings of isolation. Above I discussed that one of his major concerns was feeling isolated. These feelings were compounded by his coping responses which included withdrawal from other individuals and instead turning to writing. Nigel explained why he decided to stop discussing his cancer experience with others when he described how his father responded. Nigel explained:

*I know what you're going through. And I thought, no you don't know what I'm going through, you've got no idea what I'm going through and I actually wrote you know like, you do not know what it's like to lose your hair or go to sleep at the end of the day not knowing if you're going to wake up the next morning and so don't you dare say you know what I'm going through. I know people do it with the best intentions to give you that bit of reassurance and confidence and come on you know, but I thought, no way, you don't.*

This quotation reveals Nigel's feelings of isolation, his anger, his fear of death and why he decided to write instead of talk to people. There was a perceived absence of support which led to his strong feelings of isolation. This is possibly explicable given two prominent characteristics of our society: individualism and an intense fear about death (Becvar, 2005). Rather than trying to comfort him because of a genuine concern for his well being, Nigel felt that people were actually trying to reassure themselves. Therefore, not only did he feel very alone with his cancer, but also and most profoundly, he felt he was alone with his fear of death which he did not think others could truly understand. This is evident in the piece that he wrote which he gave to me at the end of the interview.

#### ***Stay Positive***

*Good intentioned people tell you to stay positive. Why?  
Positive that I have got cancer and that it has changed my life forever.  
Positive that I could die. Positive about the pain and constant worry.  
Positive about the endless treatment, scans, blood tests and uncertainty.  
Positive about the impact that it has on my family.  
Positive that things are never going to be the same again.  
So don't insult me by telling me to stay positive.  
It might make you feel better, but it does me no favours.*

Nigel explained that he was a great believer in expressing himself and found it helpful to write his thoughts and frustrations. This piece revealed and confirmed the numerous concerns and anxieties which have been explored above. It also demonstrated that Nigel was very aware of his intense feelings while he was going through the experience and thus he felt the need to cope by withdrawing from those around him who he did not believe could understand his experience; instead he found solace by writing. The one other area which did seem to help Nigel cope with his illness was the support he received from his work.

### 9.5.3 Work Support and Masculine Way of Handling Illness

Although on the one hand Nigel withdrew from those around him and tried to cope with his illness on his own, on the other the hand he did mention several times how “brilliant” his work colleagues and boss were. This type of coping response falls within the category discussed in previous cases of “Masculine Way of Handling Illness” in that it allowed for Nigel to admit he needed support but in a way that enabled him to maintain his pre-diagnosis self-concept of a strong capable man. For example he said:

*My boss at the time was actually out of the country on business and he rang me, he was actually in South Africa and he rang me, they managed to get hold of him, and he just said, look just don't worry about it, get yourself sorted out and then we'll be there for you and they were, 100%, actually 100%.*

Nigel was extremely touched that his boss managed to call him all the way from South Africa and he repeated “100%” twice to emphasize how supportive they were. He went on to explain that his colleagues wanted to have a “visitors’ rota” to come see him in hospital. However, he did not want them to come when he might be “chucking up” or losing his hair so he decided he would call them when he was having a good day and ask someone to come down. The willingness of his colleagues to be supportive, flexible and understanding was tremendously important to Nigel. Moreover, he also acknowledged that he was very fortunate because he did not have financial pressure to return to work. His employer continued to pay him full salary for the year he was treated. He recognized how lucky he was that “it was all taken care of” and that he did have tremendous support. His finding and sometimes accepting support from his colleagues seems to have enabled

Nigel to handle his illness in a “masculine” way while still admitting that the cancer experience had been the biggest challenge of his life.

## **9.6 Conclusion**

Nigel was a thoughtful, articulate man who openly discussed both the physical as well as the emotional challenges that he and his family had confronted over the course of his illness. On the one hand, Nigel seemed to rely on primitive defenses such as splitting in order to reassure himself that he had the “good” cancer and the “brilliant” doctors which helped him to cope with his very valid fear of his possible death. Even with the benefit of time, this fear was so real that the defense strategy of splitting was evident in the interview. However, with regards to his sons and wife and how he handled them, Nigel seemed to have recognized that when he was battling his cancer he needed to withdraw from them and yet at the time of the interview he felt guilty about this course of action. This is suggestive of someone who had shifted into a depressive position whereby his losses have been acknowledged and mourning was taking place. While Nigel was a very sensitive and astute man who clearly had reflected a great deal on his experience even prior to the interview, having the chance to explore it at length seemed to have provided him with an opportunity to make some sense of his experience. Moreover, he seemed genuinely pleased to be able to provide suggestions as to how to make things easier for men and their families in the future. Additionally, his struggle of what and how to speak to his boys about his disease confirmed the idea that I had already begun to formulate before this interview that more on-line relevant information targeted at both fathers and sons is needed to help families cope during a very challenging time.

## Chapter 10

### Participant 1011: Brad

#### 10.1 Introduction

Brad was a friendly, engaging 37 year old polish immigrant who had graduated from university in Poland and had come to the United Kingdom with his wife of nine years. He had started his own building company. They had two sons who were two and six at the time that Brad was diagnosed with Stage 2a testicular seminoma. He had undergone an orchidectomy, one dose of carboplatin and a round of radiotherapy. At the time of the interview, there was no evidence of disease. Brad candidly shared his experience which focused primarily on the details of his cancer ordeal and the impact this had on his wife, children and family. Throughout his experience, he seemed determined to preserve his role as the strong father, husband, and son. Even when he discussed the physical changes which he had experienced it was primarily in the context of how he would explain them to his sons. He described himself as a man who liked figures; therefore, he knew that with testicular cancer he did have a good chance of survival; however, he still worried about how it would affect his future. In addition to relying on figures and intellectualization as defenses, he also employed minimizing, humor and viewing his cancer as the “good” one.

When discussing what would have been helpful to him during his experience, he admitted that he would have liked to have had an opportunity to share his experience with other men. Furthermore, he confessed that not only had he not spoken to his children about his illness, he had not even thought about how to do it. After discussing this in the interview he recognized that it was extremely important to tell his sons in an age appropriate manner and was very grateful for having the opportunity to discuss this in detail with me. Throughout his ordeal, Brad was determined to look at the positive: he had the good cancer, strong support from his wife, family and friends and received excellent treatment. His genuine appreciation for all that he had made him a delightful man to interview.

#### 10.2 Psychosocial Concerns

##### 10.2.1 Concerns for Children

Brad’s primary concern was for his children. While he did provide a very detailed account of his medical experience, the one theme that he returned to the most was how his illness

was affecting or might affect his sons. Interestingly, as the interview progressed Brad's perspective on what he thought was effecting his sons and how and what he should tell them shifted. Initially, he discussed how the cancer treatments temporarily impacted on his physical relations with his children and altered his normal role in the family. He then mentioned his concerns about how his sons might notice the physical changes and be teased. Finally, when I mentioned possible future interventions to help families talk to children about cancer, Brad explained that he knew that his sons were at an increased risk of contracting the disease. With these concerns in mind, Brad was very receptive to learning about talking to his children in an age appropriate manner. First, however, I will look at the impact his illness had on his sons.

Brad was a traditional family man. He explained that every Sunday he and his family went to church and then after for tea and pastries at a Polish Café. Although he first suspected that something was wrong on a Saturday, he did not mention it because he did not want to disrupt their Sunday routine. He was a large fit looking man; therefore, it was not surprising when he described how physically active he was with his sons. His first reference to his sons was the following quote:

*So, and when I was at home really he didn't pay too much attention, it's like daddy's at home, he ... know that he cannot jump on me, or I cannot lift him, but honestly people, out of sight, out of mind, I have to ...stop him when he was trying to jump on me as usually. So basically children wasn't really affected.*

At this point it is important to note that English was Brad's second language and while he was extremely capable of communicating, there are some grammatical errors which have not been corrected in transcribing the interview in order to maintain an accurate account of what was said.

From this quotation it is evident that the sons were used to jumping on their Dad. There was a sense of an ongoing rough and tumble relationship with his sons with Brad being in the role of the "sturdy oak". Brad's comments suggest that while he was unable to continue as normal, the boys had not seemed to notice. Lewis and colleagues (1989) in a study on women with breast cancer found that fathers were concerned with the well being of the total household including the school age children. Moreover, they explain that families are dynamic adaptive systems which both maintain a stable and routine arrangement during a

mother's illness as well as adapting to meet the demands of the mother's condition (Lewis *et al.*, 1989). Similarly, this seems to be the case with Brad. He was determined to keep their routine while gently shifting the children away from their normal behavior. He was so concerned about ensuring what was best for them; he sent them on their traditional summer holiday back to Poland without him while he remained in the UK for further treatment, he said:

*So why would I keep children at home? It's nothing happening to me, I'm fully capable to drive or anything like that, and because, why would I keep them? To feel sorry about me? To cheer me up? OK, don't worry, it will be fine, knew that it will be. So they went on holiday without me. And I had more time to make up on the time I was spending in hospital in the afternoons; I wasn't in rush going home because it was empty.*

From this excerpt there is evidence of a man who was not only putting his children first by encouraging them to go on holiday without him, he was also demonstrating that he felt he was capable of caring for himself during his treatment as well as maintaining his role as breadwinner. This behavior is suggestive of someone who was enacting traditional hegemonic ideas which reinforced the cultural beliefs that men are powerful and their bodies are structurally efficient; therefore, they are reluctant to ask for help or care (Courtney, 2000).

While Brad seemed confident in his physical ability to care for himself and recover, he did struggle with how his sons would perceive the fact he only had one testicle. Later he said:

*So the, being embarrassed about your body, about anything, this will come later...on one side I wouldn't like make him really embarrassed, like public, gym and male taking a shower together, on the other hand not to feel too relaxed about that because there are some limits. So I didn't really think, one day he might find out, well, what is the age you can start telling that daddy has only one ball, or something like, or peanut.*

While in the beginning of the interview Brad was confident that he did not need to tell his sons his condition, from this quote it seems evident that he was beginning to question when and how to explain his illness to them. He used humor to lighten the discussion but plainly it was of concern to him. Moreover, he recognized the importance that he needed to set an example for his sons on how to act in public settings. Certainly, the behavior of the father does affect the ongoing development of the child and ultimately how the child interacts with his peers (Lewis *et al.*, 1989). For Brad, he recognized how he informed his son would

be extremely important. He mentioned several more times in the interview that he did not want his sons to hear about him through gossip but he did not want to needlessly worry them by using the word “cancer”.

As the interview progressed and I mentioned possible future interventions of providing families with more information about talking to children, Brad seemed particularly interested. He was keen to maintain his role as the father in charge who provided accurate information when it was appropriate and necessary. He seemed to have been toying with these questions prior to the interview but was not certain how to handle his concerns. He explained:

*I was concentrated on myself, and you're right, that's again what I was reading, my sons are in a highest risk of getting the same like me, they male, they've got a father with testicular cancer, it doesn't have to, it's still low percentage, but much higher than people who are having healthy fathers. So, and you're right, they, it can happen very early, when they are 16 or 17, so being aware, that is important.*

During the course of Brad's illness, he was concentrating on himself; however, with the benefit of having the opportunity to discuss his situation he was able to bring to the forefront an idea which he knew about but had not acted on. In other words, he had read that his sons would be more at risk but had not decided how, when and what to tell them. However, once he had the space to think about and discuss this concern he was keen to act on it. He explained:

*I was thinking later on to tell them... Good thing to say, it's, about this testicle missing, it's, I wouldn't like him to find out at the age when he's, suddenly think about you're like a half man or something. If he finds out early it will be like a growing up with some problem and it will never be a problem if you know about that already. It's like children having fathers with, I don't know, not able to walk or something, they're so used to that.*

The fact that Brad used the expression “half man” does suggest that he was concerned about the change to his physical image (which will be discussed more below). What is relevant here is that by the end of the interview Brad was determined to tell his eldest son about his condition in order to avoid his physical state becoming a “problem”. By taking responsibility for telling his sons, he maintained his role as the strong father figure while minimizing the negative perceptions the boys may develop as well as trying to ensure that his boys would be aware of their own risk of contracting testicular cancer. Moreover, the



importance of a cohesive family environment with open communications is related to improved psychosocial adaptation for the family environment (Cooley & Moriarty, 1997). By the end of the interview it was evident that in Brad's case, he wanted to set an example for his children by openly discussing the difficult topic of his cancer in the hope that as his sons grew up they would be able to discuss sensitive topics with him. This determination to preserve his role in the family is also evident with his wife.

#### 10.2.2 Concerns for Wife and Family

Initially, Brad had hoped to keep his concerns about being diagnosed with cancer until he had the definite details in order to protect his wife and maintain their daily routines. He explained that while he had suspected something was wrong on the Saturday, he did not mention going to the GP or the follow up scan. Unfortunately, his wife heard a message on the answering machine from the hospital. Brad explained:

*So she heard all that information because she was next door and she asked me, what's going on? What hospital? What treatment? What is happening?...I knew how she behaves, I knew how she is, she's worried.*

In this excerpt, Brad repeated her questions thus showing how anxious he thought his wife was. He continued by stating that he "knew" how she would behave thus he wanted to protect her. This enactment of the conventional protector-provider role is in keeping with the research discussed by Sabo and Gordon (1995) on men whose wives had mastectomies. They found that men enacted the traditional conjugal roles during the difficult period of diagnoses, hospitalization and short-range treatment. Similarly, Brad was trying to protect his wife from any unnecessary stress. This protective role continued through his cancer treatment.

Brad explained that his wife was struggling to cope with their sons since he was unable to help as much during his treatment phase. He explained:

*... my mother in law who was really lovely, she even arrived that summer and help us a lot, I mean ... (his wife) needed more help than me because she, she's a housewife, she looks after the children, but she does also photography courses, so she's got a lot of, to do at home as a project while she's full time busy with kids.*

This excerpt demonstrates how cancer can be defined as a family illness because of the enormous emotional and practical impact it has on every family member (Bressi *et al.*,

2005). Brad was clearly concerned about his wife juggling with her normal everyday jobs as well as her increased responsibilities; thus they had brought his mother-in-law over from Poland to assist.

Brad also explained why he did not have similar concerns or support from his own parents. Brad's brother had been diagnosed with Hodgkin's Lymphoma when he was nine years old. At the time, the treatment had been brutal and the whole experience had been extremely stressful for the entire family. Because of this, Brad believed that when he was diagnosed and even during his treatment, his parents were not quite as supportive as they might have been because it did not seem as serious as his brother's condition. Below I will discuss how this may have impacted on why he chose to employ minimizing as a defense; however, what is relevant in this section is that Brad, who normally seemed like a very caring concerned man, did not seem overly worried about telling his parents about his cancer. He definitely seemed primarily concerned with his own wife and children. The other concern which was not as pressing but he did mention and allude to several times during the interview was the challenges to his self-image and physical changes.

### **10.3 Individual Anxieties**

#### **10.3.1 Challenges to Self-image and the Prosthesis**

Above I have discussed that Brad was concerned about the physical changes to his body because he was concerned what his sons would think. This suggests that on some level the orchidectomy had given him cause for concern. However, it was only in the context of discussing it with his sons that he mentioned this topic. It was not until he was specifically asked in the second sub-session whether he had been offered a prosthesis that he mentioned concerns about his physical appearance. His thoughtful and heartfelt reply, although lengthy, eloquently described his views.

*Yeah, they did offer. But they also warn me that artificial part of something put it into my body, might cause some troubles eventually, well some, how they describe it? I'm just looking for a word for it. Infection, yeah, infection or anything. And I was thinking, I'm, you have to be confident with you feeling a man, what is the main part of the men, of the male body? What makes you a man? It's your brain not at all anything else. So by cutting your legs, your testicle or anything, they will not make you a woman or like a, anybody else. It's your brain, this is where you are confident to stay a man, to be an example for your kids, to be your kids' hero, this is where you are. If you are failing doing that it's not a problem of*

*number of testicles you're having, that's one. Second, I'm already married, we already conceive as many children as we wanted so an artificial testes will not help conceiving any more children anyway, plus, well I was thinking a lot, how would I behave if my wife had a breast cancer and had one breast removed? And was thinking, I would never ever try to pretend or behave like, to make her feel less as a woman... she behaves like that as well. So basically I'm not 20 years old bachelor who is having a casual sex every weekend...So I was thinking, if I have to go on another operation because I've got infection because of the stupid artificial part, so I just, I wasn't even thinking one minute for it.*

This response poignantly captured Brad's struggle with what the experience of having a testicle removed meant for him. Unlike the men in the studies done by Moynihan (1987) and Gordon (1995) who denied that their illness had any long-term effect on self-image or their feelings of masculinity, Brad admitted that he had to think about what it meant for him. For him it was an opportunity for reevaluation, redirection and reconstruction of himself (Charmaz, 1995). He described how using his brain and being a hero was what made him a man, not his testicle. Moreover, by challenging himself to question how he would feel if his wife had a mastectomy, he further re-evaluated what was truly important to him. He seemed very confident in his decision that he did not for "one minute" even think about it. However, by having it removed he was confronted with the question what makes someone a "man". Ultimately he, like the men in a study by Gritz and colleagues (1989), felt good about his body image without a cosmetic replacement.

### 10.3.2 Fear of Recurrence and Death

As an engineer with a head for statistics, Brad explained that throughout his diagnoses, treatment and even to the day of the interview he could cope with having testicular cancer. However, every three months when he had to attend his clinic appointments, his fears about what might have been or could happen would still come to the surface. For example he said:

*... I've got the feeling, that's a strange feeling, everything was fine but I, I still know that if I would deny it, if I would ignore it, if I wouldn't go quickly enough I could die, that, and far away from it but knowing that by not doing anything I could actually not survive it, makes me feel how lucky I am.*

From this excerpt it is evident that Brad recognized that if he had not taken action quickly he could have died. Cooper (1982) described "somewhere, in even the most carefree or apparently coping personality, will lurk the fear of imminent death" (Cooper, 1982, p.613).

This seems to be the case with Brad who realized if he had not taken swift action his future would have been very different. However, even having been told by his consultants that he had no evidence of disease he still felt anxious attending his routine hospital appointments. He explained:

*Obviously every three months now, nobody really talks about that, and then when the day comes it's OK, how was it? Fine. And did they tell you anything? ...They won't tell me exactly on the day but probably they would call me the day after if nothing happening. So basically you have to wait two, three days, but the probability of getting that phone is very low.*

From this quotation there is a sense that the fear of recurrence resurfaces every three months. This quote suggests that not only was Brad worried, but his wife was also anxious. Brad's fear of recurrence is in keeping with the study done by Skaali and colleagues (2009) exploring the fear of recurrence in long term testicular cancer of 1336 survivors. Their hypothesis that high levels of fear of recurrence in long-term testicular cancer would be rare was NOT the case. Moreover, they found that higher levels of emotional distress were linked with higher levels of fear (Skaali *et al.*, 2009). Thus while Brad did not seem to be riddled with fear, he certainly continued to be anxious around the time of his clinic appointments.

However, even with Brad's honest admission of his underlying anxiety about the possibility of his death, there was also a sense that Brad felt he could cope with this fear. Brad felt secure in his family. Wives can provide invaluable, intimate support and children can provide a sense of continuity for men as proof of past potency and an ongoing future (Bullen, 2010). The importance of Brad's wife's support may be further explained by applying psychodynamic concepts. Winnicott's concept of holding as described by Hinshelwood (1991) emphasizes that physical holding is a metaphor for psychological holding. This is not only how infants develop trust and feel secure but also this theme of safety continues throughout a person's life (Hollway & Jefferson, 2000). Brad seemed to feel safe in his place within his family. Therefore, even though he did not like to worry his wife, they did discuss his condition at length. By having a significant other with whom he could share his fears together, they were able to "detoxify" these fears and make them bearable. Like Cooper (1982), Brad learned that there was no overcoming a fear based on reality, only the confrontation of it.

## **10.4 Coping Responses and Defense Mechanisms**

### 10.4.1 Support from Family and Friends

When describing his experience, Brad candidly discussed his fears and concerns as well as how he coped with them. While on the one hand he seemed extremely self-contained and resilient, on the other hand he also openly admitted that he relied on his wife, family and friends for support. By looking at these sources of support more closely, there is evidence of not only the practical support that he received but also the more unconscious defenses that were at play.

In particular, I have discussed above how Brad's wife played a major role in "holding" Brad's underlying anxieties about his fear of death. In order to understand Brad's defense mechanisms, it is helpful to explore this relationship a bit more closely. In addition to caring for Brad's practical needs and taking more responsibility for the children during the course of his treatment, his wife also seemed to take on some of his emotional concerns. Applying psychodynamic concepts is helpful to understand how Brad's wife seemed to be expressing his fears. Specifically, Klein (1946) explains the concept of projective identification whereby an individual unconsciously transmits their experience to someone else who then finds themselves having to cope with these feelings and emotions (Moynan & Jureidini, 1994). When Brad described how his wife asked numerous questions such as "How was it?", "Did they tell you anything?" in fact he was expressing his own fears. In a sense Brad had "gotten rid" of these worrying and troubling emotions by evoking these feelings in his wife. This allowed him to project them out; thereby maintaining his own self-concept of being the "sturdy oak" father who was comforted by the positive statistics. Bion's concept of containment, which refers to the capacity to hold on to feelings without getting rid of them, is also helpful in understanding this case (Hollway & Jefferson, 2000). Brad's wife was able to contain his fears until a point when the feelings were detoxified and then Brad and his family were ready to move on. For Brad this was a true sign that he was a "cancer survivor".

Brad was very appreciative not only of his relationships with his wife but also his friends and other family members. He described how his 20 year old brother-in-law had come over

to keep him company, watch boy movies and be his personal assistant while he recovered after surgery. Similarly, he described how his mother-in-law came over to help with the children which also meant he “had the pleasure of typical Polish home cooking”. And finally, he explained that while he didn’t require too much practical support when his wife and children went to Poland for a holiday his friends took him out one night for a “beer festival”. He said:

*..on Monday I was going to hospital here, I was thinking if I will have still alcohol in my blood, but I think I needed some kind of, I would say forgetting night or something. So my, when we got really, no, not really drunk but drink all these things, my friend just look at me and say, I can’t even think behaving in such an easy going way... All my friends were like, oh wow, you get this, oh my, I’m sorry, are you OK?*

In this excerpt, Brad reveals that perhaps he was more worried than he normally admitted because he needed a “forgetting night”. He was appreciative of his friends not only taking him out but also expressing concern and worry for him. Of course, by showing these emotions at a “beer festival”, rather than in a sentimental setting, he was able to accept their concern. This seems typical of Brad to be able to express his feelings but couched in a traditionally macho manner.

#### 10.4.2 Masculine Way of Handling Illness: Minimizing, Intellectualization and Humor

Above I have discussed how the participants have responded in what I have termed the “masculine way of handling illness”. This label refers to particular responses or defenses which have been employed by the participants as a way of preserving their masculine self-concept, which also includes physical appearance, social functioning, self-image and self appraisal/worth (Bullen, 2000). Evidence suggests that several aspects of hegemonic masculinity including physical strength, sexual potency, emotional resilience and the ability to provide for one’s family, all can be challenged when men have penile (and probably testicular) cancer (Bullen, 2000). Therefore these men employ a range of coping responses to help them adjust to their potentially life threatening and certainly life-altering disease. While these defenses are not exclusively employed by men, what makes the term masculine way of handling illness specific to these participants is that the defenses are not used exclusively to cope with the illness on its own, but also to help maintain their self-concept. The most common of these defenses which Brad employed were intellectualization, minimizing and humour.

#### *10.4.2a Minimizing*

When Brad described the effects of all three treatments, he always downplayed the physical and practical impact it had on him. Throughout the interview he repeatedly commented that it was like having the flu or a “three day break”. Even after the initial surgery he explained:

*So I was feeling like on a holiday and nobody was really bothering me because everybody was knowing that I could not really work too much, but I was still mobile, which was good because I didn't have to do anything.*

This quote is typical of how Brad described himself when he was recuperating from one of his treatments. Again there is a sense that Brad's coping was in part influenced by his unconscious perceptions of idealized masculinity whereby he was “getting on with it” as a way of maintaining his image as the strong, masculine “coper” (Bullen, 2000). He explained that the chemotherapy did not affect him too much. Similarly, when he talked about his experience of having radiotherapy, he focused on how nice all the medical staff and the other patients were. Throughout the interview, Brad maintained the stance that during the treatment and even with hindsight the side effects were “not that bad”.

#### *10.4.2b Intellectualization*

Brad was a man that relied on facts and figures to help him cope with his situation. He explained that he was an engineer and his education was technical so “numbers and figures, that tells me a lot.” He relied on positive statistics and Lance Armstrong's experience to reassure himself that he had a positive prognosis and did not need to worry. Similarly, when he returned to work after his chemotherapy and found himself short of breath walking upstairs, he concluded this was normal because the chemotherapy had killed the haemoglobin which transfers the oxygen; therefore, he should not be surprised that he was a bit more tired.

Although when describing his experience Brad's dependency on the facts and figures helped, interestingly when reflecting back on this time, he became emotional. He explained:

*My wife, well she went up to hospital with a heart problem, she was feeling some pain, she was so worried. Maybe I'm getting more nervous at the moment than, having that interview, than I was at the time. I was sleeping through all night easily; I didn't have any problems in sleeping. I was waking up and I, I've seen my wife's eyes, she didn't sleep at all. She was more worried and she ended up with some tablets which were making the, her not nervous or something. Not me, I didn't need that, I'm just more nervous talking about, now about this, and quite shaky, probably my hand is shaking or something. I'm not sure what it is happening, suddenly started. But at that time I wasn't that worried, I was just focused on these numbers, about probability, about that, OK, it's like, it was a little bit like a plane journey, you know that you cannot control it, you are above, you can fall and nobody will survive but in, statistically it's the safest way, statistically you are more likely to be killed while you're driving to the airport than actually on the plane. So I just took those numbers.*

This lengthy quote reveals a great deal about Brad and his wife. Again there is evidence that Brad was projecting his concerns into his wife who was having trouble sleeping while he remained focused on the figures and was sleeping well. What is particularly illuminating and also provides evidence that his coping responses were a short-term defense mechanism, was the fact that at the time of the interview he found himself feeling more nervous and his hands were shaking. He was surprised to find himself responding this way. However, what appears to be transpiring reflects one of the fundamental principals of the IPA analysis which is that human beings are sense-making creatures and therefore when participants are providing their accounts they are reflecting and trying to make sense of their experience (Smith *et al.*, 2009). Brad no longer had to keep his emotions in check in order to cope with his experience and therefore he was able to reveal that in fact he had been anxious and worried.

Utilizing psychodynamic concepts to describe this process one could speculate that at the time when Brad was confronted with the most primitive fear, the fear of death, he resorted to paranoid-schizoid defense mechanisms particularly splitting and projecting thereby riding himself of his true anxieties in order to cope. However, once the true threat had subsided he was able to view this danger from a more depressive position mode of functioning where he was able to express and hold onto his own feelings of fear and loss rather than project them outwards. He was able to begin the process of mourning partly because of the tremendous support he had received from his wife, the comfort he had from



his sons and his ability to redefine what made him a man. Moreover, he seemed capable of doing being the patient with a smile on his face and a chuckle.

#### *10.4.2c Humor*

In reviewing the transcript, it is difficult to find specific quotes that demonstrate the extent to which Brad seemed to employ humor as a way of coping with his disease. For example, given that English was not his first language, one might question whether his reference to his testicle as a “peanut” several times during the interview was a mistranslation or actually a way of lightening what might otherwise have been an awkward discussion. During the course of the interview, I found myself smiling and laughing which suggests that these were not language difficulties but rather a definite attempt at using humor as a way of coping.

One example of when Brad’s humor shone through was when he was describing how he felt after having his orchidectomy. He explained that he was not really worried because he was now “unique with one peanut...I have to stay popular among one girl only, I’m married.” Brad was describing what otherwise might be a very sensitive subject. For men, humor can play an important role in men’s social interactions and provides a strategy for self-disclosure (Thorson *et al.*, 1997). This is shown in this quote whereby Brad was able to reveal that he was aware of his changing body image but was comfortable with the change.

Brad also described how he used humor when he was a patient receiving chemotherapy treatment. He explained that when he was having chemotherapy he was “smiling and chatting with his wife and the rest of the other patients who had a good humor.” Again because English is his second language I am not sure if Brad meant that the men were in “good humor” meaning they were in good spirits; or they were sharing jokes so they had good “senses of humor”. However, either way, it is evident that while Brad was having chemotherapy treatment he was not suffering too much physically or emotionally and in fact was himself “in good humor”. Brad seemed to benefit from the use of humor as a coping mechanism both during his cancer experience as well as at the time of the interview.

It enabled him to reveal personal emotions, facilitated communication and provided him with a socially sanctioned vehicle to address normally off-limit topics (Oliffe *et al.*, 2009).

#### 10.4.3 Good Cancer Bad Disease

Brad mentioned several times how difficult he found it seeing some of the other patients. He stated:

*So basically I can be, I would say proud of myself that I really went through that, honestly, and I'm sometimes feeling like a, like a big C survivor, but honestly, by going to that hospital and seeing other people, children, with no hairs, with much, much heavier treatment, I was feeling really lucky that I was having only that and didn't really affect, part of my body was removed which I don't need any more... And not everybody that's lucky I'm afraid, what I could see here (the hospital), and seeing those other people make me think you are lucky and you cannot feel sorry for yourself because you wouldn't be fair for all those people around because... I haven't seen anybody crying in that hospital.*

This quotation shows how fortunate Brad felt he was both at the time of his treatment and at the time of the interview. He described in detail the type of people and how they were suffering and in comparison to himself. He was trying to rationalize that the organ he lost was not something he “need any more”. And thus rather than pine over his loss, he felt that he should consider himself lucky. Again it is helpful to apply psychoanalytic concepts to add depth to our understanding of Brad’s defenses. Klein discussed that individuals often split objects into ones with unrealistically good and unrealistically bad characteristics which is the basis for the paranoid-schizoid position (Hinshelwood, 1991). This position is what individuals may resort to in the face of threatening occurrences because it permits them to believe in a good object which can be relied on and a “bad” object which can be split off and located elsewhere (Hollway & Jefferson, 2000). For Brad, at a time when he felt extremely threatened, by categorizing his type of cancer as a “good” object whereas the other types were “bad” ones, he was able to cope with his illness. This enabled him to not only deal with his condition but also reminded him how “lucky” he was. This is evident again in a later quotation:

*They surviving, they fighting for it, they looking mess but they smiling, they saying hello to you when you pass in the corridor, and it's not fair. It's not fair to behave like that. And maybe those times when I was coming here, it wasn't like I was glad that, oh they've got much worse type of the cancer so I'm, I will survive or anything, the spirit they were having, that was something for me to not even think about getting worried.*

Brad felt that if the other patients could continue to smile when they may not survive that he should “not even think about getting worried”. Clearly, he did worry; however, the point is that by splitting his cancer into the “good” one, he was able to maintain a fighting spirit and also appreciate that he was in fact a “big C survivor”. This is reminiscent of Gordon’s study (1995) that found that the men employed strategies to cope with the challenges testicular cancer posed to their masculine identities. For some men surviving the cancer ordeal provided an opportunity to test themselves and demonstrate an ability to “put up a good fight”.

### **10.5 Conclusion**

Brad was an extremely articulate, caring father and husband. What was evident throughout the interview was that his primary concerns were for the well being of his wife and children. He did worry about his future and struggled with the primitive underlying anxiety of his possible death but was able to cope with this by defenses such as splitting and projection. By having a supportive and containing wife, he was able to preserve his self-concept of being the strong father and husband. However, being diagnosed and treated for cancer had also forced him to re-evaluate his own self-concept and what it meant to be a man. He recognized that he had to redefine what this meant for him; ultimately by contemplating what was truly important to him such as honest relationships with his sons and a loving relationship with his wife. Brad was particularly grateful for having the opportunity to discuss his experience at length and did seem to benefit from having a safe place to reflect on all that had happened and make sense of it. In the end, he seemed proud that he was a “big C survivor”.

## **Chapter 11: Cross Case Analysis**

### **11.1 Introduction**

This study was undertaken as an attempt to develop an understanding of the lived experience of men who are fathers with cancer. In addition to exploring the experience of each participant, this study also endeavors to understand both the commonality of the experiences as well as the differences. The cases above have been examined in the complex way in which the participants' experience is both social and psychological or "psychosocial" (Hollway & Jefferson, 2000, p. 138) I will present the procedure for developing the common themes and assertions, explain the rationale for this procedure and why it was vital in ensuring, as much as possible within a qualitative study, the validity and reliability of the study, explain the need for triangulation, discuss the emergent themes and finally conclude with assertions based on these themes.

### **11.2. Procedure**

In order to ensure that the cross case analysis is not simply a listing of the case findings, it is essential to keep the participants' contextual meaning while still trying to ensure a systematic and comprehensive exploration of the phenomenon. Therefore, I have chosen to broadly follow the cross case analysis procedure developed by Robert Stake (2006). Stake suggests reviewing each case by looking for the prominence of evidence to develop themes, then rating the utility of each case to support the identified themes and finally developing some assertions. He presents a very specific technical procedure whereby the analyst reviews each case looking at the evidence which he calls "findings" to support the themes which have emerged.

In this study, I have defined the "findings" as specific actions, behaviors or expressions of thoughts or feelings which the participant revealed during the course of the interview. These findings, according to Stake's procedure, will then support the development of a theme. For example, when a participant mentioned that he went online numerous times for information about what to tell his children but was not satisfied with what he found, the finding would be articulating concerns while the themes would be a lack of information and concern for children. In this manner, I have gone through each case study several times to

identify the findings as evidence to support the themes. I then rated how prominent the findings were in each case on a scale of 0 to 3. If a finding was rated 0 then it was not evident at all in the case where as if it was rated 3 it was a dominant action, behavior or topic for the participant. Next I selected between three and six findings which seemed to contribute the most to understanding the theme and identified which cases had ample findings and were thus most useful in supporting this theme. (These findings and themes will be discussed in detail below.)

Although this is not a quantitative study, in order to develop a general sense of which themes were most important to most men, I have developed a Finding Chart based on this set of numbers. (Appendices 8 and 9: Worksheet 1A and Worksheet 1B). These figures are “guestimates” and are based on how prominent a finding was in each participant’s interviews. After assigning a number to each finding, I then totaled all the findings’ numbers for each theme for each participant. This number (which is in bold type) represents how much evidence there was in an interview about a particular theme. These numbers were helpful in determining which themes were the most prevalent for each individual as well as which cases had the most evidence to support each theme. I also utilized these figures to determine which cases would be included in the dissertation. These findings and themes, combined with the quotes and analysis of the interviews, were utilized to develop an understanding of the experience of being a father with cancer. In other words, assertions were developed which in Stake’s words are the “heart” of the final report (Stake, 2006, p.72).

Put succinctly, I have utilized Stake’s suggested procedure to:

1. Insure there is enough evidence or “findings” to support a theme for each participant,
2. Establish which participant’s account had the most evidence to demonstrate a theme,
3. Prioritize which themes were most prominent for all the men.

While I have used numbers and calculations to tabulate these figures and worksheets, for the most part, I will not refer to these numbers in this discussion. Instead, the numbers were tools to ensure that the themes were founded on evidence and not “hunches”.

### **11.3. Validity, Reliability and Triangulation**

In the Methodology Section the importance of validity, reliability and scientific attitude in a qualitative research study as a whole was discussed. The purpose of engaging in Stake's complex and time consuming procedural process of identifying findings to support the themes was to ensure the validity and reliability of the development of the themes in order to ultimately draw assertions for a comprehensive cross case analysis. By "labeling" the findings in this study, I hoped to ensure that readers would willingly accept the identified recurrent similarities and differences and thus the themes and assertions would withstand critical challenges.

Similarly, Stake in developing this procedure was aware that the analyst may have certain "hunches" but the conclusions must be based on evidence because these assertions need to survive critical challenges (Stake, 2006, p.78). He argues that one form of validation, triangulation, can be vital in ensuring a picture that is as suitably meaningful which is relatively free of biases, oversimplification and being over interpreted. For Stake (2006), triangulation is a key process of ensuring that each finding has more evidence than a single correlation or a quotation, checking that the views are consistent with outside sources and engaging in discussions with colleagues.

Applying the concept of triangulation to the participant chapters discussed above, the emergent themes were linked to current research studies. The individual cases were also discussed with colleagues and supervisors as part of the ongoing triangulation process. Thus I have met some of the criteria for triangulation within the case studies themselves. Therefore, for the purpose of this chapter the essential ingredient was to ensure that the themes were not based on one comment or action. Therefore, by following Stake's technical procedures, I was able to ensure that each theme was based on several findings across cases and thus provided a valid explanation of describing what the participants were experiencing. Stake acknowledges that no observation or interpretation is perfectly repeatable; however, triangulation combined with this procedure should clarify how the themes were identified to ensure a meaningful and valid picture of the phenomenon.

I will now present the most prominent themes found in all the cases (See also Table 11.1). As above the themes have been divided into the three main categories: psychosocial concerns, individual anxieties and coping responses and defense mechanisms. Although I am only presenting five case studies in the dissertation, examples of the dominant themes and excerpts from all ten participants will be discussed in this section; therefore, Appendix 1 includes all the Participants Pro Forma sheets which succinctly provides additional relevant information about the men.

Table 11.1 Prominent Themes

<b>Psychosocial Concerns</b>
Concerns for Children
Concerns for Wife and Family
Lack of Information
Work Concerns
<b>Individual Anxieties</b>
Challenges to Self-image and Masculinity
Challenges to Self-concept, Role Changes and Masculinity
Fear of Recurrence and Late Diagnosis
Fear of Death and Annihilation
<b>Coping Strategies and Defense Mechanisms</b>
Relying on Wife and Family for Support
Masculine Way of Handling Illness: Minimizing, Intellectualization, Maintaining a Stoic Façade, Idealization and Humor
Good Cancer Bad Disease (Splitting)

#### **11.4. Psychosocial Concerns**

##### 11.4.1 Concerns for Children

Interestingly given that the participants were invited to participate in a study about being fathers with cancer, while all of the men did talk about their children, it was not the dominating theme. When reviewing the findings (specific actions, behaviors or expressions of thoughts or feelings) and referring to the Findings Worksheets, the totals suggest that the men clearly had worried about their children but it was not their primary concern.

In this section, I will identify each of the findings which support the emergence of the theme “Concern for Children” and discuss how the findings manifested themselves with particular emphasis on keeping the evidence linked to the case details. The main ways that the participants demonstrated concern for their children were exhibited in the following behaviors, actions or communications:

1. Articulating concerns,
2. Engaging in protective behavior,
3. Engaging in special father/child activities,
4. Returning to topic.

All of the fathers did articulate concerns about their children. This took different forms depending on the sex, age and personality of the children. What was particularly noticeable was that most fathers admitted struggling with how, what and when to tell their children. For fathers with younger children they were concerned about unduly frightening them, how to explain physical changes and for their own peace of mind ensuring that they “did not leave any unfinished business” in the unlikely event that their disease progressed. Several of the fathers had not informed their children because they thought the children were too young but suspected at some point it would be important to tell them; they wondered when it would be appropriate and wished they had the opportunity to speak to either professionals or parents in similar situations. For example Don who had two young daughters said:

*...I think I will tell them in later years but I think it would be useful to find out what you do tell to a child that age and then making a decision... I think as a couple my wife and I would like to find out what people think about telling children this age.*

For fathers with older children, particularly boys, the men articulated their struggle to tell their sons and encouraged them to check themselves. Simon, a father with three sons, told his boys “You can’t not do it...I do remind him, not excessively but the odd reminder”. Additionally, the men worried that their teenage boys were “alone with the illness”. Particularly at a developmental stage when teenagers are breaking away from family ties, the fathers wrestled with how to be supportive of their sons while recognizing their movement towards independence. Chris with two adolescent sons said of his eldest son:

*I think he spoke to some of his friends about it actually but I’m not sure but I’ve always hoped, I mean you have to let him make his own choices in the matter and*



*sometimes they talk about things they don't want to talk about and other times they don't talk about things you think they should talk about. . .*

In addition to articulating concerns, all the fathers described in fairly great detail actions which were suggestive of engaging in protective behavior. Many men went to great lengths to hide the physical symptoms from their children whether it meant coming home the same day after an orchidectomy or not letting the children visit them in hospital. Additionally, they did not want to “frighten” their children so avoided crying in front of them or using of the word “cancer”. Two of the fathers even encouraged their wives and children to go on holiday without them. Brad with two young sons said:

*So why would I keep children at home?... To feel sorry about me? To cheer me up?... So they went on holiday without me.*

Yet if the fathers missed holidays or avoided normal activities such as playing football, several of the men did engage in special father-child activities such as outings to theme parks or bought them special computer games they could play together. For some, they realized that while they could not continue in their “normal” role of father, they could still participate in their children’s lives in other ways.

In addition to the behaviors and concerns the participants presented, what is particularly illuminating is not the details but how often the fathers returned to the topic of their children. Because this was an “open question” interview, the participants were able to present the topics of their choice as often as they liked. All except one of the fathers returned to the topic of their children numerous times. Particularly, they seemed to return to the topic of what they had told their children and what they should tell them. They seemed to find it extremely challenging talking to their children especially when the cancer had recurred. For example, Nigel who also had three sons said:

*So, as I say, different messages for different age ranges but then there's obviously when it came back the second time much, much more difficult because you go up, you start or you think you've got over it and everything's going to be fine and then all of a sudden you get this complete bolt out the blue kind of thing and then just*

*saying, and then that was really difficult. Well are you going to be all right, are you going to die? I don't know.*

Clearly the fathers exhibited behaviors, verbalized concerns and engaged in activities which suggested that during their cancer experience they struggled with how best to handle their children. While they may not have devoted as much time to discussing these concerns compared to other concerns, what they did share was poignant and heartfelt. Clearly for these men having cancer had an impact on the whole family.

#### 11.4.2 Concerns for Wife and Family

The participants voiced concerns and exhibited similar behaviors and reactions in relations to their wives and immediate families as they did with their children. These findings include articulating concerns, engaging in protective behavior, and returning to the topic. Additionally, some men acknowledged the need to enlist additional support for their wives. While the men's concerns relating to their wives tended to revolve around "being useless" or a "burden", their concerns relating to their families were quite varied.

With regards to articulating concerns about their wives, several of the men admitted that they relied on their wives to find the information on the internet and take on more responsibility regarding caring for the children. Moreover, they also felt "guilty" because while they were getting the attention of friends, family and medical staff, their wives seemed to be left to cope on their own. Nigel who had three sons and had battled with a life threatening recurrence explained:

*The person I felt really sorry for was my wife because she has no parents to turn to... who was looking after her? And she had so much to contend with, she had the kids, she had me, she's trying to run the home ..in the end we did say, something's got to give here ... I said, you cannot fall over as well so but she found it really, really tough, really tough.*

This quotation is typical of how many of the participants felt their wives had so much to contend with. Moreover, several of the men admitted that while they were able to concentrate on the statistics and focus on "getting better", their wives were carrying the emotional burden for the entire family.

Interestingly, while most of the men discussed telling their own parents, it was not always in a positive light. In some cases the men described an unhelpful or negative response from their parents. Some of the men had lost a parent or step-parent to cancer thus making it more difficult for the remaining parent to be a support. Chris who had lost a stepfather to cancer summed it up by saying “For her (his mother) the word cancer tends to mean death. It doesn’t have any other connotations.” Because of this attitude many of the men were reluctant to tell their parents. In many of the cases where the men didn’t tell their own parent or kept the discussion to a minimum, it meant relying more on their wife. Because the men were very cognizant of the increasing dependency on their wives, several of them agreed to enlist additional support.

Over half of the participants made reference to enlisting some additional assistance for their wives. In every case mentioned this took the form of asking either the participants’ parents or the wives’ parents to help in both child care and emotional support for the wife. The participants that did seek support of grandparents acknowledged that they were extremely grateful and in some cases even felt “guilty” that they had to turn to the older generation. For example, Sal said that

*... I feel incredibly guilty having cancer because I put an elderly couple through something that someone of mid thirties shouldn’t have to put them through. It should be the other way round, they should be the ones that are ill and I’m the worrier.*

This quotation revealed not only Sal’s need for his parents’ assistance but also his desire to want to protect his parents as well. This engaging in protective behavior was another common finding regarding how the men treated their parents. Several of the men wanted to protect their parents particularly if there was already a history of cancer in the family; thus the men would avoid speaking to their parents about their disease.

While each of the men had a unique situation regarding his parents’ reaction, they all, except one, did mention their parents and usually more than once during the interview. Similarly, all of the men discussed how their disease impacted on their wives and in many cases this took the form of relying on their wives to help them obtain information about their disease.

### 11.4.3 Lack of Information

All of the men, except one, mentioned that they had not received adequate information regarding their disease, the treatments and/or how to talk to their children. Although the specific details about what information they wanted varied, nine of the men did introduce the topic of lack of information. (Interestingly, the only man who did not discuss the topic was the one who had fairly extensive disease at the point of diagnosis. He was given a great deal of information about all three types of treatment. Additionally, he was the only one given a leaflet about talking to his children when he was diagnosed which he had found extremely helpful.) This section will focus on the experience of the other nine participants who exhibited their frustration with the lack of information by the following findings:

1. Articulating concerns,
2. Articulating frustration with the medical team,
3. Describing a need to “surf the net” in order to obtain information,
4. Describing feelings of isolation,
5. Returning to the topic.

I will examine each of the findings in more detail as well as discuss the main topics which the men felt they needed more information about.

Because the research question asked the men to tell about their experience from the point that they suspected something was wrong, most of the men began with their own suspicions and then their first visit to the GP. In a few of the cases, this initial visit did not lead to an adequate response or diagnosis; thus their concerns for adequate information started at the very beginning of their experience. For example, George explained his frustration when he said:

*...it was the very first visit to the GP and he was kind of like it's really nothing, really nothing... And he said you can go for tests at the hospital. I can put you, your name down and they will send you a letter. If you want me to, if you really want me to do that. And I went OK then, I wouldn't mind because I am not getting any other information from you.*

Immediately, it is evident that George was frustrated with the information he was receiving. Similarly, Don explained that directly prior to his surgery he:

*... saw the surgeon, registrar, I'm not sure and they described the operation really, really quickly. And again you've got to try and get all your questions in as fast as*

*you can before you forget and also ask questions based upon what they're saying which is just hard.*

This quotation is an example of Don articulating his concerns about the lack of information as well as his frustration with the hospital team. This lack of information from the hospital team became particularly frustrating and alarming for the men when they were experiencing side effects from treatments which they had not been warned about. George seemed to sum up the frustration for all nine participants with the lack of information when he explained:

*There is a certain lack of information about testicular cancer that relative to all the other types of cancers, it is quite straightforward and fairly, he ho and humdrum. They just get you in and out really but for me I think it was a lot more work than I thought it was going to be because they paint the picture that you'll be fine.*

With the common theme of not receiving adequate information, perhaps because as George suggested testicular cancer is a fairly “straightforward” disease with an excellent prognosis, it is not surprising that eight of the participants described “surfing the net for information”. The men discussed which topics they wanted more information about, their frustrations with the internet and how this information could be improved. The main topics the men wanted more information about were:

1. Detailed information about the disease at the time of diagnosis,
2. Possible progression of disease,
3. Post-operative information and side effects from treatments,
4. How and what to tell their children,
5. Information about a prosthesis,
6. Reliability of information on the internet.

Many of the participants described how they, and often times their wives, went online looking for more details about their disease and the possible course it might take. Moreover, many of the men after treatment were more uncomfortable than they had been led to believe they would be; therefore, they wanted confirmation that what they were experiencing was “normal”.

Several of the men explained that they had gone online to find additional information about what to tell their children but felt frustrated and concerned that the information they found was inadequate or inaccurate. For example, Matt and his wife who had three sons wanted information about genetic links and were frustrated because they couldn't find the facts

they wanted. Similarly, Simon who also had three sons discussed how they were annoyed with both the lack of information from both the medical team and the internet about what and how to tell their children. He said:

*...I like the internet, I think it is great, but I think there's certain things that you just let the professionals deal with, because I think there could be some false ... there's a lot of crap out there that you don't really want to pay attention to... more from the kid's side probably, because it was a bit more, I suppose a bit of a shock tactic, because some of them (the websites) are quite graphic.*

This quotation is an example of a man who was looking for information that he would have preferred to receive from a “professional” or at least on a website that was “endorsed” by the hospital (which currently does not have information about talking to children when a parent has cancer). Other men admitted that they had not even thought about looking for information about how to tell their children online and yet acknowledged that if they had seen something on a website they would have read it.

Similarly, several of the men admitted feeling very alone with their disease particularly around the question of whether to have a prosthesis. They explained that they had not received enough information on the topic and in several cases were reluctant to discuss it at length with their doctors. While some looked on line for practical information, several wondered about other men's responses. For example, Jack candidly admitted that he wondered how other men felt about it and was not sure what he should do.

While the men varied on what topics they would have liked more information about (except for more information about speaking to children which may have been biased based on the topic of the study), all of the men, except the one, mentioned needing more accurate and reliable information at several times during their interview. While some of them admitted they would have liked this information from the medical team, others acknowledged that if they were confident in the source they would have been satisfied to find it online. Some of their suggestions for improving the websites included having more information on the hospital websites particularly around the side effects of treatment, details about how and what to tell their children, responses (including thoughts and feelings) from other men in order to help feelings of isolation and normalization and finally the pros and cons of having

a prosthesis. Clearly, there is room for improvement on providing fathers with testicular cancer the information they need.

#### 11.4.4 Work Concerns

The men had a variety of professions from animators to financial investors to computer consultants (See Table 11.2: Employment Chart.) Yet even with the variety of jobs, for the most part, the participants felt that their work environments had been very supportive. However, several men still had concerns about how having the disease may impact on them professionally. There was only one participant for whom work concerns was one of the dominating themes. Two men, on the other hand, barely even mentioned the topic other than to identify their occupation. For those who did discuss work, the findings included:

1. Articulating concerns and providing examples,
2. Maintaining a stoic façade,
3. Returning to topic.

The majority of the participants began by describing how supportive their work had been. For example, George's company sent him a parcel of gifts to cheer him up during his chemotherapy. However, the men also revealed that they were concerned they might be less employable in the future, that they might appear weaker because they missed so much time and, particularly for those who were self-employed, they struggled to get back to work as fast as possible to ensure they would not lose their contracts and income.

Several participants emphasized going back to work as quickly and competently as possible. Sal in particular wanted to maintain his work façade and said:

*I thought, if I come back part time that's still showing signs of weakness. I thought, no I'm going to come back full time and show them I can do it.*

While Sal was particularly concerned with holding up his appearances, most of the other participants similarly mentioned that they returned to work as soon as they possibly could and all of them were working at the time of the interview.

Table 11.2: Employment Chart

	Number	%
<b>Profession</b>		
Project Manager for Building Company	2	20
Accountant/ Finance Director	2	20
IT Consultant/ Computer analyst	2	20
Animator	1	10
Psychologist	1	10
Marketing Manager	1	10
Civil Servant	1	10

Above I have discussed at length the major concerns the participants presented which fall within the realm of the “psychosocial”. I will now shift and explore the more individual anxieties and fears.

## 11.5. Individual Anxieties

### 11.5.1 Challenges to Self-concept and Masculinity

Not one participant ever specifically stated that he felt that his “self-concept or masculinity had been challenged”; however, there was evidence in all of the participants’ interviews that this was a recurring theme. By exploring their actions, behaviors and articulated concerns, or the “findings”, there are examples of how the men struggled with their self-concept and masculinity. In the individual case studies and Literature Review chapter, I have discussed at length the concept of masculinity as well as defined the term “self-concept”. However, in order to provide a platform to build this theme, it is helpful to briefly summarize these two terms again. The term hegemonic masculinity refers to the stereotype of a masculine male with characteristics such as strength, resilience, independence, power, and man as the “sturdy oak” (Bullen *et al.*, 2010, p. 935).

For many men their sense of masculinity is closely linked to their self-concept which can be defined as:

*self-concept is a cognitive or descriptive component of one's self (for example, "I am a fast runner"), which is made up of one's self-schemas, and interacts with self-esteem, self-knowledge, and the social self to form the self as whole. It includes the past, present, and future selves (Myers, 2010).*



From the findings it appears that most of the participants were struggling to adjust from the past self-concept to the present one which included being a cancer patient and all that entailed. Sabo and Gordon (1995) suggest that men living with physical disabilities and illness are situated on the margins of society. They propose that in a society where physical strength and ability are key components of hegemonic masculinity men with disabilities will struggle to construct a workable masculine identity or self concept (Sabo & Gordon, 1995, p. 12). Moreover, they may avoid articulating their concerns about their masculinity. For example, when asked specifically if having testicular cancer had affected their masculinity, the participants in Moynihan's study were all unanimous in their denial (Moynihan, 1998, p. 107). However, by reviewing not only what the participants said but also their actions, behaviors and strong emotions, one can speculate that in fact having testicular cancer had affected both the participant's self-concept and sense of masculinity. Specifically, the men revealed their struggles in the form of:

1. Articulating concerns, providing examples and revealing strong emotions,
2. Emphasizing current roles,
3. Maintaining a stoic facade,
4. Returning to topic.

As mentioned above, many of the men found the treatment much more debilitating than they anticipated. Thus when they were discussing the impact it had on them it was often in relation to not returning to work or to physical activities as quickly as they had expected. In describing these particular incidents where their "past" self would have been capable of these activities often the men would reveal quite strong emotions. Facing a chronic illness can alter the self-concept and lead men to reformulate their male identity and relationships (Charmaz, 1995). This struggle to reshape their self concept is evident in several of the examples the participants provided. For example, when George was describing how he expected to return to work in a few days after his chemotherapy but then found he was too ill he called his colleague to say he would need an extra week, he then explained that ALL his colleagues went out at lunch and bought him a small gift which they sent over to cheer him up. When describing this incident it was the only point in the interview when George was moved to tears. He went on to say that he had been quite "blasé" about his illness but that clearly his work had taken it all very seriously. This is perhaps an example of

projection whereby George was projecting his concerns onto his colleagues in order to rid himself of the fears and appear strong and “blasé” to his work colleagues.

Similarly, Matt, Sal and Nigel all discussed how important their work was to them and emphasized how many hours they worked and how frustrating they found it when they had to cut down due to the side effects of treatment. Some men equate their masculinity with work success making it hard to accept becoming ill and to express their fears and needs (Moynihan, 1998). Thus it is not surprising that these participants tried to hide the extent of the physical impact of their illness and were unwavering in their desire to return to work as quickly as possible. Nigel summed it up by saying that he was “determined to get back to prove to myself, I think, what I could do”. Clearly, the men wanted to maintain the past concept of themselves as successful working men.

In addition to emphasizing their role as professional men and bread winners, many of the participants also struggled with their temporary change in their role as the reliable, rough and tumble dads. Nigel candidly admitted that when he was in treatment he could not be the father he wanted to be and felt he was emotionally unavailable to his sons. Similarly, George, Simon and Don all admitted that they had struggled when they were no longer able to pick up and rough house with their children. This suggests that they missed the past self who was capable of these activities.. Charmaz, (1995) in her study of gender and male identity, explains that one of the processes men facing chronic illness is the need to preserve the self in order to maintain coherence while experiencing loss and change (Charmaz, p. 260). Clearly, the participants in this study were trying to maintain their roles. The men described feeling relieved when they were physically capable of returning to engaging in activities such as playing football and lifting their children.

In addition to returning to work and rough and tumble play as quickly as possible, many of the participants engaged in protective behavior in order to hide from their wives and children how ill they felt during the treatment phase. In other words, even when they were feeling physically exhausted they tried to maintain a stoic facade for the sake of their family. This maintaining a stoic facade was one of the participants’ main coping responses; therefore, it will be explored in detail below. However, what is relevant here is that most of the men did provide multiple examples of how they struggled with the desire to return to

work, to play with their children or to avoid being a burden to their wives. Essentially, what they were describing were their own struggles to cope with their changing self-concepts which had previously included work and physical activities as components of their masculinity but were being temporarily challenged by their disease and its side effects (Sabo & Gordon, 1995). While the side-effects of the treatment were temporary, the loss of a testicle, was permanent and thus may have presented a challenge to their self-image, which will be discussed now.

#### 11.5.2 Challenges to Self-image

None of the men directly stated that having testicular cancer was a “challenge to their self-image”; however, as is the case with the challenges to self-concept, there is enough evidence to suggest that each participant did struggle with their self-image and hence another component of their masculinity. Furthermore, even if the participants had been directly asked about their feelings regarding their masculinity and self-image, men often want to present themselves as highly masculine and thus often underreport symptoms and emotional consequences. Instead what they report is based on the stereotypical myths of masculinity (Moynihan, 1998). As mentioned above, for the purpose of this study, I have defined the term “self-image” to mean a person’s mental model of his physical being. How a man views himself physically and his feelings about the effect of surgery on his masculinity may be a key factor in understanding why a patient chose to have a prosthesis and how he perceives his body (Chapple & McPherson, 2004, p. 655). The findings which support the theme of challenges to self-image include:

1. Articulating concerns and revealing strong emotions,
2. Emphasizing physical activities,
3. Providing examples and projections,
4. Discussing prosthesis,
5. Returning to topic.

Again it is important to remember that the men were not specifically asked to discuss how this disease had impacted on them physically so it is interesting to note their willingness to articulate their concerns as well as reveal strong emotions. (It should be mentioned here that none of the men mentioned the impact of their disease or the treatments had on their sex life. Nor did they even allude to it; therefore, it will not be considered in this study.)

With regards to the physical challenges the treatments had on the men, they were forthcoming in articulating their concerns and revealing strong emotions. For example, George, who was in the process of adopting a second son, admitted that after having all three types of treatment he felt:

*oh I feel a bit more vulnerable now, it's the first time I've been ill in any way, I feel tired, I feel older, I don't feel capable of looking after a two year old again... I just don't feel up to it anymore, but as soon as you start feeling better again you go, oh I think I can...*

There is evidence from this quotation of a man whose self-image had been altered by the physical consequences of the treatments. Traditionally, men are expected to be tough, ready for adventure and good at sport; therefore it is not surprising that George seemed saddened and less confident in his abilities (Chapple and McPherson, 2004, p. 655).

Similarly, Nigel who had also been through all three types of treatments poignantly described how he looked when he attended an award ceremony at his work. He explained:

*what was funny there was clearly my appearance because I went down to about 8½ stone and I was determined though to get into a suit that day so I had a suit on and my appearance clearly struck a lot of people and the, it was, as it was going through the afternoon I suddenly realized people think this is the last time they're going to see me.*

This quotation reveals a man who was “determined” to present a professional façade and yet he realized during the course of the ceremony that he physically looked very weak and was “on death’s door”. Both of these quotes suggest that the cancer and its treatments take not only a physical toll on the men but also an emotional one.

In some cases the men tried to emphasize how quickly they were able to return to their pre-cancer treatment physical activities. Bob explained that he was fencing within two weeks of his surgery. Jack on the other hand, had been determined to stay as fit as he could even during his treatments. After both the surgery and chemotherapy he was still riding his bike the six miles to work. This determination to maintain his level of physical fitness suggests a man who had an unwavering desire to preserve his self-image. Similarly, in a study by McCaughan and colleagues (2012) on the coping behavior of men and women after chemotherapy, they found that men engaged in practices that aligned them with their gender identity and views of masculinity. For example, the participants minimized the

significance of the side effects or said they had no problems (McCaughan *et al.*, 2012, p. 69). This clearly was the case for Jack and Bob.

In contrast, other participants admitted that their physical abilities had been altered and they were still struggling to return to their pre-cancer activities. For example, Simon explained “*I’m sort of like easing back into it, and how unfit you can get in three months...*” While Simon was quite open about how the treatments had impacted him, other participants found it easier to “project” some of their feelings onto other people as a way of revealing how “one might” feel particularly with regards to the loss of a testicle and in some cases having a prosthesis. For example, George said:

*But if I was a younger bloke I would be disappointed that it’s not perfect in a sense... I suppose it’s damaged in a way... That’s going to give you a certain amount of insecurity I imagine because it doesn’t feel the same.*

While George was not directly stating that HE was disappointed, one suspects that he did feel “damaged” which of course would affect his self-image. Jack, on the other hand, had chosen not to have a prosthesis and yet at the time of the interview he admitted that he felt having another operation just to have a prosthesis put in would be “wasteful” on the NHS resources; however, he was not completely comfortable with his original decision not to have one. In these examples, the participants did not make the direct link between having a testicle and their sense of masculinity although certainly there seems to be a connection. However, Brad did poignantly sum up the connection in his slightly limited English when he said:

*What makes you a man? It’s your brain, not at all anything else. So by cutting your legs, your testicle or anything, they will not make you a woman or like a, anybody else. It’s your brain, this is where you are confident to stay a man, to be an example for your kids, to be your kids’ hero, this is where you are a man.*

What is particularly relevant is not the exact details of each case, but rather the fact that almost all of the men mentioned the decision to have a prosthesis without being directly asked which suggests that their physical appearance was important to their self-image and sense of masculinity. This is in keeping with a study by Chapple and McPherson (2004) on why men decided to have a prosthesis who found the three main reasons men opted for prosthesis were loss of masculinity and self-image, social relationships and to ensure their body shape looked normal (Chapple and McPherson, 2004, p. 660-661.) They concluded

that men needed to be counseled on the advantages and disadvantages of having a prosthesis and should be given time to consider issues such as appearance and self-image (Chapple and McPherson, 2004, p. 660-661.) Similarly the men in this study had struggled with their decisions and many wished that they had more information at the time of surgery. Nigel, who was not offered the option of having a prosthesis, summed it up when he said:

*I've given that quite a lot of thought actually and I'm not angry, that's the wrong word, that's the wrong expression, but I think I would have liked to have been offered the option. .. I would like to have discussed it with somebody at some point and said, right these are the options.*

All of the participants at some point discussed the impact that the disease and its treatment had on them physically. Some of the men returned to the topic numerous times during the interview whether it was to repeat how they had continued to maintain their level of fitness or to admit that the treatments had curtailed their activity. Additionally, most of the men had given careful consideration about the prosthesis even if they had not been given as much information from the medical team as they would have liked. Moreover, they were also open and forthcoming about their decisions in an interview about being a father with cancer, which also suggests that the topic was very important to them. Clearly, the findings suggest that having testicular cancer and its treatments did impact on the participants' self-images.

### 11.5.3 Challenges to Faith and Finding Meaning

Interestingly, only two out of the ten participants specifically mentioned their faith and how having cancer had challenged it. However, six out of the ten participants did discuss how having the disease had made them re-evaluate what was important in their life and they had also tried to find some meaning from their experience. All six of the men openly discussed their struggle to find meaning and provided specific examples of their conflict. One of the two men who did mention their faith, Don, spent a great deal of time during the interview discussing his struggle as well as the need to find some meaning.

Don struggled with why God had singled him out to have cancer, he admitted:

*... this whole thing was a bit of a religious waking or revisit at a different level because sometimes you just do religion for the sake of, you just kind of go through*

*the motions. And so this in way it got me to re think it and I don't think a bad thing has come of it but made me think more.*

This quotation succinctly summarizes the dilemma Don faced as his faith had been challenged because he questioned why he had been chosen to have cancer. However, having come through it, Don no longer took his faith for granted but rather it became something he had carefully and thoughtfully reflected on. Don was a particularly quiet and reserved man, yet he firmly believed that it was now his responsibility to ensure that more men were aware of testicular cancer. This is similar to the study by Carpentier and colleagues (2011) of perceptions of masculinity on men with testicular cancer which concluded that men agreed that while disclosure was difficult it was important as part of an advocacy role. During his cancer ordeal, Don had questioned God and was envious of his parents' unyielding and unwavering faith; ultimately, he came through believing it had made him stronger and given him an important mission.

Nigel, on the other hand, was the only other participant who directly articulated his struggles with God. He simply said "it does call into question...whether you believe or not". While Nigel, who at one point had only been given a 50% chance of survival, did not share his response about his faith, he did openly admit that he had realized how important his role of being a father was and was planning to change his career as a high flying civil servant in order to devote more time to his family. One suspects that deriving meaning from his cancer experience was an important part of adjusting to his diagnosis, treatment and survivorship and helped him to redefine his life and learn to live with the uncertainty of being a cancer survivor (Foley *et al.*, 2006, p.255).

Several of the other participants, who did not mention issues of faith, articulated their struggles with their attempts to find some meaning from their experience. For the most part, the reasons seemed to take one of two forms, either the men wanted to share their experience so others would be aware of the disease or having confronted a life-threatening illness they had re-evaluated what was important to them. For example, Jack explained that he hoped by speaking to as many people as possible "a chain of people" would ultimately do something more about it (increasing awareness about the disease).

Other participants also explored how having cancer had changed their lives. For Chris, it meant the need to take better care of himself physically and to stop being a “couch potato”. While both Bob and Sal admitted that having cancer had made them re-evaluate what was important in their lives. They revealed that while they had been career oriented, after their experience in Bob’s words “my immediate family and having a normal life with them was overwhelmingly what mattered to me.” When confronted with an uncertain future, men reflect and reappraise their lives. Those who attend much more to work than their families and describe themselves as Type A personalities, may choose to devote more time to their families (Charmaz, 1995, p.273). Clearly this was the case for these men.

#### 11.5.4 Fear of Late Diagnosis

The participants were diagnosed at different stages of the disease. Some only required surgery while others needed all three forms of treatment (See Table 11.3).

Table 11.3 Participants’ Treatments

<b>Treatment</b>	<b>No.</b>	<b>%</b>
Orchidectomy only	2	20
Orchidectomy/chemo	3	30
Orchidectomy/radiation	1	10
All three	4	40

However, regardless of when they were diagnosed, several of the men still struggled with how close they had come to not being diagnosed early enough for successful treatment. These participants were extremely forthcoming in articulating their concerns about not being diagnosed promptly and providing examples of what could have happened. Jack, who was diagnosed with Stage 2 Seminoma and ultimately required all three forms of treatment, was particularly distressed that he had not taken action sooner. He started the interview by stating:

*I'll start with something I've not told anyone, and I actually suspected and may have found it a little bit earlier and then for some reason it just went out of my head, it's a bit crazy, not much earlier, but I went on holiday...But I don't know why to this day I didn't kind of, it just went out of my head, I was on holiday, maybe it was other things on my mind.*



Clearly, the fact that Jack began the interview with this comment suggests that he was still struggling with why he had not taken action sooner. He was an extremely organized and efficient man; thus his actions were completely “out of character” for him. This atypical behavior is suggestive of a man who was extremely frightened and had employed the primitive defense of denial as a way of coping with something almost unbearable.

Similarly, Simon, who was also a very competent man and had a family history of testicular cancer, struggled with the importance of being diagnosed early and mentioned it numerous times. He was in a particularly difficult situation because his father, grandfather and brother all had testicular cancer and he had three sons ranging in age from 11 to 17. He remembered very clearly that he had found something on the 22<sup>nd</sup> December but did not want to worry anyone over Christmas; therefore, he had not gone to the doctor until the 4<sup>th</sup> January. While this may not seem like a very long period, for a man with such an extensive family history, it must have been a very worrying time. One particularly poignant quote was:

*...from a man's point of view, especially in that area, is that you've just got to deal with it, and people I spoke to, friends and that said oh, you're so brave, I don't know how you can go through with it. And I said but its cancer, you've got to deal with it.*

For Simon with three vulnerable sons, he was particularly keen to ensure that his sons “dealt with it” as quickly as possible. George, Nigel and Sal also mentioned their frustration and difficulties with being diagnosed and how if they had been diagnosed sooner they might not have required such extensive treatment. Of course, what is underlying this frustration is not just that these men required extensive treatment but also their ultimate fears that if they waited too long they may be facing death.

#### 11.5.5 Fear of Death

While only approximately half of the participants actually articulated that having cancer had ignited a fear of death in them, for all of them this fear was present in some form. By utilizing psychodynamic concepts to help us understand the unspoken and sometimes unconscious underlying fears that individuals confront, a clearer picture of the

experiences of these men emerges. Specifically, according to Kleinian theory, anxiety is inherent in the human condition and the fear of personal annihilation is one of the fundamental anxieties which is present in the earliest stages of existence and continues throughout life (Hollway & Jefferson, 2000, p. 138). Each individual has unique psychological processes with internal realities which impact on their ways of responding to and defending against their own anxieties. If there has been sufficient and reliable “containment” and holding by the primary carers, as described both Bion and Winnicott, whereby the infant has felt contained, then some of the greatest fears will have been detoxified and the infant will have developed a sense of trust and feel some sense of safety in depending on others even when confronted with external threats (Hollway & Jefferson, 2000, p.138). If on the other hand, the process does not take place effectively, the infant will introject not a comforting experience but rather what Bion calls “nameless dread” which is severe anxieties that do not bode well for the infant’s future development (Menzies-Lyth, 1975b, p. 213).

This psychodynamic process of understanding the depth and primitive nature of the most basic of fears, that of death, combined with the development of a capacity to cope with this threat provides a theoretical model from which we can base our discussion of how the men in this study responded to their actual confrontation with a life threatening illness. Although nothing is known about the early relationships of the participants, it is possible to speculate that while the men may have minimized their worries, by reading between the lines one can develop a greater understanding of their fears.

The overwhelming majority of men with testicular cancer are now surviving for at least 10 years, with survival rates in the UK soaring to 96% in 2009 according to Cancer Research UK ([www.cancerresearchuk.org/cancer-help/type/testicular-cancer/](http://www.cancerresearchuk.org/cancer-help/type/testicular-cancer/)). However, even with these statistics all the men in this study at some point in the interview acknowledged their fear of confronting a life threatening illness and possible death. Their fears were exhibited in several ways including:

1. Articulating concerns,
2. Round about means or contradictions,
3. Revealing strong emotions,
4. Returning to topic.

Some of the participants did directly and often poignantly articulate their concerns about the fear of death. Interestingly, many of them prefaced their discussion of their fears by acknowledging that they knew statistically it was unlikely, never-the-less they were still worried and the fear was present.

This quotation from Sal describing how he felt when they found the cancer had spread is similar to what several of the other participants said. He explained:

*But I, at this point, I was concerned, I was worried, I was, yeah, I was starting, for the first time I was thinking, I could die from this, that was the first time that I thought I could die from it.*

In this very direct quote there is evidence of a man facing his fears. Cooper (1982, p. 613) explains that there is no “overcoming a fear based on reality, only confrontation of it”. This desire to confront rather than overcome the fear seems present in several of the men. For example, Brad said:

*... I still know that if I would deny it, if I would ignore it, if I wouldn't go quickly enough I could die, that, and far away from it but knowing that by not doing anything I could actually not survive it, makes me feel how lucky I am.*

This quote shows that Brad accepted that if he did not take action he would die. And yet he finished by describing how lucky he was. This suggests a man who was capable of facing the external reality of his condition and was also open to trusting that with the support of the medical team he could survive. This was similar to many men who explained that day-to-day they were able to live with and almost forget they had cancer until they had to return for their three monthly clinic appointments. Then the reality and fears would resurface and they would describe feeling anxious and frightened all over again. Chris explained:

*Dr .... has said that to me... you look anxious and I probably hadn't necessarily realized I looked as anxious as I was but and I guess that's reassuring...I think what he's saying is, don't, that you don't need to worry. I mean I guess one's always looking for positive reassurance in these crises, all you want someone to say is, it's gone away.*

From this quotation it seems that Chris felt “contained” and reassured by the doctor that he didn’t need to worry. For many of the men struggling with their internal fears of death, the doctors were an important source of containment. Even when they could read the statistics online, it was the actual reassurance of the medical team which provided the necessary holding to minimize their underlying fears. Both Sal and Nigel actually stated that if it had not been for the doctors’ support they wouldn’t have made it, and they were not referring to the physical treatment but rather the emotional support. Nigel stated that the doctors got him “through kicking and screaming”. While Sal said during his treatment that if the windows had not been “welded shut, I think I would have jumped”. Clearly, these men were terrified and suffering and yet with the support and “holding” of the medical team they were able to survive.

In addition to directly articulating their concerns and for some men returning to the topic on several occasions, the men also exhibited their fears either in the shape of contradictions. In other words, they did not directly state that they were concerned about the possibility of their untimely death but this fear, or nameless dread, was present. Again applying psychodynamic concepts, one might speculate that all these men confronted with the crisis of a life-threatening illness employed both conscious and unconscious defense mechanism including denial, repression, avoidance and displacement. Of particular interest is that Freud (1962) explained that denial referred to the unconscious inclination to avoid pain by minimizing the acknowledgement of distressing feelings; often short-lived and in response to crisis. Needless to say coping with cancer is a crisis; thus it not surprising that some of the men denied or avoided discussing the very fundamental fear of death but their fears were revealed in other ways. (Coping responses and defense mechanisms will be discussed in more detail below.)

With regards to contradictions which reveal the underlying fears of several of the men, Bob specifically stated that he “wasn’t concerned about any of that (the thought he was going to die)” and yet he went on to discuss how his wife was terrified and wondered how she would cope without him. This contradiction is a form of projection whereby Bob was ridding himself of their fear and placing it onto others. Similarly, George, an intelligent man, who also never mentioned the word death, did slip when describing his biopsy; he

used the word “autopsy”. Undoubtedly this is a classic example of a “Freudian slip”. Jack also referred to feeling like “death” after his chemotherapy which he described as poison rather than medicine.

The participants also described specific incidents which revealed strong emotions regarding their fears of death. For example, Don described at great length the video he made for his daughters the night before surgery “just in case”. Nigel described being in the hospital and “wondering if he would wake up in the morning” because he felt so ill. These incidents show that even with the reassurance of statistics and the support of the medical team, the most basic internal fear, of death, was still lurking within.

Above I have presented the major psychosocial concerns as well as the individuals’ anxieties and briefly mentioned how with external support particularly the family and medical team, the participants were able to cope with their life threatening disease. I will turn now to examine in detail the defense mechanisms and coping responses that the participants employed.

### **11.6. Defense Mechanisms and Coping Responses**

As discussed above, according to psychodynamic theory, how the individual copes is dependent on his unconscious defenses which were developed based on early relationships. While the men did not discuss their early life history during the interview by carefully examining how they described their experiences, we can develop a sense of not only their coping responses but also their particular defense mechanisms which are hidden a bit further below the surface. These defenses and responses play out in different ways for each of the men but do have some commonality. Below I will identify the most common defenses and coping responses and then explore how they were revealed and the significance of these responses.

From the careful and detailed analysis of each of the cases, the most common coping responses and defenses fell into the following categories:

1. Looking to wife and family for support,
2. Good cancer bad disease,

3. Masculine way of handling illness including minimizing, maintaining stoic façade, intellectualization, idealization and humor.

Clearly these categories are not mutually exclusive, nor do they cover every response of each of the participants; rather they are a means to explore the most common responses and defenses that were evident in the interviews.

#### 11.6.1. Wife and Family as a Main Source of Support

Families are dynamic and adaptive systems and as such they strive to both maintain a stable and routine level of functioning while also restructuring as necessary when confronted with a family member's illness (Lewis *et al.*, 1989). Thus it is not surprising that when describing their experience, most of the men provided examples of how their families had adjusted to their illness and had been their main source of support.

In the cases of the participants in this study, it is helpful to explore how the individuals responded and often relied on their spouses as a source of containment as well as how the family as a unit adjusted and coped. The following findings demonstrated how important the family support was to the participants:

1. Articulating feelings,
2. Showing appreciation,
3. Providing examples.

Eight out of the ten men openly admitted how they relied on their wife and in some cases their family as the main source of support. For the two men who did not, they provided examples which demonstrated that they did benefit from some support even if it was a case of projecting their fears onto their wife. First, the men who openly acknowledged how they leaned on their wives both practically and emotionally will be presented.

Simon, who had an extensive family history of testicular cancer and had three sons, candidly stated that he and his family “had all been in this together”. He explained that even during his treatment he still made an effort to sit with his family at dinner which he believed was an important time to find out what was going on for everyone, in other words open communication. This example demonstrates how families strive to keep routine even when confronted with a family illness. Similarly Chris, who was given the option of having chemotherapy, explained going ahead with chemo was a “decision that he and his

wife took together”. He was not alone in that several of the men discussed how they had “made all the decisions together”. A few of the men also shared details of how they spoke to friends and brothers about their illness. Simon stated that having his brother who had gone through it “helped a lot”. Brad similarly was grateful to his brother-in-law who came over from Poland to keep him company, watch boy movies and act as his personal assistant. Clearly, many of the families rallied around the participants who felt appreciative of this support.

In addition to making decisions together, many men felt that their wives bore the brunt of worrying and some even acknowledged this. Matt, for example, explained that his wife was the one who continued to encourage him to seek medical assistance even after the GP had sent him home saying he was fine. Many of the participants explained how they had seemed to focus on their medical condition while “the wife” did the worrying. This was an example of the defense mechanism of projection whereby the men would split off their unwanted fears by projecting them onto their wives who then were able to “hold” the emotions. In the cases of these men, the wives were able to “contain” the emotions and then in a sense detoxify them allowing the men to face the reality of their situation and to cope with their physical condition. These men went on to say how grateful they were for the support of their wives. Even James, who never articulated that his wife was a support, described on two occasions how his wife did the worrying for the two of them. He focused on eating right and staying fit and she worried about “it”. Again this is an example of projection and splitting. The evidence suggests that all the participants in this study turned to and relied on their wives and family as a major source of support. This is in keeping with a study by Bullen (2010, p. 939) which found that rehabilitation was possible for men in strong supportive relationships which provided the reassurance of a continued, if somewhat reconstructed, masculine role.

#### 11.6.2 Splitting: Good Cancer Bad Disease

The psychoanalytic concept of splitting underpinned some of the coping responses of the participants. First, in several cases the men split the doctors into the bad ones versus the good ones; they described the “useless” GP compared to the almost heroic surgeon or oncologist. Second, all of the participants admitted in some form that they had the “good”

cancer to get. They all recognized that cancer can be a devastating disease and thus they felt lucky at the type of cancer they had. Interestingly, the use of splitting as a defense seemed to be compounded by the hospital personnel. The evidence for splitting both into the good versus the bad doctors and the good versus the bad disease is apparent in a majority of the interviews and both will be discussed separately.

Several of the participants, when explaining the early stages of being diagnosed and treated, described either their experience with the GP or the initial consults in a very negative light. For example, George struggled to get his doctor to even refer him for more tests and Nigel was misdiagnosed by his GP for almost six months. While the frustration for the participants is understandable, the strength of the feelings that were revealed when describing these interactions much later suggests a deeper conflict. Again utilizing psychodynamic concepts is helpful in understanding this. Splitting is a defense mechanism used when anxiety becomes intolerable. For example, a child makes sense of the world by splitting the complicated loving creature that looks after him as the good mother and the one who leaves him hungry as the bad mother (Moylan & Jureidini, 1994, p.234). Similarly, confronted with a life-threatening illness, the men may have resorted to their most primitive defense mechanisms. Klein (1946) explained that individuals split off the feared part of the self and project it on to outside object (or persons). This splitting of objects into good and bad is the basis for what she defined as the paranoid-schizoid position which is the position that we all resort to in the face of life threatening occurrences. It allows the individual to believe in a good, rescuing object and rid the self of the “bad” threats from bad objects (Hollway & Jefferson, 2000, p. 20). Perhaps when faced with the diagnosis of cancer, the men regressed to this position whereby they viewed the initial doctor as bad in contrast to the all powerful surgeon or oncologist who would save them. This is evident in how the men described the GPs above and the surgeons or oncologists below. Matt said:

*..and I just remember him coming past and he put his arm on my shoulder saying don't worry about it, it will be great. Thanks. So he was excellent. That's the whole, there's just this huge... whoa, he was just very, very good.*

The words he used to describe and even the way he stumbled trying to find adequate words, show a man who viewed this doctor with great admiration. Similarly, Nigel described his team of oncologists as “fantastic” and, “absolutely brilliant”. By splitting off the good



doctor in a somewhat stereotyped way, the participants in some cases developed a paternal transference with the doctor who they saw as strong, authoritative and courageous, in effect their hero (Moylan & Jureidini, 1994, p.37). What is interesting is that not only did the men see their doctors in this light at the time of diagnosis but even reflecting back, these images still held. While Klein explains that people shift between the paranoid-schizoid position and the more mature depressive position, which acknowledges the existence of both good and bad within the same object, for these men it was important to sustain their belief in the good doctor and hence they still appeared to be functioning in this area in the paranoid-schizoid mode. This may be explicable in that even though the men were free of disease at the time of their interviews, it is usually five years before they are given “the all clear”; therefore, they needed to preserve their belief in their heroes.

In addition to splitting their doctors into good and bad ones, the men also split the type of cancer into good and bad. They did this by providing statistics, describing more debilitating treatments and side effects and comparing themselves to other patients they saw in the hospital or knew. For example, Jack described himself as “lucky” stating that the survival rates for this “one” (type of cancer) was very high. Sal mentioned that the doctors told him his chance of survival was over 90% and that of all the cancers to get this “was the golden ball”. Similarly George, Chris and Bob also described themselves as either fortunate or lucky because testicular cancer was “the one to get” since the prognosis was “really, really good”. Not only did the men repeat the words “really” and “very” often, they also repeated on several occasions either references to the statistics or the positive information that the doctors had given them.

When describing coming into the hospital for treatments, some of the men shared experiences of observing other patients. Matt explained that he had only one dose of chemo and said it:

“was a bit sobering because you see others that have six and seven and eight and nine. And it’s a different...I just felt incredibly lucky.”

Similarly, Brad poignantly revealed how he considered himself lucky compared to other patients when he said:

*They are surviving, they fighting for it... And maybe those times when I was coming here, it wasn't like I was glad that, oh they've got much worse type of the cancer so*

*I'm, I will survive or anything, the spirit they were having, that was something for me to not even think about getting worried.*

What is evident in these examples is that by splitting their type of cancer into the “good” one, the men seemed able to focus on the possibility of a positive outcome. For all of the participants, it was an important coping response in maintaining a fighting spirit throughout their ordeal. Furthermore, this splitting and emphasis on testicular cancer being “the one to get” also seemed to be reinforced by the medical team.

As mentioned above, Sal’s doctor said he had “the golden ball” and Matt’s doctor had told him “not to worry”. These reassuring words seemed common amongst the oncologist and surgeons when speaking to patients with testicular cancer. Menzies-Lyth (1975a) discussed the development of socially structured defence mechanisms in organizations, specifically hospitals. She explained that the defence system developed over time as the result of collusive interactions, usually unconsciously, amongst its members. The socially structured defence then becomes an accepted part of the external reality with both old and new members accepting it. Within a cancer hospital, for both the established members of the medical team and the new patients, there seems to be an unspoken, informal agreement whereby the testicular cancer patients are considered the “lucky ones”. One might speculate that this may be part of the reason these patients do not receive all the information and support they required or would have liked because the doctors and nurses, who have a limited amount of time and emotional energy, chose to focus on the “more serious” cases.

Interestingly, patients such as Don are quite accepting of this and recognize that the “busy” doctors only have so much time and they don’t want to bother them with too many questions. Moreover, Menzies-Lyth suggests that the resistance to social change is likely to be greatest in institutions whose social defense systems are dominated by primitive defenses and anxieties (Menzies-Lyth, 1975a, p. 79). Certainly a hospital that only treats cancer patients would fall within that category. Thus it is not surprising that although the participants were all extremely different with their own unique coping styles and defenses, they all seemed to employ the primitive mechanisms of splitting and labeling their cancer (which is still life-threatening!) as “the good one”.

### 11.6.3 Masculine Way of Handling Illness

In the section on challenges to self-concept, I mentioned the idea of maintaining a stoic façade as a coping response in order to preserve the image of being a strong father. This is just one coping response that the participants employed as a means of handling their illness and its side effects. Other coping responses and defenses that were evident in the interviews include:

1. Maintaining a stoic stance and minimizing,
2. Intellectualization and idealization,
3. Exhibiting contradictions,
4. Humor.

All of these defenses and responses could also be employed by women with cancer; however, what became evident from the interviews is that for these participants these defenses were employed not just because they helped them to cope with their situation but also because they ensured that the men could maintain their self-concept and feelings of masculinity while confronting their cancer. This coping behavior demonstrates how men will engage in practices that align themselves with their gender identity and masculinity (McCaughan *et al.*, 2012, p. 64). Of course, not every incident of employing a particular defense was specifically used to maintain their self-concept or feelings of masculinity; however, for these men this set of responses helped them to cope with both their disease and the challenges to their self-concept while also maintaining their sense of masculinity. I will now explore each of the responses in more detail.

McCaughan and colleagues (2012) found in their study that men often initially presented with a stoic stance that was consistent with the concept of hegemonic masculinity which portrays men as reluctant to show themselves as vulnerable particularly in the public domain. Similarly, the men in this study described incidents where they purposefully tried to appear strong rather than vulnerable. For example, when Matt, who had two daughters and a son, was describing how he told his teenage son about his diagnosis he said:

*...so yeah, I'd had a rational conversation with him. He's a boy isn't he?*

This quotation implies that his conversation with his son was different and less emotional than the ones he had with his daughters. He acted in the more socially prescribed traditional male role of being stoic, avoiding feelings and avoiding emotional disclosure (Gordon, 1995, p. 249). In contrast he explained he had a bit more of a “heartfelt” discussion with his eldest daughter perhaps based on the assumption that women are often stereotyped as expressive, emotional and compassionate (Moynihan, 1998).

Several of the participants clearly minimized the side effects of the treatment. For example, Don described the surgery as an “inconvenience” and Matt described having “a cup of tea and a biscuit” during his chemotherapy. Downplaying the side-effects also seems to be related to gender identity and masculinity because men more than women report having no concerns with side effects while some women may experience total preoccupation (McCaughan, 2012, p. 69).

Several men when describing how they coped with their illness referred to Lance Armstrong as an inspiration (the interviews were before he admitted to taking steroids). They seemed to employ the defenses of both identification and idealization with Armstrong as a role model in how to handle their illness. For example, Sal explained how Lance Armstrong had it “all over the bloody place” and he survived and won the Tour de France. The men identified with a man who was the epitome of a successful, competitive, and strong man (Gordon, 1995, p. 249). Moreover, Armstrong “beat” cancer and there is the sense these men also wanted to be seen beating their disease.

Some of the participants also employed intellectualization as a defense. For example, Brad mentioned how he was an engineer and thus relied on the “numbers and figures” to tell him “a lot”. Above I have discussed the use of statistics in splitting, what is relevant here is that the participants relied on numbers, statistics and information to not only cope with their situation but also maintain their self-concept. Intellectualization is the overuse of abstract thinking which is self-serving in aiming to reduce psychic discomfort (Maxmen, 1986, p. 68). When Brad was discussing the statistics and even how he concluded that his shortness of breath was related to the lack of oxygen in his blood, this demonstrated how he controlled his emotions by relying on facts. Rather than saying he was frightened when he

found he was short of breath walking up the stairs, he instead immediately went to the explanation for his condition. This suggests that in fact the fear was present yet he was reluctant to verbalize it.

Similarly, there were numerous occasions when the men stated one thing yet contradicted themselves later on in the interview by what they said or in their behaviors. For example, Jack stated he was “happy just to get on with it and... go with the flow”; however, his determination to eat well and keep cycling all through his treatment reveals a man who was anything but easy going and happy to get on with it. Evidence of contradictions in the interviews can provide a front for men who in fact are attempting to enact their masculine beliefs (McCaughan *et al.*, 2012, p. 68). Poignantly, Brad who throughout the interview had appeared in control and confident, found his hands shaking and eyes welling up when describing how he had not worried about his illness but his wife had many sleepless nights. Clearly, he was trying to appear as the sturdy oak but his reactions show the depth of his feelings.

Finally, while not all men demonstrated evidence of using humor in coping with their disease, for those who did it seemed to be a very important feature in how they confronted and discussed their illness. Moreover, it allowed men to reveal intimate details without embarrassment. For example, Simon joked that he didn’t need a prosthesis because he would never wear a Speedo. He also revealed that when talking to his sons about the need to check oneself, he emphasized that “you got to laugh, you got to make a joke of it”. These examples demonstrate how humor can play an important role in men’s social interactions and allow for self-disclosure (Thorson *et al.*, 1997). This is evident in the men’s interactions with myself as well as amongst family members, friends and acquaintances. Brad made quite a few jokes throughout his interview and also described how he was smiling and chatting with the other patients who all had “good humor”. The sharing of laughter can provide a degree of mutual safety and show an established intimacy in interpersonal relations which can also facilitate communications (Oliffe *et al.*, 2009, p. 923).

In reviewing all of the participants’ interviews there was evidence that all of the men employed some of the specific coping responses which I have placed under the umbrella of

the Masculine Way of Handling Illness including: minimizing, intellectualization, maintaining stoic facades, idealization, humour and exhibiting contradictions (See Appendices 8 & 9: Worksheet 1 and Worksheet 2). Clearly, taken individually each of these coping responses in themselves may be an adaptive technique to deal with the challenges of cancer which might also be used by women. However, taken as a group of responses and defenses and examined within the context of the interviews, a picture emerges which suggests that these men employed these defenses not only to cope with their illness but also to maintain their self-concept, self-image and feelings of masculinity. Hopefully, by viewing these responses collectively there is enough evidence to support my assertion that there exists a “Masculine Way of Handling Illness” for the participants in this study in particular and perhaps for male cancer patients in general.

### **11.7 Assertions and Conclusion**

While the current trend is to define cancer as a family illness because of the emotional impact that it has on every member of the family due to the changes it brings (Bressi *et al.*, 2005), the themes arising from this study suggest that cancer is both an individual and a family disease. The participants, who were free to discuss what was important to them, all shared concerns regarding their families and children as well as challenges to their self-image, self-concepts and sense of masculinity. On balance, they devoted a similar amount of time to these topics which suggests that throughout the course of their cancer experience, they had struggled with both concerns for others as well as their internal struggles. For example, even when they discussed or revealed their fear of death it had both a personal tone as well as how it would impact on their family. All of the men, bar one, discussed the need for additional information both for their own concerns and for their family members. The topics which were not common for all men included challenges to faith and finding meaning as well as struggles with work. Yet for the men who did discuss these topics, they had comprised an important facet of their cancer experience.

While every man did not employ the exact same set of coping responses and defense mechanisms, there was a consistency in that the majority relied on their wives for support, split the cancer into a good cancer and bad disease and relied on a cluster of defense mechanisms which I have entitled Masculine Way of Handling Illness. In particular the

men minimized the side effects, intellectualized their concerns, idealized Lance Armstrong, projected their fears on to their wives, and maintained a stoic façade throughout the course of their treatment. Moreover, a few men shared very personal feelings using humor. By looking at the interviews in general and the worksheets in particular, there is evidence that the concerns and anxieties were varied for the men. However, their coping responses and defenses were fairly similar. In other words, while each man's experience had a unique feeling with different personal challenges, for the most part the men seemed to confront these obstacles in similar ways. This is particularly helpful when considering what interventions might best help men who are fathers with cancer which will be discussed in more the concluding chapter.

## **Chapter 12: Future Implications and Closing Remarks**

### **12.1 Introduction**

In this chapter I will provide a summary of the findings as well as highlight a few key points, reflect on whether the aim was met and research questions answered, then reflect on the research process and benefits of utilizing mixed methodologies combined with psychodynamic theory as well as the limitations of the study. I will conclude with a discussion of future implications for policy, practice and research.

### **12.2 Summary of the Findings**

#### 12.2.1 Psychosocial Concerns

Based on the careful analysis of the evidence from all the cases, the concerns and anxieties which were most common for this patient population are listed in table 12.1. While there was some difference in the priorities of the psychosocial concerns, all of the men did reveal that they had worried about their children particularly what, when and how to tell them about the cancer. A majority of them worried about the relationship with their wives whether because they had become more of a burden or because the wife had to take on more responsibilities. In some cases the men struggled with issues around their own parents such as wanting to protect them, needing to rely on them for child care or requiring their help in caring for themselves during the treatment stage. Nine out of the ten men shared their frustration with the lack of information (although the topics they required information on varied and are listed in Table 12.2). There was a particular emphasis on the limited information regarding what to tell children, lack of information about prosthesis and limited details about the side-effects of treatments. The participants concerns regarding work also varied but most of them were keen to return to work as quickly as possible and to maintain their position and status at work. Although even with the desire to return to work, a couple of men re-evaluated the family/work balance and wanted to spend more time with their children.



**Table 12.1 Prominent Themes**

<b>Psychosocial Concerns</b>
Concerns for Children
Concerns for Wife and Family
Lack of Information
Work Concerns
Challenges to Faith/Finding Meaning
<b>Individual Anxieties</b>
Challenges to Self-image and Masculinity
Challenges to Self-concept, Identity and Masculinity
Fear of Recurrence and Late Diagnosis
Fear of Death and Annihilation
<b>Coping Strategies and Defense Mechanisms</b>
Relying on Wife and Family for Support
Good Cancer Bad Disease (Splitting)
Masculine Way of Handling Illness: Minimizing, Intellectualization, Maintaining Stoic Façade, Idealization and Humor

#### 12.2.2 Individual Anxieties

Utilizing both the BNIM method of interviewing and the IPA method of data analysis combined with applying psychodynamic concepts was particularly helpful in uncovering and exploring the individual anxieties. While in most cases the men did not explicitly state their specific anxieties, a careful and detailed analysis of the findings utilizing psychodynamic concepts to highlight unconscious communications led to the assertions that the participants in some form felt challenges to their self-concepts, self-image and masculinity. With regards to their self-concepts, in most cases the short-term side effects of treatment had limited their abilities to participate in normal activities such as playing with their children or engaging in sports. This had challenged how they viewed themselves as fit and able men and dads with some men sharing that they felt more vulnerable. Similarly, their self-images were also challenged by the long-term physical changes due to the orchidectomy. While some men had felt comfortable with the loss of the testicle and bluntly stated that it had not changed how they viewed themselves as a man, others at the time of the interview still seemed to be struggling with the loss and questioned their decisions not to have a prosthesis. The fact that several of the men returned to this topic numerous times during the interview as well as other factors discussed in detail in the Cross

Case Analysis chapter suggests that there was more to the issue than simply a physical change, in fact their self-image as well as their masculinity had been challenged.

Only two men mentioned that having cancer directly challenged their faith in God. For these men, the issue seemed quite profound and something they had really wrestled with. Similarly, a majority of the men felt that having cancer had forced them to reflect on their lives. Many of them felt it was now important for them to try increase awareness about the disease and take the opportunity to re-evaluate what was important in their lives. The fear of death was not mentioned by every participant but was certainly present in every interview. As discussed in the Cross Case Analysis chapter, the men revealed that even with the prospect of a very positive prognosis, they still had faced a life threatening disease: one which if they had not taken action soon enough could have led to their death. Some men seemed to have moved on and considered themselves very lucky, while others still became extremely anxious when returning for routine clinic appointments.

#### 12.2.3 Coping Responses, Defense Mechanisms and the Masculine Way of Handling Illness

The most common defense mechanisms and coping responses utilized by the participants included:

- Looking to wife and family for support,
- Splitting the cancer into the “Good cancer bad disease”,
- Masculine way of handling illness.

With regards to looking to the wife and family for support, all of the men had relied primarily on their wife as the main source of support. Many of them even acknowledged that the wife was the one who worried while they “got on with getting better”. Similarly, all of the men seemed to cope with their disease by splitting testicular cancer into the “one to get” while acknowledging how serious cancer can be. By reassuring themselves that testicular cancer had an excellent prognosis, they were able to focus on getting through the treatment and the side-effects.

I have also presented the term “Masculine Way of Handling Illness” to describe a group of defense mechanisms that the men employed not only to help them cope with their illness but also to maintain their masculinity and sense of self. The defenses they employed included: minimizing the

side effects, intellectualizing their concerns, idealizing particularly Lance Armstrong, projecting their fears on to their wives, and maintaining a stoic façade throughout the course of their treatment. Moreover, a few men shared very personal feelings using humor. While I recognize that none of these mechanisms or strategies is exclusively “masculine” what I explored in the Cross Case Analysis Chapter was that the men employed these responses not just as a coping strategy to deal with their disease but also to ensure that they continued to maintain their role as the father, husband and primary bread winner. In other words, the men wanted to preserve their sense of self and their own concept of masculinity.

### **12.3 Research Question Answered?**

The idea for this study came from a team meeting discussing the feasibility and need for a family intervention for families when a father had cancer. During the meeting, I questioned whether a family group was the correct modality to address the concerns of fathers. When I later explored the topic, I found very limited research addressing the specific concerns of fathers with cancer. Therefore, rather than design an intervention which may not actually meet the needs of this particular patient population, this study was designed with the aim of exploring their experiences and learn firsthand what issues may be worrying them which would help to inform health care professionals about what might be helpful interventions. This led to a very straightforward question: “What are the major areas of psychosocial concerns, individual anxieties and coping responses for men who are fathers with cancer?”

Given the honest and thorough responses provided by the participants, combined with the mixed methodologies, I believe that I have been able to develop a very comprehensive answer to this question. (The findings have been set out above.) Additionally, having established a genuine rapport with the participants while also exploring the verbal and non-verbal communications with the help of psychodynamic theory, I believe there was more depth to the findings than would have been possible had I conducted a study using semi-structure interviews and surveys. Moreover, I have found what I suspected from the start, a family support group is probably not the best form of intervention for these men. Below I will outline given the findings what interventions seem more appropriate.

## **12.4 Reflections on Research Process, Methodology and Reflexivity**

It is now widely recognized in social science research, that in order to do justice to the understanding of the participant's experience, researchers must also acknowledge their own part in the process (Hollway & Jefferson, 2000). Therefore, in this section not only will I reflect on the research process and present the benefits of utilizing both the BNIM and IPA methods, I will also explore how reflexivity became a vital tool in identifying areas of concern for the participants which might have been missed had I only analyzed the verbatim interview transcripts and not incorporated my own emotional responses into the research process.

### 12.4.1 The Benefits of Mixed Methodologies

I believe that there were definite advantages to employing two methodologies in this study. The beauty of the BNIM method of interviewing shined through with these men. By telling their story in their own way, in their own time, a rapport was developed between myself and the participants; hence the men shared some of their deepest and unanticipated concerns.

In addition to sharing the themes which were anticipated including concern for their children and families and lack of information, other common themes which emerged included: challenges to their self-image, concept and masculinity, frustration at the lack of information particularly regarding prosthesis and fear of death and annihilation. These topics have been discussed at length in the Cross Case Analysis chapter and above. However, what is relevant here is how the open ended BNIM style of research question encouraged the men to speak honestly at their own pace thereby allowing for a relationship between the researcher and the participants to develop. This perhaps facilitated and encouraged the men to reveal more than they might have done in a standard semi-structured interview. For example, by allowing the men to tell their story it was very interesting to note how often they returned to a particular topic. Thus although most of the men confidently stated that they were never afraid of dying and that they knew the statistics were in their favour, they all repeated this numerous times. For example one participant Bob explained early in the interview:

*Of course, I knew I would be fine. I never worried about dying or anything like that. The consultant said I had a 97% chance of survival so I just thought I have to get through the surgery.*

However, later he went on to say:

*When this young medic told me I had a 93% survival rate I was really pissed. I thought don't they teach you anything. When I challenged him he got real defensive. But that really shook me up. I mean you worry about these things, right? Doesn't he get that?*

The participant raised the topic of “survival rates and statistics” several more times. Clearly, this participant was more worried about “dying or anything like that” than he first admitted. This example demonstrates the ability of the BNIM method to allow the participant to reveal significant personal meaning (Hollway & Jefferson, 2000).

Additionally, one of the expectations of the IPA method of data analysis is to include interpretation. For example, by looking at the content, the choice of words and the number of times the participant returned to the topic, the depth of the participant's fears emerge. For instance, Bob's choice of wording shows anger and frustration, “young medic” when he means a doctor and the strong word choice of “pissed”. He seems to be projecting his own anger onto this doctor. Additionally, he changes verb tenses. This would imply a contradiction that not only was he worrying about dying during his cancer experience but he is still frightened now. These clues in the text support the hypothesis developed during the interview that this participant was much angrier and frightened than he was verbalizing. Utilizing defences such as denial, intellectualization and projection, there seems to be a deep underlying fear of death and annihilation which was not only demonstrated by the participant but was also felt by the researcher. This example demonstrates the benefits of the combination of the BNIM and IPA methods with psychoanalytic theory as a powerful and comprehensive formula for exploring both the psychosocial concerns as well as the individual anxieties that were sometimes hidden “below the surface”.

#### 12.4.2 Reflexivity

Above I have presented how the two methodologies used to elicit and analyze data were incorporated in this study to help understand the participants. Relatively recently in the field of social science research, the researchers' feelings have also begun to be recognized as another form of data. Rather than the researcher attempting to remain objective and

ignoring personal feelings, there is a shift towards the utilization of the researchers' feelings and subjectivity (Jervis, 2009). The researcher needs to be open to considering the unconscious dynamics, communications and defenses of BOTH the participant and the researcher and their co-construction of the research environment (Hollway & Jefferson, 2000). The reflexive researcher is exposed to double communications. They are exposed to the participants' primitive and unprocessed psychic material in the form of the defended subject as well the verbal communications. Additionally and with the help of supervision and peer support, the researcher should be able to explore this material as well as to understand some of the feelings stirred up for themselves in the countertransference. The case example of Bob helps to illustrate this point.

Bob started the interview by claiming that he was confident in his positive prognosis because of the impressive statistics. However, I quickly began to speculate that in fact his fears were greater than he wanted to admit. My suspicions were founded on the fact that he returned to the topic of cancer statistics numerous times AND the choice of words and tenses that he utilized. Additionally, and profoundly, as a researcher and with the help of a supervision group, I felt the intensity of his fears. In order to explain this I need to provide more context of the interview.

I met with Bob in his home which was an hour's drive for me on a day when it was snowing. I was facing the window and as Bob continued to talk, I watched the snow pile up on his country lane. I became distracted and agitated and was relieved when after three and a half hours Bob said he had no more to say. When we were reviewing this case in supervision, my colleagues noticed that I was uncharacteristically unsympathetic to this participant and was almost angry. My colleagues encouraged me to explore these feelings. I commented that in this particular interview I had felt trapped and out of control; whereas with the other participants I had been able to keep to our schedule, with this participant I had felt stuck. It was only when offered this reflexive space that I was able to ponder my responses. It was not until I felt trapped and out of control did I begin to fathom the depth of Bob's fear. Through the group discussion it became clear that Bob had projected his unbearable fears onto me. Clearly, I was not in a life-threatening situation; however, what is important to note is that by exploring my reactions I was able to acknowledge my own feelings and defenses and further begin to comprehend the depth of Bob's fears. By paying

attention to my uncharacteristic responses, I was able to discover that Bob had communicated how he was truly feeling without actually verbalizing it (Jervis, 2009).

One other key aspect which should be mentioned when discussing the importance of reflexivity within a psychosocial study is that I was a female researcher interviewing all male participants. I believe that it is important to acknowledge that being a female researcher may have enhanced the male participants' need to enact their masculinity (McCaughn *et al.*, 2012, p. 70). Moreover, Moynihan (1998) emphasized how male patients may get locked into perpetuating male gender roles and be reluctant to let a female researcher enter into the very private male world; therefore she addressed this by asking open ended questions and establishing relationships with the participants. Similarly by utilizing the BNIM interview techniques combined with my understanding of the importance of establishing a containing research environment, I also hoped that the men would feel comfortable sharing their private and personal concerns. Additionally, I also tend to employ humor myself and found that this was a useful way of allowing the men to reveal aspects that might otherwise have felt awkward or been ignored. Another personal factor which I think also helped the participants is that I am a middle aged American mother. Thus I suspect that men felt slightly more comfortable sharing their concerns than they would have had I been a younger single woman. All these factors highlight the necessity of the researchers acknowledging the multiple conscious and unconscious components which are at play within the research environment. Additionally, having a supportive supervisor and peer support system enabled me to utilize reflexivity to further understand the unconscious dynamics and communications that were also at play.

### **12.5 Study imitations**

While I believe the research design and theoretical orientation ensured a comprehensive study on the experiences of men who are fathers with cancer, there were some limitations to the study. First, is the obvious limited sample size which prevents large generalizations; however, since the purpose was to explore and the findings from the ten participants did have common themes, I believe the key concerns were identified. Second, the study design did not take into account how ethnicity and culture may have impacted on how men viewed their experience. Third, when designing the protocol which was approved, we failed to

consider whether men who adopted children may have slightly different concerns and anxieties than birth fathers. We should, therefore, have considered if the men who adopted should be able to participate in the study. We included the two participants in the study who had adopted children and did not interpret their responses in a different light. Fourth, because I was part of the Child and Family Team, the age range of the children was 5 to 12. Not only did this mean it took longer to recruit, it also meant that we may have missed the interesting perspective of fathers who only had teenage children.

## **12. 6 Future Implications**

Having now conducted an extensive literature review, analyzed ten case studies and written a cross case analysis, there are clearly future implications for policy, practices and research. Three specific areas for further work emerged:

1. Providing accurate information particularly around identified topics (See Table 12.2). This should be incorporated both in the practice of health care professionals who verbally disseminate information as well by putting it on reputable websites.
2. Further work needs to be done regarding the procedures for presenting men with the option of having prosthesis. This may lead to changing policy in the clinics to ensure that men are repeatedly given information about the option of having a prosthesis. Additionally, further research could be designed to explore why male patients are not receiving this information and how best to provide it.
3. Interventions should be planned which not only address the articulated needs of this patient population but also that take into account the defense mechanisms most commonly employed by men which not only help them to cope with their illness but also allows for the men to maintain their sense of masculinity and gender roles (MWHI). Having this knowledge could enhance how health care professionals work in practice.

I will now explore each topic.



Table 12.2

Topics Requiring Additional Information
Detailed information about the disease at time of diagnosis
Possible progression of disease
Post-operative information and side effects of treatment
How, what and when to tell children
Information about prosthesis

### 12.6.1 Accurate Information

The participants emphasized how they would have greatly appreciated more precise information on a reliable UK website. In particular, many of them found very little explicit information about the side-effects of treatment and the post-surgery aches and pains. Several men struggled when they found themselves experiencing discomfort or were unsure if their reactions were normal. Because both the cancer websites and the hospital staff had minimized the realities of the side-effects of treatment the men suffered both physically and emotionally wondering if they were abnormal or were a bit “wingy”. Many of the men reported that they would have benefited from an on-line chat room specifically designed for men with testicular cancer.

The men all stated that accurate information was vital when it came to their children. They wanted more information about what, how and when to tell their children, particularly their sons. Somewhat surprisingly, the men in the study who had told their children did not rely on their wives to inform them; instead they either told the children together or on their own. The participants acknowledged the importance of open and honest communication with their children in an age appropriate manner and were keen to learn as much as they could about this topic. They recognized the importance of the internet in the world of their children and believed that having accurate, interesting on-line information both for themselves and their children would be extremely valuable. None of the men had found any websites which provided this type of information. Clearly the men would benefit from leaflets, direct advice from health care professionals and on-line support.

### **12.6.2 Having a Prosthesis**

One of the unexpected outcomes of this study was the willingness and openness that the men exhibited regarding their thoughts on having a prosthesis. What became evident was that most of the participants had not been provided with adequate time or information to consider the option of having a prosthesis. This may in part be due to the assumptions made by the surgeons and oncologist that these men were married with children and thus would not want to consider a procedure that had risks. Yet clearly several of the men in this study wished they had been given the option. Moreover, they did not realize that having a prosthesis was still an option at a later date and many surgeons prefer to wait to avoid infections. One potential area for research would be whether the doctors handle all men with testicular cancer in the same way or just those in long-term committed relationships. It might be helpful to explore which men are not receiving adequate information and whether clinicians are making unwarranted assumptions (Chapple & McPherson, 2004). The ultimate aim may be to develop policy/ procedure which ensure that all testicular cancer patients are at least given the option and more information.

### **12.6.3 Psychodynamically Informed Implications**

By utilizing psychodynamic concepts in order to thoroughly explore the unconscious communications and defense mechanisms, additional areas for future work have emerged. Both the need for accurate information and further exploration about prosthesis were evident from the articulated comments presented by the participants. However, having delved deeper into the experience of these men what also became evident was the depth of their fears as well as the type of defenses they employed. In addition to having concerns about their children, families and work, their anxieties included fear of death and recurrence, as well as challenges to self-image, self-concept and masculinity. In order to cope with these concerns and anxieties the men employed defenses such as intellectualization, idealization, minimization, humor and avoidance. I have suggested that these defenses were employed to not only cope with their illness but also to maintain their sense of masculinity and gender role identity, or the “Masculine Way of Handling Illness”. I would, therefore, propose that when planning interventions it is vital to incorporate this understanding in the planning process and that support is provided within a masculine context (Bullen *et al.*, 2010).

For example, one of the key areas which emerged was the need to promote and improve communication within families. To this end, I would propose interventions that would allow fathers to maintain their role as the “provider”, and “sturdy oak” while also enabling and encouraging them to discuss the realities of their illness with their children in an age appropriate manner (especially encouraging boys to check themselves). Talking to their children did not come easily to the men in this study; therefore, support and guidance on how to do this is essential.

I believe that one way of achieving the goal of encouraging open communication within families with an eye on the importance of a father maintaining his gender role and masculinity is an internet video and accompanying leaflet. To this end and with the support of a UK based charity for men’s cancers, I have produced an internet video and leaflet “Talking to children about cancer”. The video is targeted primarily at fathers and sons encouraging open communications and awareness about male cancers. The video is being narrated by up and coming actor Alexander Ludwig (The Hunger Games) and tells the story of a father and his two sons struggling to talk about testicular cancer. The video is humorous but also provides the important message that fathers are there to support and provide for their families but can also benefit from family support themselves. This video subtly includes an understanding of defenses such as idealization, humor and minimization and intellectualization while also addressing the more obvious challenges of encouraging

## **12.7 Conclusion**

Hopefully by exploring and developing a thorough understanding of the lived experience of fathers with cancer by utilizing psychodynamic concepts to examine both the stated and unstated concerns, health care professionals will continue to develop effective interventions for men and their families. Similarly, by grasping an understanding of the concept of Masculine Way of Handling Illness, clinicians will be better placed to support men confronted with male cancers in not only coping with their disease but also in maintaining their self-concept, self-image and masculine identity.

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### WEBSITES

American Cancer Society: [www.cancer.org/cancer/testicular/2014](http://www.cancer.org/cancer/testicular/2014)

Cancer Research UK: [www.cancerresearchuk.org/cancer-help/2014](http://www.cancerresearchuk.org/cancer-help/2014)

Macmillan Cancer Support:

[www.macmillan.org.uk/Cancerinformation/Cancertypes/.../Testicularcancer/2014](http://www.macmillan.org.uk/Cancerinformation/Cancertypes/.../Testicularcancer/2014)

National Cancer Institute: [www.cancer.gov/cancertopics/coping/when-your-parent-has-cancer](http://www.cancer.gov/cancertopics/coping/when-your-parent-has-cancer), 2014

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## **Appendix 1**

### **Participant Pro Forma/Details**

#### **CASE DETAILS**

Study Number: 1001

Initials: G.O.

Pseudonyms: George, Vicky (wife), Steve (son) and Tom (son waiting to be adopted)

Age: 38

Race: White Other

Education: Art College/ University

Employment: Animator

Diagnosis: Stage 2a Testicular Seminoma

Date of Diagnosis: May 2012

Treatment: Orchiectomy, single agent chemotherapy and radiotherapy

Current Status: NOD

Number of Years Married: 10

Number of Children: 1

Age (At time of dx.): 5

Sex of Children: Boy

#### **CASE DETAILS**

Study Number: 1002

Initials: B.R.

Pseudonyms: Don

Age: 35

Race: Indian Asian

Education: University

Employment: Computer Analyst

Diagnosis: Stage 1 Testicular Seminoma

Date of Diagnosis: December 2009

Treatment: Orchiectomy and active surveillance

Current Status: NOD

Number of Years Married: 8 years

Number of Children: 2

Age (At time of dx.): 3 and 5

Sex of Children: Girls

#### **CASE DETAILS**

Study Number: 1003

Initials: B. A.

Pseudonyms: Bob and wife Julia

Age: 40

Race: White British

Education: University

Employment: Clinical psychologist

Diagnosis: Stage 1 Mixed Germ Cell Testicular Tumor

Date of Diagnosis: May 2008  
Treatment: Orchidectomy, active surveillance  
Current Status: NOD  
Number of Years Married: 14 years  
Number of Children: 3  
Age (At time of dx.): 9, 7, 5  
Sex of Children: The eldest is a boy the other two are girls

**CASE DETAILS**

Study Number: 1005  
Initials: J.McD  
Pseudonyms: Jack  
Age: 40  
Race: White British  
Education: University  
Employment: IT consultant  
Diagnosis: Stage 2a Seminoma  
Date of Diagnosis: October 2009  
Treatment: Orchidectomy, single agent chemo and radiotherapy completed Feb 2010  
Current Status: NOD  
Number of Years Married: 10 years  
Number of Children: 2  
Age (At time of dx.): Six and three  
Sex of Children: Girls

**CASE DETAILS**

Study Number: 1006  
Initials: PWB  
Pseudonyms: Chris, Kay, Owen, Harry  
Age: 52  
Race: White British  
Education: University  
Employment: Accountant  
Diagnosis: Stage 1 Non-Seminoma  
Date of Diagnosis: March 2009  
Treatment: Orchidectomy, single agent carboplatin  
Current Status: NOD  
Number of Years Married: 24 years  
Number of Children: 2 (adopted)  
Age (At time of dx.): 14 and 12  
Sex of Children: Boys

**CASE DETAILS**

Study Number: 1007  
Initials: DM  
Pseudonyms: Simon, Leigh and the boys



Age: 43  
Race: White British  
Education: Technical College  
Employment: Project Manager for a building company  
Diagnosis: Seminoma  
Date of Diagnosis: January 2011  
Treatment: Orchidectomy, surveillance, TRIST and ultimately radiotherapy  
Current Status: After the interview, the consultants found that the cancer spread to the lymph nodes and he needed radiotherapy.  
Number of Years Married: 21 years  
Number of Children: 3  
Age (At time of dx.): 17, 14 and 11  
Sex of Children: Boys

### **CASE DETAILS**

Study Number: 1008  
Initials: BM  
Pseudonyms: Matt, Lydia and children  
Age: 44  
Race: White British  
Education: University  
Employment: Company Director  
Diagnosis: Seminoma  
Date of Diagnosis: September 2010  
Treatment: Orchidectomy, prosthesis and single dose of carboplatin  
Current Status: NoD  
Number of Years Married: 24 years  
Number of Children: 3  
Age (At time of dx.): 20, 17 and 8  
Sex of Children: 2 daughters and the middle one is a boy

### **CASE DETAILS**

Study Number: 1009  
Initials: CW  
Pseudonyms: Nigel and Sara  
Age: 48  
Race: White British  
Education: Secondary school  
Employment: Civil Servant  
Diagnosis: Stage 2c Right Testicular Seminoma with para-aortic and liver recurrence  
Date of Diagnosis: February 2011  
Treatment: Orchidectomy, chemotherapy and radiotherapy  
Current Status: Under surveillance  
Number of Years Married: 22 years  
Number of Children: 3  
Age (At time of dx.): 6, 14, 18  
Sex of Children: Boys

**CASE DETAILS**

Study Number: 1010

Initials: DD

Pseudonyms: Theo

Age: 36

Race: White British/Italian

Education: University

Employment: Marketing manager

Diagnosis: Stage 4 non-seminomatous Germ Cell Tumor

Date of Diagnosis: February 2010

Treatment: Orchiectomy and two rounds of chemotherapy

Current Status: NED

Number of Years Married: 10 years – separated after agreeing to interview

Number of Children: 2

Age (At time of dx.): 9 and 7

Sex of Children: Boys

**CASE DETAILS**

Study Number: 1011

Pseudonyms: Brad

Age: 37

Race: White European – Polish

Education: University

Employment: Builder

Diagnosis: Stage 2a Testicular Seminoma

Date of Diagnosis: June 2011

Treatment: Orchiectomy, one rounds of chemotherapy, one round of radiotherapy

Current Status: NED

Number of Years Married: 9 years

Number of Children: 2

Age (At time of dx.): 1 and 7

Sex of Children: Boys

## **Appendix 2**

### **Participant Information Sheet**

**Title of Study:** Fathers with Testicular Cancer

**Investigator Name:** Dr. Robert Huddart      Chief Investigator  
Kathleen Russell      Co-investigator

#### **Introduction**

It is now commonly recognized that the diagnosis of cancer is a family affair and that patients and families are faced with a range of challenges. Numerous research studies have been carried out to examine the impact of a cancer diagnosis and treatment of an adult on the family including children. However, most of these studies have investigated women with breast cancer and the impact of the latter on family members. No study has previously researched the impact of being a father with cancer. This study, however, would like to learn about the experiences of cancer for men in relation to their young school age children. The data from this study will not only be used in their own right but will also inform researchers in the Child and Family Department at the Tavistock Clinic in London.

This study is to be carried out by a researcher, who is sponsored by the Institute of Cancer Research (ICR); although she is also affiliated with the Tavistock Clinic. By participating in this qualitative study you will be providing useful information about what have been some of your main concerns and what services might have been helpful for you and/or your family including your children.

#### **What is the purpose of the study?**

The purpose of this qualitative recorded interview study is to explore the major areas of psychosocial concerns for fathers with testicular cancer. This study is the initial stage of a further research to be carried out at the Tavistock Clinic. This study will aim to explore the ways that supportive interventions may help parenting and family adjustment when the father has testicular cancer.

#### *Why have I been chosen?*

We are recruiting English speaking fathers who live in the UK with school age children who have finished treatment and would be willing to spend approximately one to two hours talking about their experience of having cancer. You meet the inclusion criteria.

#### **Do I have to take part?**

No, your participation is entirely voluntary. You will not be asked to give a reason for refusal or withdrawal and your treatment will not be jeopardised as a result.

#### **What will I have to do?**

If after reading the Information Sheet, you feel that you are interested in participating in the study, we would like you to complete the enclosed form that states your interest and your contact details so that the researcher can telephone you to make an appointment in a venue of your choice and at a time that is convenient to you. A stamped addressed envelope is enclosed for its return. If you do not contact the researcher after two weeks it will be assumed that you do not wish to participate. However, this time limitation does not bar you from entering the study. You are also asked if you would like your GP to be informed of your participation in this study.

Your recorded interview, carried out with consent, will be transcribed by the researcher and analysed using a specific method that will bring your experience and other's together to allow us to understand the themes that run through your accounts. A report will be written and the results will be published in appropriate journals.

With your consent, you will be sent a copy of your transcript giving you a chance to make comments or to withdraw from the study altogether. A short final report will be sent to you but again, with your consent.

**What are the possible benefits of taking part?**

There are no direct benefits for you or your family. However, the information you provide will help not only your clinicians at the Royal Marsden Hospital to provide a better service for future testicular cancer patients but your participation will also help to plan future interventions for men and families in similar situations.

**What if there is a problem?**

On very rare occasions, some men become upset when discussing their cancer experience. You will be at liberty to either withdraw from the study at any time, or to delay the interview until you recover.

If you become upset either during the interview or post interview, we can, with your approval, arrange for you to receive support from a counselor, here at the Royal Marsden Hospital or at The Cancer Counselling Trust in London, which offers free face-to-face and phone counselling. This can be carried out confidentially if you do not wish details to be given to your clinician.

**Will my taking part in the study be kept confidential?**

Confidentiality will be strictly adhered to. You will have a study number, never a name. Your identity will never be revealed in any way. All data concerning this study will be kept locked in a safe place and the recorded interviews will be destroyed after two years following the completion of the study.

The transcript of your interview will be analysed by the researcher although members of the research team at the Tavistock Clinic, including my supervisors, will be involved in the analyses of your transcript. However, your identity will not be recognisable in any way.

**Contact details of the research team**

If you have any questions or concerns you can contact the co-investigator...

**What will happen if I don't want to carry on with the study?**

If you do not want to carry on with this study, there will be no negative consequences for you and, should you withdraw, all your personal data including your recorded interview will be withdrawn from the study and destroyed.

**Who has reviewed the study?**

This study has been approved by the Royal Marsden NHS Trust and the Institute of Cancer Committee for Clinical Research and the XXXX-Research Ethics Committee.

**Appendix 3**  
**Worksheet 1A: Findings Chart**  
**A list of participants' findings to develop themes and make assertions**

	<b>Participants</b>				
	<b>1001 George</b>	<b>1002 Don</b>	<b>1003 Bob</b>	<b>1005 Jack</b>	<b>1006 Chris</b>
<b>Theme 1: Concern for children</b>	<b>10/18</b>	<b>13/18</b>	<b>3/18</b>	<b>7/18</b>	<b>10/18</b>
Finding I: Articulate concerns	3	3	1	3	3
Finding II: Enlist additional support	2	2	0	1	0
Finding III: Engage in protective behavior	0	3	2	3	3
Finding IV: Engage in special father/child activities	3	3	0	0	3
Finding V: Role changes	2	2	0	0	1
Finding VI: Return to topic	3	3	1	3	3
<b>Theme 2: Concern for wife and family</b>	<b>8/12</b>	<b>10/12</b>	<b>0/12</b>	<b>10/12</b>	<b>9/12</b>
Finding I: Articulate concerns	3	3	0	2	3
Finding II: Enlist additional support	1	2	0	3	0
Finding III: Engage in protective behavior – avoid being a burden	2	2	0	3	3
Finding IV: Return to topic	2	3	0	2	3
<b>Theme 3: Lack of information</b>	<b>14/18</b>	<b>14/18</b>	<b>11/18</b>	<b>12/18</b>	<b>6/18</b>
Finding I: Articulate frustration w/ GP	3	1	1	0	0
Finding II: Articulate frustration w/ hospital staff	3	3	3	0	0
Finding III: Surf the internet	2	2	1	3	0
Finding IV: Medical team minimize consequences	3	2	3	3	3
Finding V: Return/time to topic	3	3	3	3	3
Finding VI: Isolation	0	3	0	3	0
<b>Theme 4: Challenges to self-image/prosthesis/masculinity</b>	<b>17/18</b>	<b>8/18</b>	<b>17/18</b>	<b>16/18</b>	<b>12/18</b>
Finding I: Articulate concerns	3	2	3	3	1
Finding II: Emphasize physical activities	3	2	2	3	3
Finding III: Reveal strong emotions	3	0	3	2	2
Finding IV: Return/Time to topic	3	1	3	3	2
Finding V: Provide examples	3	1	3	3	2
Finding VI: Projection	2	2	3	2	2

<b>Theme 5: Challenges to self-concept/role changes/masculinity</b>	<b>16/21</b>	<b>4/21</b>	<b>17/21</b>	<b>14/21</b>	<b>18/18</b>
Finding I: Articulating concerns	3	1	3	2	2
Finding II: Provide examples/ reveal emotions	3	1	3	2	2
Finding III: Emphasize roles	2	1	3	2	2
Finding IV: Maintain stoic facade	2	1	2	3	3
Finding V: Devote/return time to topic	3	0	3	2	3
Finding VI: Exhibit contradiction	3	0	3	0	3
Finding VII: Projection	0	0	0	3	3
<b>Theme 6: Challenges to faith/finding meaning</b>	<b>3/9</b>	<b>9/9</b>	<b>9/9</b>	<b>3/9</b>	<b>9/9</b>
Finding I: Articulate concerns	1	3	3	1	3
Finding II: Return/time to topic	1	3	3	1	3
Finding III: Provide examples	1	3	3	1	3
<b>Theme 7: Work concerns</b>	<b>6/12</b>	<b>3/12</b>	<b>11/12</b>	<b>10/12</b>	<b>10/12</b>
Finding I: Articulate concerns	2	1	3	3	2
Finding II: Maintain stoic facade	2	1	2	3	3
Finding III: Return/time to topic	2	1	3	2	3
Finding IV: Provide examples	0	0	3	2	2
<b>Theme 8: Fear of recurrence/late dx</b>	<b>8/12</b>	<b>0/12</b>	<b>3/12</b>	<b>4/12</b>	<b>4/12</b>
Finding I: Articulate concerns	2	0	1	1	0
Finding II: Return to topic	2	0	1	1	2
Finding III: Reveal strong emotions	2	0	1	1	2
Finding IV: Exhibit contradictions/ RF	2	0	0	1	0
<b>Theme 9: Fear of death</b>	<b>8/15</b>	<b>12/15</b>	<b>25/25</b>	<b>6/15</b>	<b>13/15</b>
Finding I: Articulate concerns	1	2	3	1	2
Finding II: Return to topic	1	1	3	1	2
Finding III: Round about means	2	3	3	2	3
Finding IV: Contradictions	2	3	3	0	3
Finding V: Reveal strong emotions	2	3	3	2	3
<b>Theme 10: Good cancer/bad dx</b>	<b>8/12</b>	<b>6/12</b>	<b>12/12</b>	<b>8/12</b>	<b>8/12</b>
Finding I: Provide statistics	2	1	3	2	2
Finding II: Compare to other pts/cancers	2	2	3	2	2
Finding III: Splitting/projection	2	2	3	2	3
Finding IV: Return to topic	2	1	3	2	1

<b>Theme 11: MWHI</b>	<b>10/21</b>	<b>10/21</b>	<b>14/21</b>	<b>17/21</b>	<b>10/21</b>
Finding I: Minimize	2	3	3	2	2
Finding II: Intellectualization	0	0	3	2	2
Finding III: Maintain stoic facade	3	2	3	3	3
Finding IV: Splitting/projection	2	2	2	3	2
Finding V: Exhibit contradictions/ RF	2	3	3	3	1
Finding VI: Humor	1	0	0	1	0
Finding VII: Idealization	0	0	0	3	0
<b>Theme 12: Wife and family support</b>	<b>6/9</b>	<b>9/9</b>	<b>0/9</b>	<b>0/9</b>	<b>9/9</b>
Finding I: Provide examples	2	3	0	0	3
Finding II: Show appreciation	2	3	0	0	3
Finding I: Articulate feelings	2	3	0	0	3

A high mark in bold means that the Theme is an important to this participant and therefore relevant to the cross case analysis. Findings= specific actions, behaviors or expressions o

**Appendix 4**  
**Worksheet 1B: Findings Chart**  
**A list of participants' findings to develop themes and make assertions**

	<b>Participants</b>				
	<b>1007 Simon</b>	<b>1008 Matt</b>	<b>1009 Nigel</b>	<b>1010 Sal</b>	<b>1011 Brad</b>
<b>Theme 1: Concern for children</b>	<b>11/18</b>	<b>11/18</b>	<b>8/18</b>	<b>12/18</b>	<b>11/18</b>
Finding I: Articulate concerns	3	3	3	3	3
Finding II: Enlist additional support	0	0	0	0	0
Finding III: Engage in protective behavior	3	3	2	3	3
Finding IV: Engage in special father/child activities	2	2	0	3	3
Finding V: Role changes	0				
Finding VI: Return to topic	3	3	3	3	2
<b>Theme 2: Concern for wife and family</b>	<b>8/12</b>	<b>8/12</b>	<b>8/12</b>	<b>12/12</b>	<b>12/12</b>
Finding I: Articulate concerns	3	3	3	3	3
Finding II: Enlist additional support	0	0	1	3	3
Finding III: Engage in protective behavior – avoid being a burden	2	2	2	3	3
Finding IV: Return to topic	3	3	2	3	3
<b>Theme 3: Lack of information</b>	<b>12/18</b>	<b>8/18</b>	<b>13/18</b>	<b>0/18</b>	<b>5/18</b>
Finding I: Articulate frustration w/ GP	0	0	3	0	0
Finding II: Articulate frustration w/ hospital staff	3	2	1	0	0
Finding III: Surf the internet	3	3	3	0	2
Finding IV: Medical team minimize consequences	3	0	0	0	0
Finding V: Return/time to topic	3	3	3	0	1
Finding VI: Isolation	0	0	3	0	2
<b>Theme 4: Challenges to self-image/prosthesis/masculinity</b>	<b>13/18</b>	<b>13/18</b>	<b>15/18</b>	<b>10/18</b>	<b>13/18</b>
Finding I: Articulate concerns	2	2	3	1	2
Finding II: Emphasize physical activities	3	2	2	2	2
Finding III: Reveal strong emotions	2	3	3	2	2
Finding IV: Return/Time to topic	2	2	3	1	2
Finding V: Provide examples	2	2	3	2	2
Finding VI: Projection	2	2	1	2	3



<b>Theme 5: Challenges to self-concept/role changes/masculinity</b>	<b>14/21</b>	<b>14/21</b>	<b>18/21</b>	<b>12/21</b>	<b>19/21</b>
Finding I: Articulate concerns	2	2	3	2	3
Finding II: Provide examples/ reveal emotions	2	3	3	2	3
Finding III: Emphasize roles	3	3	3	3	3
Finding IV: Maintain stoic facade	3	3	2	3	3
Finding V: Devote/return time to topic	2	3	3	2	3
Finding VI: Exhibit contradiction	0	0	2	0	1
Finding VII: Projection	2	0	2	0	3
<b>Theme 6: Challenges to faith</b>	<b>0/9</b>	<b>0/9</b>	<b>3/9</b>	<b>6/9</b>	<b>0/9</b>
Finding I: Articulate concerns	0	0	1	2	0
Finding II: Return/ time to topic	0	0	1	2	0
Finding III: Provide examples	0	0	1	2	0
<b>Theme 7: Work concerns</b>	<b>0/15</b>	<b>0/15</b>	<b>15/15</b>	<b>8/15</b>	<b>0/15</b>
Finding I: Articulate concerns	0	2	3	2	0
Finding II: Maintain stoic facade	0	1	3	3	0
Finding III: Return/time to topic	0	0	3	2	0
Finding V: Provide examples	0	0	3	1	0
<b>Theme 8: Fear of recurrence/late dx</b>	<b>11/12</b>	<b>0/12</b>	<b>0/12</b>	<b>0/12</b>	<b>8/12</b>
Finding I: Articulating concerns	3	0	0	0	2
Finding II: Returning to topic	2	0	0	0	2
Finding III: Reveal strong emotions	3	0	0	0	2
Finding IV: Exhibit contradictions	3	0	0	0	2
<b>Theme 9: Fear of death</b>	<b>10/15</b>	<b>8/15</b>	<b>12/15</b>	<b>12/15</b>	<b>10/15</b>
Finding I: Articulate concerns	1	3	3	3	3
Finding II: Return to topic	2	2	3	3	2
Finding III: Round about means	3	0	1	2	1
Finding IV: Contradictions	1	0	2	1	1
Finding V: Reveal strong emotions	3	3	3	3	3
<b>Theme 10: Good cancer/bad dx</b>	<b>11/12</b>	<b>12/12</b>	<b>11/12</b>	<b>0/12</b>	<b>12/12</b>
Finding I: Provide statistics	2	3	2	0	3
Finding II: Compare to other pts/cancers	3	3	3	0	3
Finding III: Splitting/projection	3	3	3	0	3
Finding IV: Returning to topic	3	3	3	0	3
<b>Theme 11: MWHI</b>	<b>16/21</b>	<b>9/21</b>	<b>6/21</b>	<b>14/21</b>	<b>19/21</b>

Finding I: Minimize	2	2	0	2	3
Finding II: Intellectualization	2	2	0	1	3
Finding III: Maintain stoic facade	3	2	2	3	3
Finding IV: Splitting/projection	3	2	1	3	3
Finding V: Exhibit contradictions	3	1	1	3	3
Finding VI: Humor	3	0	0	0	3
Finding VII: Idealization	0	0	2	2	1
<b>Theme 12: Wife and family support</b>	<b>9/9</b>	<b>9/9</b>	<b>9/9</b>	<b>8/9</b>	<b>9/9</b>
Finding I: Provide examples	3	3	3	3	3
Finding II: Show appreciation	3	3	3	3	3
Finding I: Articulate feelings	3	3	3	2	3

A high mark in bold means that the Theme is an important to this participant and therefore relevant to the cross case analysis. Findings= specific actions, behaviors or expressions of thoughts or feelings.

## **Appendix 5 UREC Approval Letter**

Ms Kathleen Russell  
Marchurst  
Off Hildenborough Road  
Shipbourne  
Kent  
TN119OA

24 November 2014

Dear Ms Russell,

**University of East London/The Tavistock and Portman NHS Foundation Trust:  
Research ethics**

**Study Title: Psychosocial concerns and individual anxieties for fathers with  
Testicular cancer**

I am writing to inform you that the University Research Ethics Committee (UREC) has received your NHS approval letter, which you submitted to the Chair of UREC, Professor Neville Punchard. Please take this letter as written confirmation that had you applied for ethical clearance from our UREC at the appropriate time; it is likely it would have been granted. However, this does not place you in exactly the same position you would have been in had clearance been obtained in advance. Therefore, when responding to any questioning regarding the ethical aspects of your research, you must of course make reference to and explain these developments in an open and transparent way.

For the avoidance of any doubt, or misunderstanding, please note that the content of this letter extends only to those matters relating to the granting of ethical clearance. If there are any other outstanding procedural matters, which need to be attended to, they will be dealt with entirely separately as they fall entirely outside the remit of our University Research Ethics Committee.

If you are in any doubt about whether, or not, there are any other outstanding matters you should contact Mr. William Bannister at the Tavistock and Portman NHS Foundation Trust.

Yours sincerely

For and on behalf of  
Professor Neville Punchard

c.c. Mr Malcolm Allen, Dean of Postgraduate Studies' Tavistock and Portman NHS Foundation, Mr. Will Bannister, Associate Director, Education and Training, Tavistock and Portman NHS Foundation Trust, Professor John J Joughin, Vice-Chancellor, University of East London